

ARTHRITIS

BY THE NUMBERS

**Book of Trusted
Facts & Figures
2020**



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INTRODUCTION

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From its inception, Arthritis by the Numbers has been designed to be used by a wide audience as a trustworthy set of verified facts meant to inform patients and patient advocate thought-leaders, elected officials, academics, drug/device industry professionals, rheumatology health care providers and researchers. With the help of our growing patient and professional volunteer review team, the 2020 edition of Arthritis by the Numbers includes more than 100 new and/or updated observations about arthritis.

We continue to elevate the level of patient involvement in the creation of Arthritis by the Numbers. We believe patients must be fully integrated into everything we do and that their diverse needs and outcomes, the ones that are most important to them, be represented.

The Arthritis Foundation launched the [Live Yes! Arthritis Network](#) in October 2018 – making connections possible, both in person and online, to empower people to live their best life. [The Live Yes! Insights assessment](#) initiative was added to the network as a tool to collect information from patients that can be used to help design new programs and research to improve the lives of people in our community. The findings from the first year’s assessments have been compiled into the [Arthritis Foundation’s First Look report](#). Some of the earliest findings tell us that sleep, fatigue and pain are important issues that affect daily lives.

When asked about their experiences over the past seven days, sleep and fatigue are very common problems for most arthritis patients:

- 71% of osteoarthritis patients felt fatigued.
- 75% of rheumatoid arthritis patients had a problem with their sleep.
- 88% of lupus patients felt fatigued.
- 79% of ankylosing spondylitis patients has a problem with their sleep.

When asked about their experiences over the past seven days, pain from arthritis affects the physical abilities and emotions of many patients.

- 51% of osteoarthritis patients could not walk or had trouble walking for 15 minutes.
- 78% of gout patients said pain interfered with their ability to participate in social activities.
- 81% of ankylosing spondylitis have trouble doing all of the family activities that they want to do.
- 91% of fibromyalgia patients have trouble doing all of the friend activities that they want to do.

As the Live Yes! Arthritis Network grows, the role of Arthritis by the Numbers will continue to evolve. That has led to some of the changes you see in this year’s edition. When you begin reading this fourth edition of Arthritis by the Numbers, you will notice a change in format. We’ve switched to a narrative form versus the bulleted format used in the first three editions. This lends us the opportunity to provide additional context, but also blend in the voices of our patient community. We have also expanded our network to include reviewers from the United States Bone and Joint Initiative (USBJI). This collaboration allows the 2020 Arthritis by the Numbers to draw from The Burden of Musculoskeletal Diseases in the United States: Prevalence, Societal and Economic Cost (BMUS).

We continue to move forward, prioritizing policies that further advance the needs of the arthritis community so we can accelerate the science that goes towards finding better treatments and cures. We invite you to get started with us by flipping through the 2020 Arthritis by the Numbers.



The United States Bone and Joint Initiative (USBJI) is a collaboration of U.S. patient and healthcare professional organizations, medical schools, government agencies, health systems providers and industry that strives to improve prevention of bone and joint disorders, and the quality of life for those affected. This goal begins with increased awareness based on data about these disorders, and more research.

USBJI publishes BMUS, which includes a [Report Builder](#) that anyone can access to help search for musculoskeletal disease data points for individual needs. The Report Builder allows you to customize a report based on the most up-to-date data available from selected data sources.

SECTION 1: GENERAL ARTHRITIS FACTS



WHAT IS ARTHRITIS?

Arthritis is very common, but not well understood. Actually, arthritis is not a single disease; it is an informal way of referring to joint pain or joint disease. There are more than 100 different types of arthritis (see Appendix 1) and related conditions.¹ People of all ages, genders, ethnicities and races can and do have arthritis. Arthritis is the leading cause of disability in the United States.

None of the types of arthritis has a cure. However, some forms of arthritis, like gout, can be well-managed and attacks decreased. Currently, people with arthritis manage their symptoms with treatments like medications, joint injections, exercise or bracing. People with severe arthritis might have their joint replaced surgically. Inflammation can be treated to reduce damage and slow down the need to replace joints for conditions like rheumatoid arthritis (RA).

Common arthritis joint symptoms include swelling, pain, stiffness and decreased range of motion. Symptoms may be intermittent and can be mild, moderate or severe. They may stay the same for years and then may get worse over time. Severe arthritis can result in chronic pain, the inability to do daily activities and make it difficult to walk or climb stairs. Arthritis can cause permanent joint changes. These changes may be visible, such as knobby finger joints, but often, the damage can only be seen by X-ray or MRI. Many types of arthritis also affect other body parts, like the heart, eyes, lungs, kidneys, digestive tract and skin.

Prevalence

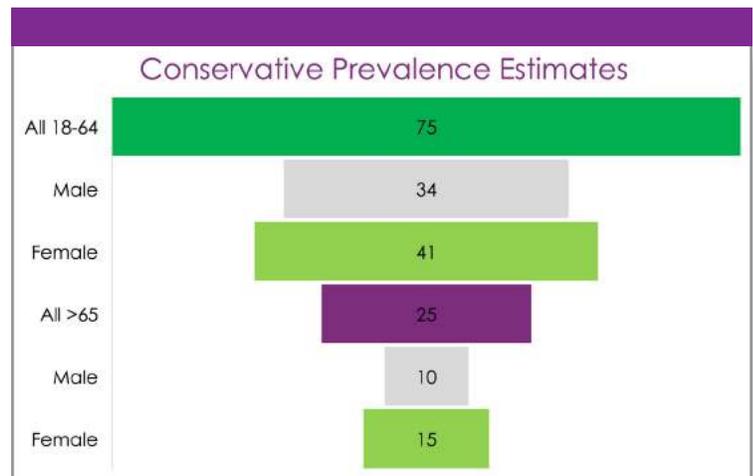
We don't know the true number of people with arthritis because many people don't seek treatment until their symptoms become severe. In national surveys, over 54 million adults responded that they have doctor-diagnosed arthritis. Additionally, almost 300,000 children have arthritis. By these estimates, more than 1 in 4 U.S. adults has some form of doctor-diagnosed arthritis. This estimate is higher in rural areas of the country where access to specialized care is harder to come by. In rural areas, the conservative estimate is 1 in 3 U.S. adults has been diagnosed with arthritis.² According to the American College of Rheumatology, only 7% of all rheumatologists practice in rural areas, where 20% of the population lives.³

A recent study suggests that these prior estimates of arthritis prevalence in the U.S. have been substantially underestimated. Most likely, arthritis prevalence is almost double these numbers. Based on the adjusted estimates that include people with arthritis symptoms as well as those with doctor-diagnosed arthritis, over 92 million adults may have arthritis.⁴

It should be noted that back or neck pain, aching, or stiffness were not included in the numbers. While researchers try to find more accurate ways to estimate the prevalence of this disease and the burdens it causes, we do know that most forms of arthritis are more common among women, and the group of diseases considered as arthritis is increasing in people of all ages.

Age and Gender

In addition to almost doubling the estimated number of adults with arthritis, the recent estimates also indicated this disease affects a larger proportion of adults younger than age 65. The conservative estimate (that included only doctor-diagnosed patients) indicated that approximately 75% of U.S. adults with arthritis in 2015 were younger than 65 years old.



Note: Rounded proportion estimates of 2015 people with arthritis by age group and gender from Barbour – MMWR [66] 2017.²

About 68% more people in the total U.S. population suffer from arthritis than previously thought, with a larger increase in the number of adults younger than age 65 being affected. With these numbers, more than 1 in 3 people (both men and women), aged 18 to 64, have doctor-diagnosed arthritis and/or report joint symptoms consistent with arthritis.

Because the number of people over age 65 is smaller than the number of people in other age groups, the proportion of people with arthritis in this age group is much higher. By the adjusted estimate, in the U.S.:

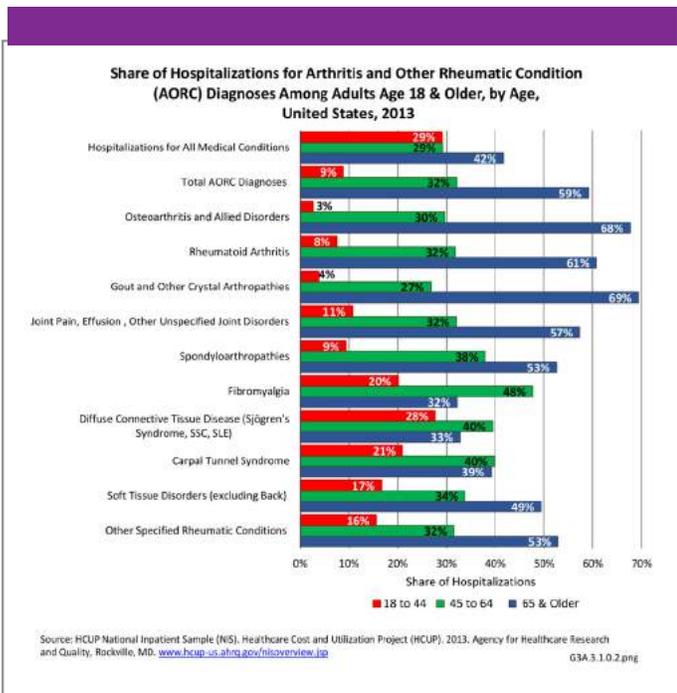
- More than 1 in 3 male senior citizens suffer from arthritis symptoms.
- More than 2 in 3 female senior citizens suffer from arthritis symptoms.⁴

By new estimates,

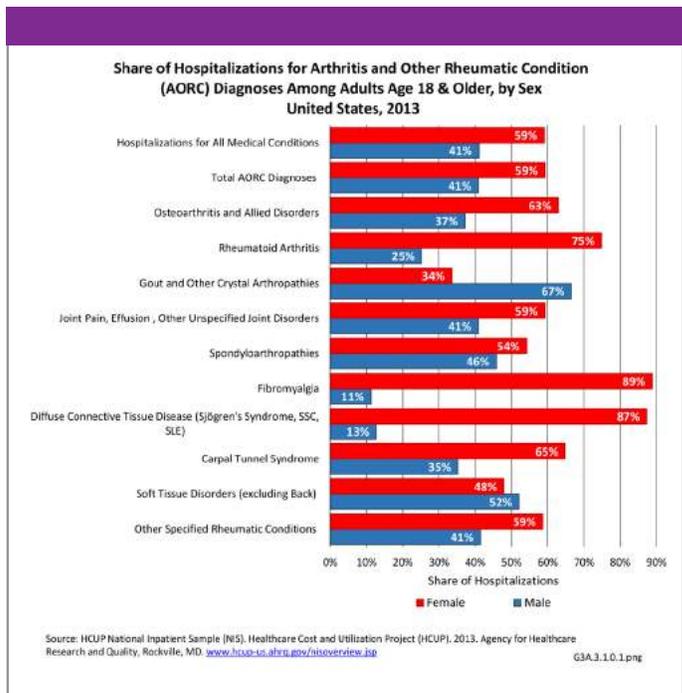
1 in 3 people age 18-64 have arthritis.

While only 19% of the total U.S. population is over age 65, their chances of having arthritis are much greater. This leads to the inaccurate perception that arthritis is only an old person's disease. Since many younger adults don't seek medical care until their symptoms are advanced, this further supports and feeds into the misperception of arthritis only occurring in older adults, as shown by hospitalization statistics. Older Americans are hospitalized more often because of arthritis and other rheumatological conditions.⁵

Hospitalization records also show that women are more likely than men to be affected with most forms of arthritis (with the exception of gout).⁶



Note: Accessed from USBJI Burden of Musculoskeletal Diseases in the United States, 4th edition.⁵



Note: Accessed from USBJI Burden of Musculoskeletal Diseases in the United States, 4th edition.⁶

Change Over Time

The proportion of the U.S. and global population with arthritis has been increasing over time, but at a much higher rate since the mid-20th century. A 2017 study that focused on the prevalence of knee osteoarthritis (OA), the most common joint site affected by OA, examined and compared skeletons of people over the age of 50 who lived during the early industrial age (from 1800 through early 1900s), the postindustrial era (from late 1900 through early 2000s), and prehistoric hunter-gatherers and farmers (from about 6,000 through 300 B.C.). The study found that knee OA in the more recent postindustrial skeletons was about 2.6 times more common than in skeletons from people born in the late 1800s and about 2 times more common than prehistoric skeletons. And while many doctors believe that increased life expectancy and higher population obesity rates are the main factors that led to the spike in OA, the study research team thinks that other factors may be key. An important factor may be the decline in individual physical activity.⁷

While OA is the most common form of arthritis, beyond OA, it is clearly documented that the number of people with arthritis is increasing. According to the Centers for Disease Control and Prevention (CDC) estimates, about 46 million U.S. adults had doctor-diagnosed arthritis between 2000-2005. That number rose to about 50 million between 2005-2010.⁸ Between 2002-2014, almost two-thirds (64%) of adults with doctor-diagnosed arthritis were younger than 65 years old, further demonstrating that arthritis is not limited to older adults.⁹ By 2015, it was estimated that 54.4 million adults had doctor-diagnosed arthritis.² By conservative estimates, the number of U.S. adults with doctor-diagnosed arthritis is projected to increase by 49% to 78.4 million (25.9% of all adults) by 2040.¹⁰ By including those with arthritis symptoms who have not yet been diagnosed from the adjusted estimates, we are already past that number.

Factors to Consider

If you have heart disease, diabetes or are overweight/obese, you are more likely to suffer from arthritis. Arthritis is more common among adults who are obese than among those who are normal weight or underweight.¹¹ Almost half of all adults with heart disease (49.3%) or diabetes (47.1%) also have arthritis. Almost one-third (30.6%) of all adults who are obese also have arthritis.²

Among people with arthritis, nearly 1 in 4 adults with arthritis also have heart disease. Almost 1 in 5 also have chronic respiratory conditions, and nearly 1 in 6 also have diabetes. It is believed that arthritis likely comes first and results in these other health problems.¹²

Obesity affects 36.5% of all adults in the U.S. From 2009 to 2014, an increase in obesity prevalence in older adults with doctor-diagnosed arthritis occurred among those with poor health characteristics, as might be expected.⁹ However, even though obesity has been recognized as a risk factor for arthritis, the prevalence of obese people with all types of arthritis decreased significantly between 1999 and 2014.¹³

An increase in obesity prevalence also occurred among adults with doctor-diagnosed arthritis who reported meeting physical activity recommendations, those with very good/excellent health, or those without heart disease.² The missing part in this equation is physical activity.

Numerous studies have been done about the health dangers of sedentary lifestyles. A decline in individual physical activity levels can contribute to the development of disease, just as an increase in physical activity levels can help those with physical conditions. Studies have shown that physical activity can reduce pain and improve physical function by about 40% in arthritis patients.² One study showed that between 2008 and 2015, fewer people with arthritis met aerobic and muscle strengthening guidelines than people without arthritis. This may indicate that people with arthritis need additional strategies to address potential barriers to physical activity – those barriers include pain, psychological distress and inadequate medical support.¹⁴

Pain and Other Health Burdens

Joint damage and pain can cause activity limitations for people with arthritis. The prevalence of severe joint pain among adults with arthritis was stable from 2002 to 2014, but the absolute number of adults with severe joint pain was significantly higher in 2014 (14.6 million) than in 2002 (10.5 million) due, in part, to an increasing older population.⁹

In 2014, more than 1 in 4 adults with arthritis had severe joint pain (27%). Among those adults, the highest prevalence was among persons 45 to 64 years old (31%). Severe joint pain was higher among women (29%) than men in that age group, but especially for those who were in poorer health with more comorbidities like obesity, heart disease, diabetes or serious psychological distress.⁹

Adults with arthritis and comorbidities are more likely to have activity limitations. By conservative estimates, between 2013 and 2015, about 23.7 million (43.5%) of those with arthritis reported activity limitation due to their arthritis.² The number of adults reporting activity limitation due to their arthritis will increase 52% by 2040, using conservative estimates.¹⁰

Using conservative estimates, more than half of adults with arthritis and heart disease (54.5%) or arthritis and diabetes (54%) have activity limitations. Almost half of adults with arthritis and who are obese (49%) have activity limitations.² Obese arthritis patients are more likely to be physically inactive, have activity and work limitations, report depression and anxiety, and have an increased risk of expensive knee replacement.¹⁵

Back pain is a fairly common problem among adults and may not always be caused by arthritis. About 15-21% of the U.S. adult population reports frequent and long-lasting low back pain. Nearly 14% report low back pain lasting longer than two weeks at a time, while 5-10% of patients have low back pain lasting more than three to six months. About 1-2% of adult patients have been diagnosed with herniated discs.¹⁶

While back pain is common, the cause is often unclear, and classification is controversial. However, most back pain probably starts in the muscles and/or ligaments or is caused by degenerative changes in the spine itself (the vertebrae and the discs that separate them).¹⁶ There are many forms of arthritis that can affect the back, including OA, ankylosing spondylitis, psoriatic arthritis, RA (which can affect the cervical spine), osteoporosis, spinal stenosis, scoliosis and fibromyalgia. Gout rarely affects the back.¹⁷

Lumbar spine (lower back) OA is very common. About 80% of Americans experience low back pain (LBP) at least once during their life, making it the second most common condition after the common cold in frequency. It is one of the most common reasons for doctor visits, affecting more than 30% of U.S. adults. Between 40-85% of people with chronic LBP may have lumbar spine OA.¹⁸ Low back pain can be from a form of spondyloarthritis, such as axial spondyloarthritis, or psoriatic arthritis, which is inflammatory.

Constant fatigue, anxiety and depression are also common problems for people with arthritis. About 1 in 3 U.S. adults with arthritis, 45 years and older, report having anxiety or depression. Anxiety is nearly twice as common as depression among people with arthritis, despite more clinical focus on depression.¹⁹ However, arthritis is strongly associated with major depression (attributable risk of 18.1%), probably through its role in creating functional limitation.²⁰

Arthritis is the most common chronic condition among chronic users of opioids in the U.S.



(Hudson 2008)

Employment Impact and Medical Cost Burden

Arthritis is the leading cause of disability among adults in the U.S.¹¹ While stroke is often considered the most common cause of disability, both arthritis and back pain likely have a greater impact on functional limitations than stroke.²¹ Back pain is a leading cause of work disability,¹⁶ with back pain and arthritis (OA and RA) being the most common and costly conditions requiring rehabilitation in the U.S. Back pain and arthritis affect over 100 million people and cost over \$200 billion per year.²¹

Musculoskeletal conditions like back pain and arthritis are likely to have the greatest impact on the health care system because of their high prevalence and the level of disability they cause.²¹ Annually, 172 million days of work are lost in the U.S. due to arthritis and other rheumatic conditions.²²

In 2013, fewer adults with arthritis (77%) were able to work compared to adults without the disease (84%). The total medical costs and earnings losses due to arthritis in that year were \$304 billion (about 1% of the 2013 U.S. gross domestic product), with the total earnings losses higher than medical costs.²³

In 2013, earnings losses were \$164 billion (for adults with arthritis between ages 18 and 65). This translated to the average adult with arthritis earning \$4,040 less than an adult without arthritis. Medical costs related to arthritis for this group (about 66 million people) were about \$140 billion; the average medical costs per person were \$2,117.²³ To put this in perspective, the median household income in 2013 was \$52,250, according to the U.S. Census Bureau.

Taking a closer look at medical costs in 2013, there were 105.7 million health care visits due to arthritis (more than 10% of all visits that year). Hospitalizations related to arthritis treatment accounted for 6% of visits, while ambulatory care accounting for 94% (77% physician office, 6% outpatient and 11% emergency department).⁶ Most diagnoses for any medical conditions are made in a doctor's office. However, hospital discharges and emergency department visits are seen more frequently for musculoskeletal conditions than for health care visits for all conditions overall.²⁴

We will continue to see increases in the number of patients with arthritis and the associated costs to individuals and society. Health care services worldwide will face severe financial pressures in the next 10 to 20 years due to the increase in the number of people affected by musculoskeletal diseases. It is predicted that by the year 2060, the number of individuals older than the age of 65 in the U.S. will grow from the current 15% (47.8 million) of the population to 24% (98.2 million). Persons age 85 and older will double from current <4% to more than 8%.²⁵ But as already noted, the oldest portion of arthritis patients may not be the largest. With that in mind, let's look at some of the most prevalent forms.

OSTEOPOROSIS

Bones are living tissue made up of calcium and other minerals. Bone tissue is replaced regularly in a process called bone turnover. Osteoporosis, which means porous bone, is a disease that happens when your body loses too much bone and/or makes too little bone. The bones become thinner and brittle (less dense) and are more likely to break (or fracture) with pressure or after a fall. Bone loss happens without any warning signs. It's why osteoporosis is called a silent disease.

From childhood into young adulthood, the body produces more than enough cells to replace those that die, resulting in stronger, denser bones. By age 30, bones are at peak bone density and cell turnover, in most people,

**Arthritis is the
Leading Cause
of Disability
among adults in
the U.S.**



(Barbour 2013)

remains stable for several years. Losses in bone mineral density (BMD) occur when bone cells start to die at a more rapid rate than new cells are produced. This may lead to the development of osteopenia (a less severe form of bone density loss) and osteoporosis.

Any bone in the body can be affected by osteoporosis. However, the spine, hips, ribs (for which there is no clinical treatment) and wrists are the most commonly fractured when a person with osteoporosis falls. Osteoporosis can also cause a hump in the upper back or loss of height.

Who's Affected?

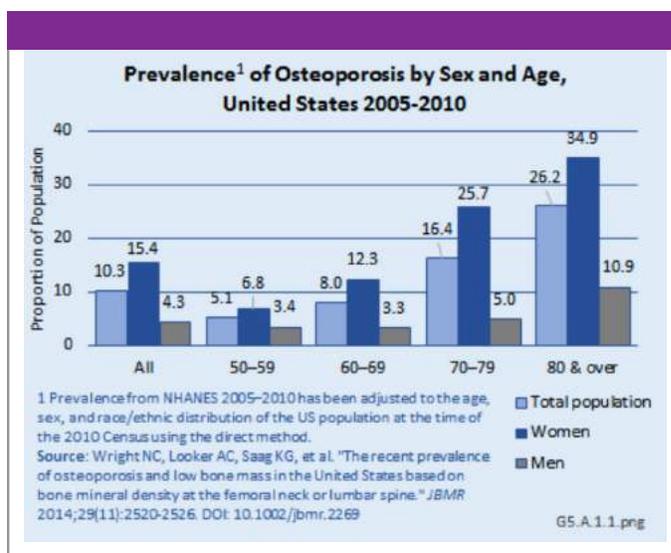
Osteoporosis is more common in women. It is the main cause of bone fractures in post-menopausal women and older adults. However, men can also get osteoporosis. While osteoporosis is more common in people age 50 and older, it can occur in younger people.

Risk factors for developing osteoporosis include family history, gender, race, weight, diet and exercise. Risk factors for low BMD in younger (pre-menopausal) women include low body weight, amenorrhea, lack of physical activity, smoking, low dietary calcium and vitamin D consumption, pregnancy, and being part of the white or Asian population. Of the pre-menopausal women who develop this disease, it is thought that 50-90% have a secondary cause. Secondary causes can include drugs (like glucocorticoids, anticonvulsants, heparin and alcohol), endocrine diseases (like growth hormone deficiency and type 1 diabetes), malnutrition or malabsorption diseases (like anorexia, inflammatory intestinal disease and celiac disease), inflammatory diseases (like rheumatoid arthritis and lupus), organ and bone marrow transplants, and other causes.¹

For osteoporosis prevention, it is recommended that women ages 18 to 50 years should consume 1,000 mg of calcium and 600 IU of vitamin D daily, as well as perform regular weight bearing exercises, avoid smoking and alcohol, and limit caffeine consumption.¹

Prevalence

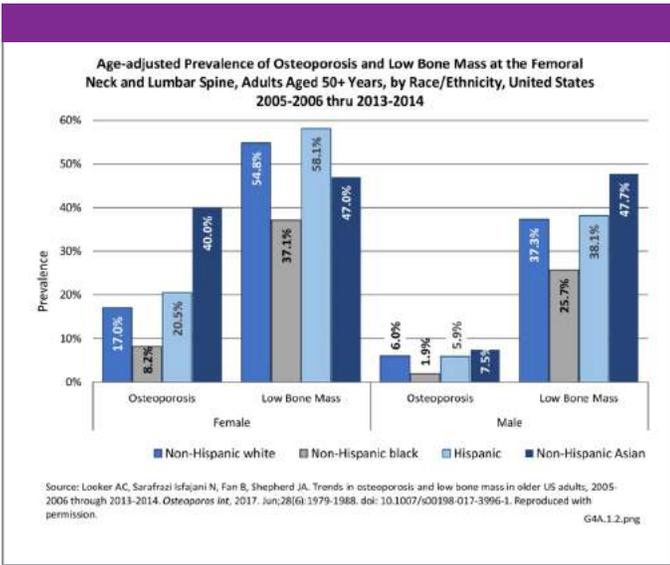
Osteoporosis is usually diagnosed from BMD scan measurements of the upper thigh (femoral neck) bone and lumbar spine (lower back). Women are more affected by osteoporosis than men in the same age group at every age.²



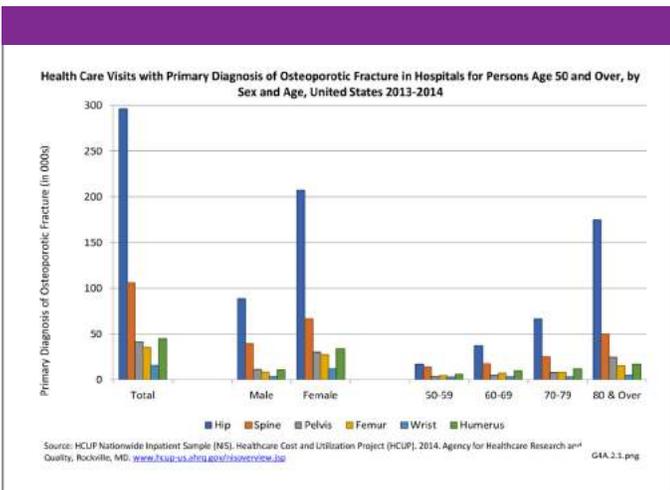
In 2010, osteoporosis and low bone mass combined affected more than half (53.6 million) of adults age 50 and above. About 10.2 million adults had osteoporosis and another 43.4 million had low bone mass.³ Age is a greater factor than sex in prevalence rates. While men show a similar increase in prevalence with age, it continues to occur at a much lower rate than that seen in women.²

The prevalence of osteoporosis by race and ethnicity differs by BMD of either the hip or spine. Data obtained in the decade from 2005-2014 showed that for adults over age 50, non-Hispanic Asian women and men had the highest prevalence of osteoporosis. Hispanic and non-Hispanic white women had the highest prevalence of low bone mass, while Asian and Hispanic men had the highest prevalence of low bone mass.⁴

Note: Accessed from USBJ Burden of Musculoskeletal Diseases in the United States.²



Note: Accessed from USBJI Burden of Musculoskeletal Diseases in the United States.⁴



Note: Accessed from USBJI Burden of Musculoskeletal Diseases in the United States.¹⁰

Globally, over 200 million women suffer from osteoporosis. About 1 in 3 post-menopausal women have this disease in the U.S. and Europe. Worldwide, osteoporosis in women increases with age. One in 10 women age 60 and 1 in 5 women age 70 are diagnosed with this disease. By age 80, more than one-third of all women (2 in 5) and about 2 in 3 women age 90 are diagnosed with this disease. Aging populations will be responsible for a major increase in the global number of people with this disease.⁵

Health Burdens

In 2006, it was estimated that osteoporosis leads to about 2 million fractures a year in the U.S.⁶

People with osteoporosis can break a bone from a minor fall, or even from sneezing or bumping into furniture. Half of all adults over age 50 are at risk of breaking a bone due to this disease. Spine fractures are the most common fractures caused by osteoporosis. They are the gateway to more serious and expensive fractures, like hip fractures.⁷ Once a person has a hip fracture, they are more likely to suffer additional fractures.⁸

The consequences can be extremely serious, especially for hip fracture patients. Half never regain previous function after a hip fracture. Only 15% of patients can walk across a room unaided after a hip fracture. One in 4 patients end up in a nursing home, and more seriously, 1 in 4 hip fracture patients over 50 die within a year of the fracture.⁹

Women account for 71% of all fractures and 75% of all fracture-related costs.⁸ Data obtained in the decade from 2005-2014 showed a total of 19.5 million hospital discharges for fragility fractures among adults aged 50 and older. Women had more than twice the prevalence of these types of fractures (3.7%) than men (1.8%). Hip fractures were the most common type of fragility fracture, followed by spine fractures.¹⁰

While fractures related to this disease are more common in women, studies have shown that the fracture-related death rate is higher in men. Men represent almost a third of the fractures and pay a quarter of the total cost burden of disease-related fractures.⁶

The number of fractures related to osteoporosis and related costs in the U.S. is predicted to increase, especially for minority groups. Over the next 20 years, the total number of osteoporosis fractures and related costs will increase for the non-white population. A 2.7 fold increase in number of fractures and costs for Hispanic and other racial/ethnic populations is predicted by 2025.⁶

Globally, osteoporosis causes at least 8.9 million fractures a year (one fracture every three seconds). For people over age 50, 1 in 3 women and 1 in 5 men will have osteoporotic fractures. At least half of the hip fractures due to this disease will occur in Asia by 2050.¹¹

Economic Burdens

As the number of fractures increase, the direct (medical) and indirect (disability and loss of productivity) costs will continue to increase. In 2006, annual direct costs to Medicare patients with fractures were more than 1.5 times higher than patients without fractures.⁸ By 2008, direct care costs during the first post-fracture year were about \$8,000 for vertebral (back bone) fractures, \$11,300 for non-vertebral fractures and \$30,000 for hip fractures.¹²

In 2015, broken bones from this disease cost U.S. patients and the health care system \$19 billion a year. By 2025, it is predicted that this disease will cause 3 million fractures and costs will exceed \$25 billion a year.⁹

Globally, the cost is high. About 40% of osteoporotic fractures occur in people of working age. The direct annual cost of treating osteoporotic fractures of people in the workplace is \$48 billion in Canada, Europe and the U.S. This does not take into account indirect costs, such as disability and loss of productivity.¹³

Prevention

Many younger, post-menopausal women (in their 50s and 60s) often mistakenly categorize osteoporosis as a largely unavoidable part of aging. A recent survey of postmenopausal women indicated the following incorrect assumptions about this disease:

- Three in 10 women believe that drinking milk or taking calcium supplements alone will prevent osteoporosis.
- One in 4 believe there is no way to build new bone at their age.
- Three in 10 women with osteoporosis believe the risk of a bone fracture or break cannot be reduced in women their age.¹⁴

Due to limited recognition and discussion about the link between osteoporosis and fracture, only 2 in 10 older women in the U.S. who suffer a fracture are tested or treated for osteoporosis. Surprisingly, about 96% of post-menopausal women who have not been diagnosed with osteoporosis and have had a fracture or break from falling were not told by their doctor that it could be linked to osteoporosis.¹⁴

Bone density tests can help spot bone loss in people who might have no symptoms. The test is painless, quick and safe, and can alert people to bone loss before a fracture occurs. It can also be used to track the effects of medicines used to manage bone disease. The lower the bone density, the greater the risk of having a fracture. To reduce the chances of breaking a bone and improve bone density, patients should follow their health care providers advice and take osteoporosis medicines as prescribed. Patients should also improve their diet, take calcium with vitamin D supplements and take part in an exercise program that improves muscle strength and includes weight bearing exercises.¹⁵

While walking and stretching are highly recommended, Tai Chi Chuan (Tai Chi) can also be beneficial. Tai Chi is an ancient form of slow and relaxed exercise that has been shown to be beneficial to bone mineral density and may help prevent osteoporosis. Tai Chi practice is time-dependent. A longer period of practice is required to improve BMD. It is beneficial towards balance and coordination and can improve physical performance and reduce fear of falling.¹⁶

A 10-year study with women showed that 12 selected yoga poses appear to be a safe and effective means to reverse bone loss in the spine and femur (upper leg bone). The women practiced the yoga routine at least every other day for two years. The average age when women started the yoga practice was 68. About 83% of the women had lower-than-normal bone density at the start. However, by the end of the study, most showed significant increases in bone density in the spine. No bone fractures or other injuries were caused by doing yoga. The study showed there may also be some benefit to hip bone density.¹⁷

SECTION 2: OSTEOARTHRITIS (OA)

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WHAT IS OSTEOARTHRITIS?

Anyone who injures or overuses their joints, including athletes, military members and people who work physically demanding jobs, may be more susceptible to developing this disease as they age. Osteoarthritis is the most common cause of disability in adults.²

While OA is a chronic condition that can affect any joint, it occurs most often in knees, hips, lower back and neck, small joints of the fingers, and the bases of the thumb and big toe. Advanced age, obesity, genetics, gender, bone density, trauma and a poor level of physical activity can lead to the onset and progression of OA.³ A poor level of physical activity can mean overuse, which we know can lead to joint degradation, or underuse, which may lead to under conditioning of compensatory muscles. Occasionally, OA develops for unknown reasons, unrelated to age, weight or injuries.

In normal joints, cartilage covers the end of each bone. Cartilage provides a smooth, gliding surface for joint motion and acts as a cushion between the bones. In OA, the cartilage breaks down, causing pain, swelling and problems moving the joint. As OA worsens over time, bones may break down and develop growths called spurs. Bits of bone or cartilage may chip off and float around in the joint. This can cause inflammation and further damage the cartilage.

Many people develop OA over time as they age, but a significant number of people develop OA at younger ages, often as the result of injuries to their bones and joints. This type of OA is often referred to as post traumatic OA (PTOA). Five common athletic injuries have been identified as placing people at greater risk of developing PTOA. Three of these injuries involve the knee: anterior cruciate ligament ruptures, meniscus tears (the second most common joint damaged in athletes) and patellar dislocation. The remaining two involve the shoulder (shoulder dislocation) and ankle (the most commonly injured joint in the body).⁴

In athletes or younger individuals, injury, occupational activities and obesity are the main factors that contribute to the development of OA. Diagnosis of OA in the athlete is often delayed and difficult because of high tolerance to pain, as well as the athlete's desire to return to play quickly.⁵

Regardless of when or how a person develops OA, in the final stages of disease progression the cartilage wears away and bone rubs against bone, leading to joint damage and more pain. When OA becomes severe, other than treating symptoms with pain medications, the only option for treatment becomes joint replacement. Currently, there is no cure for OA.

Despite the challenges of this disease, OA patients remain optimistic. According to a 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation, 92% of these patients say there are lots of ways around any problem.

Osteoarthritis (OA)

is the most common form of arthritis, affecting an estimated

30.8 million¹



Living With OA – Raquel’s Story

Most people think they don’t know anyone living with arthritis. Ten years ago, Raquel Masco didn’t think she knew anyone with arthritis either. That’s when she began experiencing unusual symptoms.

“First, something happened to my skin,” she says. “Then, my hair fell out. I had trouble swallowing. I thought maybe it was allergies, maybe it was just from being active. Then I started feeling tingling in the bottoms of my feet, my hands and pain in my back and legs. I come from a family of strong women where you just keep going. If you’re in the hospital on a Monday, you come home and mow the lawn on Tuesday. Nobody knew I was in pain. But I couldn’t physically get out of bed. It started to affect my job. I’m a hands-on mom, and it was hard for me to keep that up.”

Raquel remembers being poked and prodded so many times by so many doctors who said nothing was wrong with her. It wasn’t until she was in a serious car accident that she learned she’d been living with arthritis for more than a decade.

“I got rear-ended by an 18-wheeler sitting at a red light,” she says. “I had to have an MRI, and it showed I had osteoarthritis.”

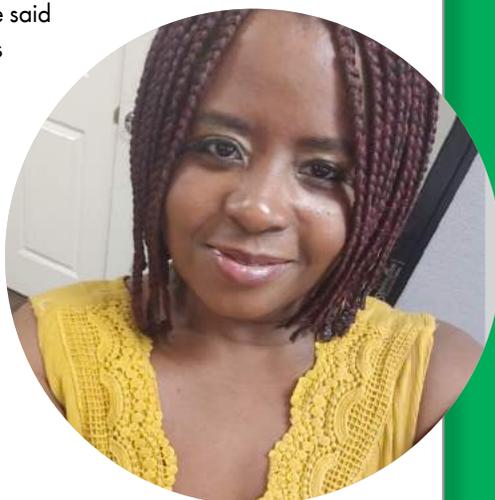
Connecting with people who have been through a similar journey has been transformative for Raquel.

“Finding the Arthritis Foundation was a blessing with a community of people who understood,” she says.

Once Raquel started sharing the story of her diagnosis and living with arthritis, she said other people started coming out and sharing their arthritis story – including friends she’d known for years.

“Others walking through this same journey know what I’m going through and understand,” she says. “Hearing the treatment that helped others, going to conferences and knowing what to talk to my doctor about is invaluable.”

Today, Raquel runs a nonprofit organization in Texas dedicated to empowering single mothers to live above and beyond their own expectations so they can thrive in every area of their lives. When she’s not working or volunteering for the Arthritis Foundation, she enjoys acting. She acts, writes and directs in a community theater and recently started her own production company to create more inclusive productions, including elevating people with disabilities.



“Being an arthritis warrior means taking the best care of myself, fighting for my best life, and then helping fight for others who may not be able to speak up,” says Raquel. “I fight for the Arthritis Foundation because they care about people who are living with arthritis, and I’m doing everything in my power to make an impact for a cure.” - Raquel Masco

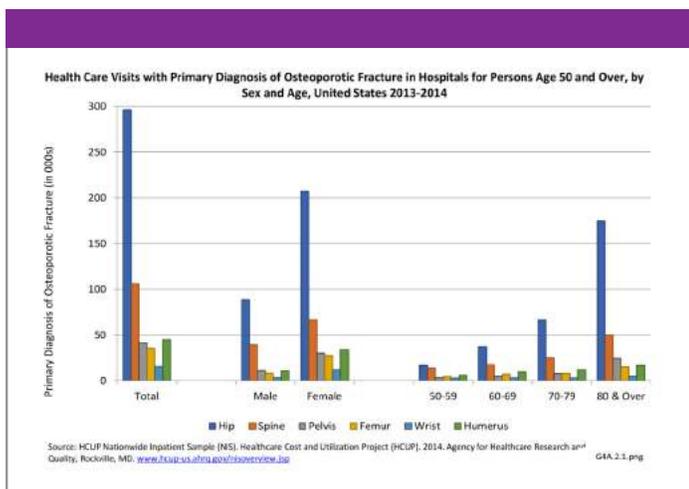
Prevalence in the General U.S. Population

Today, more than 32.5 million adults in the U.S. have doctor-diagnosed OA.

Age, Gender, Race and Ethnicity

According to Medical Expenditure Panel Survey from 2008 to 2014, about 32.5 million adults in the U.S. reported having doctor-diagnosed OA. The largest number of adults with OA by this classification demographically were non-Hispanic whites (25.3 million), middle aged (45-64 years old; 14.8 million) people or senior citizens (65 years or older; 13.8 million).⁶

Not all segments of the population are affected equally with OA. Among people younger than age 45, OA is more prevalent among men. Among those age 45 and older, it is more prevalent among women.⁷ In the Medical Expenditure Panel Survey from 2008 to 2014, non-Hispanic white people



Note: Accessed from USBJI Burden of Musculoskeletal Diseases in the United States.⁶

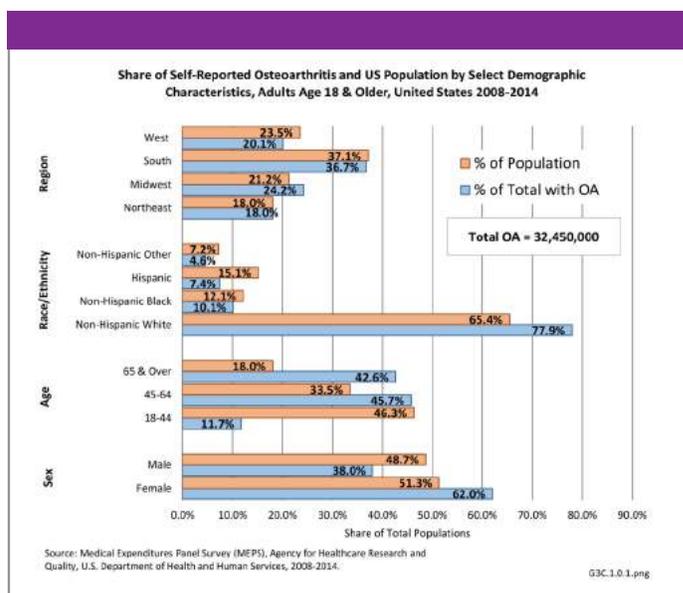
made up about two-thirds (65.4%) of the total 2014 U.S. population, but made up more than three-quarters (almost 78%) of the total proportion of people with OA. The same can be said for senior citizens, who made up less than one-fifth (18.0%) of the total U.S. population, but made up more than two-fifths (42.6%) of the total proportion of people with OA. Women, who made up a little over half (51.3%) of the total 2014 U.S. population, made up almost two-thirds (62.0%) of the total proportion of people with OA. Additionally, people who were married or with a partner (55%) were more likely to report having doctor-diagnosed OA than those who were divorced, widowed, separated (35%) or never married (10%).⁶

Pain and Other Health Burdens

In March 2017, the Arthritis Foundation hosted an OA Patient-Focused Drug Development (PFDD) meeting to elicit what is most meaningful for OA patients via public comment, online polls, patient panels and patient focus groups. The results of that meeting were published in the OA Voice of the Patient report. Patients clearly rate pain and tenderness as the symptoms that have the most impact on their daily lives. After pain, stiffness was identified as a significant symptom that impacted daily life. Other impactful symptoms included functional impairment in such activities as walking and standing, loss of flexibility, sleep disturbance and fatigue, grating (bone on bone) sensation, joint swelling, disfigurement, and other numbness and instability.⁸

A significant amount of time and energy is required to continually manage daily symptoms, including advanced planning for treatments and other regular activities, including vacations. Many people with OA say that the pain, fatigue, disfigurement and mobility limitations lead to social isolation, which impacts all their relationships. OA causes an emotional toll because others don't understand the challenges one experiences with this disabling disease. Pain and physical limitations are a source of shame and embarrassment for many.⁸ A greater proportion of individuals with OA are reported to have depression (12.4%), as compared to individuals without the disease.⁹

As with other forms of arthritis, OA is linked to increased rates of obesity, diabetes and heart disease, impacting overall health and making health care more challenging.¹⁰ Friends, family and co-workers may not understand the impact of OA because it may be largely invisible. Coworkers may assume they are getting special treatment with modifications and the patient may feel ostracized for requiring the changes.⁸



Note: Accessed from USBJI Burden of Musculoskeletal Diseases in the United States.⁶

Scientific research supports what patients are telling us. Current therapies, including pain management, improved nutrition and regular programs for exercise, do not lead to the resolution of OA.¹¹ Pain management is central to OA patients. In the U.S., about 65% of patients with OA are prescribed nonsteroidal anti-inflammatory drugs, commonly referred to as NSAIDs, making them one of the most widely used drugs in this patient population.¹² Commonly used NSAIDs include drugs like aspirin, ibuprofen and naproxen. Opioids do not appear to be cost-effective in OA patients without comorbidities, principally because of their negative impact on pain relief after procedures like total knee replacement.^{13, 14}

While OA can affect any joint in the body, it frequently occurs in the knees, hips and hands. Knee OA is the most commonly diagnosed joint site. The lifetime risk of developing symptomatic knee OA is 45%. The lifetime risk of developing symptomatic hip OA is greater than 25%.¹⁵ About 40% of U.S. adults are likely to develop symptomatic OA in at least one hand by age 85.¹⁶

Knees

The chances of developing knee OA increase with each decade of life, with the annual incidence of knee OA being highest between age 55 and 64 years old. The prevalence of knee OA has been increasing over the past several decades in the U.S., mirroring the aging population and the growing obesity epidemic.¹⁷

There are 14 million individuals in the U.S. who have symptomatic knee OA. Nearly 2 million are under the age of 45, about 6 million are age 45 to 64 years, and about 6 million are age 65 or older. This means that more than half of all patients with symptomatic knee OA (about 57%) are younger than age 65. Most will live for three decades or more after diagnosis. For these patients, there is substantially more time for greater disability to occur.¹⁷

The prevalence of symptomatic knee OA is higher in women than men in all age groups.^{18, 19, 20} Women, particularly those 55 and older, tend to have more severe OA in the knee, but not in other joint sites.²¹ About 80% of people with knee OA are from the non-Hispanic white population and about 20% identify as being a member of a racial or ethnic minority. Among adults at least 25 years of age, 7.5% of non-Hispanic whites, 6.9% of non-Hispanic blacks, 4.4% of Hispanics and 6.2% of other non-Hispanics had symptomatic knee OA in 2007-2008. The prevalence of advanced disease was 57% among both the non-Hispanic white and non-Hispanic black populations with symptomatic knee OA and 48% among Hispanics and 55% among other non-Hispanic persons with symptomatic knee OA. However, the number of people with OA who identify as being a racial or ethnic minority is increasing.¹⁷

For many complex reasons, patients often put off seeking medical attention until the health issue can no longer be ignored. By the end stages of OA, total joint replacement is often necessary to address the degradation of the joint and the associated symptoms that severely limit day-to-day function.²² Sadly, more than half of all individuals diagnosed with symptomatic knee OA are in end stages of OA and have had enough joint deterioration to make them eligible for total joint replacement. Although many patients eventually require total knee replacement, they spend an average of 13 years exhausting pain-relieving drugs and other non-surgical methods before undergoing surgery.²³

It's estimated that 54% of knee OA patients will receive total knee replacement over their lifetimes under current guidelines.²³ From 1999 to 2008, the utilization rate of total knee replacement procedures in the U.S. more than doubled for the overall population and tripled for patients age 45 to 64.²⁴ In 2010, 2011 and 2012, between half a million to about three-quarters of a million total knee replacements were performed on Americans annually.^{6, 25, 26}

Coupled with increasing knee OA prevalence, the rising costs of health care may inflict a tremendous societal economic burden in the future. There are currently no medical or surgical treatments that will improve this alarming trajectory.²⁷ The current trend suggests that there may be a lifetime 29% increase in direct medical costs due to this procedure among knee OA patients.²³

About 50% of patients with anterior cruciate ligament ruptures develop PTOA five to 15 years after injury, including those who have been treated and/or had surgery.⁴ The younger a patient is when they undergo their first total joint replacement surgery, the more likely they will be to require revision surgery, sometimes multiple revision surgeries, as

they get older. More than 55,000 revision surgeries were performed in 2010 in the U.S., with almost half (48%) of them in patients under age 65.²⁶ It is estimated that by 2030, nearly 2 in 3 total knee replacement revision patients will be under 65 years.²⁸ Risks of revision surgery are especially pronounced in the younger patient who may be more physically active, and consequently, subject to multiple revision surgeries over a lifetime.²⁶

Hips

The lifetime risk of symptomatic hip OA is estimated at 25.3%.²⁹

Hip and knee OA cause the greatest burden in terms of pain, stiffness and disability, leading to the need for prosthetic joint replacement in the most severe cases.³⁰ The most severe fracture resulting from OA involves the hip, which requires hospitalization and leads to permanent disability in half of all patients and fatality in 1 in 5 patients.¹¹ Total hip arthroplasty is a highly successful medical intervention, having favorable long-term outcomes in improvement of physical functioning, survivorship and self-reported quality of life.³¹

The number of total hip replacements performed on patients age 18 to 64 has increased by 91% between 2003 and 2013.³² In 2010 and 2011, there were about half a million (between 465,000 to 512,000) hip replacement procedures done annually in the U.S.⁶ Across all patients, primary total hip replacement is projected to grow by 75% between 2010 and 2020.³³ One study estimated that more than 50% of total hip replacements will be performed in patients younger than 65 by 2030.²⁸

Hands

The risk of developing symptomatic hand OA by age 85 differs across gender, race and body mass index (BMI – weight).

- Women are nearly twice as likely as men (47% versus 25%) to develop it.¹⁶
- Those in the white population are more likely to develop it than African Americans (41% versus 29%).¹⁶ A large community-based, U.S. study showed that even after adjustment for gender, age and BMI, African Americans are less likely to have radiographic (x-ray) evidence of hand OA than those that identify as white.³⁴
- Obese people are at greater risk than non-obese people (47% versus 36%).¹⁶

Studies show a relationship between hand OA and the presence of OA in other joints, especially the knee. A large population-based study of elderly Icelanders showed a strong link between the severity of hand OA and the prevalence of total knee replacement (TKR) due to OA.³⁵ A smaller Swedish study found similar results. X-ray evidence of hand OA was found to be associated with an increase in the frequency of knee OA following surgery for a meniscal tear.³⁶ Hand OA has also been associated with hip OA. The Icelandic study showed a relationship between the severity of hand OA, the presence of hip OA in conjunction with increased BMI and the prevalence of TKR due to OA.³⁵

Shoulders

A 2014 study found infection was the most common surgical cause of re-admission after shoulder replacement, and that patients incurred an average hospital cost of \$11,000.³⁷ Infection is a devastating complication after shoulder repair or replacement that can lead to substantial morbidity. Recent studies have reported a rate of infection of 0.27% after shoulder repair and up to 15% of shoulder joint replacement.³⁸ Most shoulder prosthetic infections are diagnosed after patients are discharged.³⁹

In 2015, the 90-day re-admission rate for shoulder replacement was reported to be as high as 6% and rising.

The rate of revision for failed shoulder replacement per 100,000 population has grown by 400% over the last two decades. Revisions in 2015 were reported to account for up to 10% of all shoulder joint replacements. The length of required hospital stays for these procedures is an important part of the costs. Factors associated with the risks of longer lengths of hospital stay, re-admission within 90 days and revision surgery include age, gender, race and hospital caseloads.⁴⁰

Economic Burdens

Earning losses due to OA were estimated at \$80 billion per year between 2008 and 2011, and they continue to rise.⁴¹

A study in 2012 demonstrated that OA was the most common cause of work loss and affected more than 20 million individuals, costing the U.S. economy more than \$100 billion annually.⁴² The costs of short-term disability, workers' compensation and absenteeism are much higher among persons with OA.⁷ It has been estimated that the costs due to absenteeism from OA alone are greater than \$11.6 billion due to an estimated three lost workdays per year.⁴³

OA consumes a tremendous amount of medical resources and causes considerable disability.⁴⁴ It accounts for more than 25% of all arthritis-related health care visits.⁴⁵ People with evidence of OA have much higher health care costs over a single year than those of similar age and gender without evidence of OA.⁷

Hospitalizations for joint repair, replacements and revisions are responsible for a large part of those costs.

For those over age 65, in 2011, the Medicare program reimbursed U.S. hospitals \$3.5 billion for total knee replacements (the program's largest expenditure for a single procedure).⁴⁶ In 2013, joint replacement procedures ranked fourth (total knee), seventh (total hip), 16th (partial hip) and 19th (revision knee replacement) of all musculoskeletal procedures. These procedures are projected to increase dramatically by 2030, particularly by persons under the age of 65.⁴⁷

- In 2010, each total knee replacement revision surgery was associated with total costs, including direct costs of care and such indirect costs as wage losses, of \$49,360.⁴⁸
- In 2012, over 1 million total joint replacements, at a cost of \$18.8 billion, were performed in the U.S.⁴⁹
- By 2013, knee OA contributed more than \$27 billion in health care expenditures annually.²³
- In 2013, each primary total knee replacement cost an average of \$20,293 and each revision TKA cost an average of \$26,388.²³

In 2012, OA was estimated to cost the U.S. economy more than **\$100 billion** and the costs continue to rise.



Comorbidities like diabetes, cardiovascular disease and obesity also add to the costs. Patients may be able to lower these costs by paying attention to diet, maintaining a healthy weight and exercising regularly, as well as working as patient partners with health care providers to control or reduce the effects of comorbidities. Between July 1, 2007, and June 30, 2012, people without significant comorbid conditions who underwent knee or hip replacement procedure had a greater decrease in OA-related health care resource utilization and costs after they recovered from surgery.⁵⁰

As expensive as these surgeries are, they can be cost effective in that they enable patients to gain back mobility, increase productivity and improve quality of life. There are risks associated with each procedure, which patients and their health care providers must weigh against the benefits gained. Compared with non-surgical treatments, total hip replacement increased average annual productivity of patients by \$9,503.⁵¹ Hip OA profoundly affects quality of life in the U.S., with estimated costs as high as \$42.3 billion from 904,900 hip and knee replacements in 2009.⁵² The total lifetime societal savings for hip repair or replacement were estimated at almost \$10 billion from more than 300,000 procedures performed in the U.S. each year.⁵¹



Global Prevalence and Burden

Globally, OA ranks fifth among all forms of disability.⁵³ It's the most common joint disease of the developed world and a leading cause of chronic disability, mostly driven by the higher prevalence of knee OA and/or hip OA.⁵⁴ In developed nations, OA is one of the 10 most common disabilities in older individuals, especially those who remain active in the workforce.⁵⁵

As the world's population continues to age, it is estimated that degenerative joint disease disorders like OA will impact at least 130 million individuals by the year 2050. In 2016, at least 15% of all adults over the age of 60 were believed to experience OA. For patients over age 60, women were, and still are, almost twice as likely to have OA than men; about 18% of women compared to 9.6% of men in this age group suffer from OA.¹¹ The prevalence of OA increases with age and affects up to 80% in people over age 65 in high-income countries.⁵⁶

Worldwide, the total number of years lived with disability caused by knee and hip OA increased by 60.2% between 1990 and 2010, and by 26.2% per 1,000 people. By 2013, OA moved up from 15th to 11th in the list of the most frequent causes of disability.⁵⁷ By 2014, hip and knee OA represented a substantial cause of disability and are responsible for approximately 17 million years lived with disability globally.⁵⁸

That number is increasing, and not just in older adults. Adolescents and young adults with anterior cruciate ligament injuries are prone to develop OA before they reach age 40.⁵⁹ Knee injuries remain the most prevalent worldwide. By 2012, there were 700,000 cases annually in the U.S., accounting for 12.5% of posttraumatic osteoarthritis cases. This proportion was often reflected globally.⁶⁰

Australia

In 2015, the cost of arthritic disease in Australia was estimated to be \$24 billion per annum, affecting 1 in 8 adults.⁶¹

By 2015, more than half of the 1.8 million Australians with OA were between 25 and 64 years old.⁶² An increasing incidence of sports injuries could result in an increasingly large future burden of OA in the population, with a corresponding increase in health service delivery and musculoskeletal injury/disease burden in future years. As in the U.S., comorbidities play a role in the increasing number of people with OA who need joint replacement. People requiring total joint replacement are 26% more likely to have cardiovascular disease than people without OA.⁶¹ In Australia, 13% of primary total hip replacements and 7% of primary total knee replacements are done in people under age 55.⁶²

While direct health care costs are often reported, indirect costs may be 8 times greater than direct costs, indicating that the true burden of OA is underestimated.⁶¹ Indirect costs include those expenses incurred from stopping work or reducing work productivity. Arthritis pain and disability are responsible for a significant number of people retiring early. The costs of retiring early in Australia due to arthritis include over \$9 billion in lost gross domestic product, and additional societal costs are associated with reduced work productivity.⁶²

United Kingdom

Knee replacements are being performed much more frequently in the U.K. There were more than 80,000 primary knee replacement procedures done in 2011 are increasing by around 3% annually. Since 2006, most knee replacement patients have been obese (body mass index of 35 or greater), and this proportion is growing. In 2006, 15% of patients were obese. By 2013, 21% percent of patients were obese.⁶³

By 2015, there were around 5,000 (6%) revisions out of 88,000 total knee replacement procedures performed in England each year. Younger, more active patients are at greater risk of implant failure, as are obese patients. The need for revisions is bound to increase considerably with the increase in primary procedures and the tendency to operate on younger and more obese patients.⁶³

Spain

In Spain, remote areas have higher rates of OA (hand, hip, knee). OA patients in the most remote areas were younger, more likely to be male, had a higher percentage of obesity, and were often smokers and high-risk alcohol users.

The increased prevalence of obesity accounts for 50% of the excess risk of knee OA observed. Public health interventions to reduce the prevalence of obesity in this population could reduce health inequalities.⁶⁴

In developed nations,
Osteoarthritis is one of the
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Living With Military OA – Nick’s Story

Nick Steen is a military veteran, an osteoarthritis (OA) patient and a juvenile arthritis (JA) dad. He joined the Army right out of high school in 1994 and was honorably discharged four years later. During his time in the military, Nick learned how to be a leader and how to save lives, but he also learned he had OA.

As a heavy machine gunner, Nick was either carrying a 30-pound gun or approximately 600 rounds of ammunition that often weighed over 50 pounds, in addition to the normal load. As you can imagine, jumping out of airplanes with this type of weight often made Nick turn into an anchor as he crashed to the ground. His training pushed his joints to their limit.

There were times that Nick considered his osteoarthritis as a sign of weakness, or something he deserved for not taking care of his body. For a while, he even refused to take the pills prescribed by the VA to treat his pain. In the end, he did more damage than good by trying to ignore his OA.

Nick gained a new perspective when his daughter was just 18 months old and was diagnosed with juvenile idiopathic arthritis. All the sudden, arthritis was a part of his family’s story in a new way.

Now, Nick and his daughter share their arthritis journey together. She has essentially lived her entire life with this disease, and his adult life has been shaped the same way. They are partners that tackle arthritis together, encouraging each other when they flare and celebrating together when they overcome the challenges of their disease.

“In sharing my experience with my daughter, my partner in this journey, I have come to learn that this disease is not a sign of weakness,” says Nick. “This disease does not care who you are or what you’ve done. It attacks us all – and so we all must take a stand against it together.”

Sharing his story with his community has helped Nick tremendously. Nick and his daughter discuss their experience with each other, their community and their country to help raise awareness and advocate for a cure.



“I served my country proudly and I would do it again. But I am concerned that my choices to help keep this country safe have now caught up to me in the form of OA.” - Nick Steen

Prevalence in the Military

Tactical Athletes

People in service professions like the military, firefighters, law enforcement and first responders experience high levels of physical requirements on their jobs. They are sometimes referred to as tactical athletes. Globally, the physical fitness and work-related demands of such occupations have increased the risk of acute traumatic joint injury. Their jobs require a lot of repetitive bending, squatting, kneeling and lifting that can increase the chance of developing OA. As an example, 1 in 3 military veterans in the U.S. lives with arthritis.⁶⁵ The rate of osteoarthritis in military service members is 26% higher than the general population for veterans aged 20 to 24 and twice as high as the general population for those 40 and older.⁶⁶

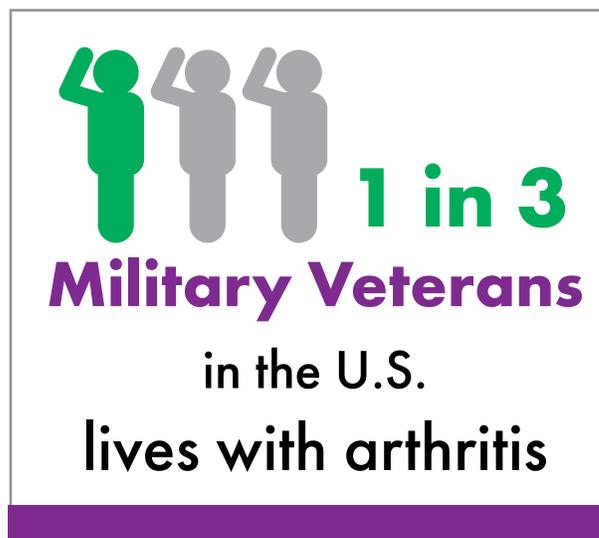
Globally, Swedish firefighters are about 2.5 to 3 times more likely to have knee or hip OA than the general population.⁶⁷ For Danish soldiers on combat duty in Afghanistan, the risk of suffering knee problems and the severity of symptoms increased with the amount of time spent patrolling in armored vehicles.⁶⁸

In the U.S., military rank and branch of military service appear to be occupational risk factors associated with OA. It has consistently been a leading cause of military disability discharge for more than a decade, regardless of whether the estimates are from peacetime or periods of combat.⁶⁷

Compared to the general population, active duty military are significantly more likely to experience an OA diagnosis anywhere in the body, but especially in the knee and hip. The prevalence of lumbar (back) and cervical (neck) OA were 49% to 76% higher in some military populations (like active duty pilots and veteran parachutists) compared to the general population. Overall, those serving in the Army and the junior enlisted ranks experienced the highest rates of OA.⁶⁷

The risk for U.S. active duty military to develop OA increased from 2005 to 2014. The risk for knee OA increased for older veterans, African Americans, those with senior military rank and members of the Army or Air Force.⁶⁹ When compared to the general population of people over 40 and those of lower rank service members in the Army, Navy and Marines, the risk for military service members to develop hip OA is higher due to the extreme activity and occupational demand of their jobs.⁷⁰

As the military population ages, OA is represented differently based on gender, race and ethnicity. The results of a 2016 study showed that for service members age 25 and older, the overall rate of OA was higher among African Americans and non-Hispanics than other racial/ethnic group members. By gender, the rate of shoulder OA was higher among men than women. However, among service members age 30 and older, women had higher rates of knee and pelvic region/thigh OA than men.⁷¹



Human and Economic Burdens of Arthritis in the Military

Posttraumatic OA of the knee is the most common indication for total knee replacement among young military personnel aged 50 and younger.⁷² As soon as 20 months after injury, PTOA is recognized as a disabling condition.^{73, 74}

This is significant for several reasons. First, consider that the U.S. military has been engaged in active combat since 2001, the longest period of continuous active combat in U.S. history. This has resulted in over 14,000 service members evacuated from combat due to disease and injury.⁷⁵ However, OA results from far more issues than just combat injuries. Injuries sustained in training, leisure or sport that ultimately put the patient on the path to PTOA are just as common. For U.S. military personnel (2005-2013), 74% who had total knee replacement had a previous injury before the development of end-stage PTOA.⁷² Arthritis is the most frequent reason for medical discharge and among the most common conditions treated by Veteran Affairs health care facilities.⁷⁵

For veterans with arthritis and arthritis plus back pain, there is a higher rate of diabetes, high cholesterol, high blood pressure and obesity as compared to veterans with no pain diagnosis. Further, traumatic brain injuries, post-concussive syndrome, posttraumatic stress disorder and behavioral health disorders, combined with the stigma attached to these issues, complicates the diagnosis and treatment of chronic pain in this patient group. Chronic pain due to musculoskeletal pain and combat-related polytrauma pain has been reported in up to 50% of the veteran community and 44% of all U.S. service members after combat deployment, compared to 26% in the general population.⁷⁶ Veterans with arthritis plus back pain had the highest pain clinic use and prescription use of opioids and anti-inflammatories.⁷⁷ This is significant because arthritis, a disease that can cause chronic moderate-to-severe pain, is one of the most common conditions among chronic users of opioids in the U.S.^{78, 79}

**Back and Neck
Osteoarthritis are
49% - 76%
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the general population**

What the Numbers Mean, Kathy's Story: Rethinking Life With Severe OA

Meet Kathy Geller, who touched many lives during the years she spent as an Arthritis Foundation exercise trainer and education program presenter – a role model for successful self-management. Following, in her own words, is Kathy's story about living with severe degenerative osteoarthritis (OA) and how the statistics she reviewed in this edition of Arthritis by the Numbers relate to her personally.

Question: What changes has your osteoarthritis made to the way you live?

Kathy: During my 18-year struggle with severe OA, I wasn't always a Champion of Yes. Yes, I helped others battling arthritis, but inwardly, I was overwhelmed by all the things I said no to because of arthritis. No – I couldn't hold my first grandchild because my hands were in casts after joint replacement. No – I had to give up my profession because I could no longer assist clients or lift the equipment necessary to train them. No – I couldn't stay in the family home my husband and I built because it was too difficult for me after the 10-plus OA surgeries I've endured, most recently to fuse two-thirds of my lumbar spine.

To say the quality of my life has been affected would be an understatement. My home environment consists of one-floor living. I have every imaginable arthritis-friendly utensil, jar opener, lightweight serving dishes and more. I think twice before traveling – how far will I have to walk through the terminal, do I need to check in my bag rather than lift it into an overhead bin? I must conserve my energy and pace my day.

Giving in should not be confused with giving up. I finally accepted I am living with a chronic disease. OA is not life-threatening, but it's insidious. It slowly chips away at your cartilage and your spirit. With the help of the Arthritis Foundation, I've begun to turn no into yes. I have found my voice through the Foundation's Ambassador program.

Question: What advice would you give to a newly diagnosed patient or parent/caregiver?

Kathy: My advice is to make sure you are seeing the right physician. This is a relationship you will have for a long time. It's crucial you feel a connection that enables you to open communication and develop a partnership. Find out all you can about the type of arthritis you have. Learn and practice as many self-management skills you possibly can, keeping body weight under control, staying active, exercising and pacing yourself. Don't be afraid to ask for help.

Arthritis has a significant effect on my life, but it doesn't define me. I appreciate the quiet times not filled with surgeries, recovery and therapy. And I know I'm strong and prepared to confront the active times when OA strikes again.



“Arthritis has a significant effect on my life, but it doesn't define me. - Kathy Geller

SECTION 3: GOUT

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WHAT IS GOUT?

Gout is not an autoimmune disease, although it can cause intense inflammation. Gout arises from metabolic disturbances that eventually lead to joint inflammation. Metabolic diseases occur when the body has disturbances in the processes that regulate the production of energy at the level of the cell. For patients with gout, the body processes uric acid differently, which can lead to the buildup of uric acid or reduction in the ability of the body to eliminate this chemical. Uric acid is a breakdown product of purines. Uric acid levels can be related to the types and amounts of food we eat and how our body processes (metabolizes) them.

Gout develops in some people who have high levels of uric acid in the blood. Rich food and drink can contribute to the development of gout, but the real cause is how the body breaks down purines into uric acid and how it is excreted from the body by the kidneys. People who have kidney disease can have higher levels of uric acid in the blood since their kidneys do not adequately eliminate this chemical.

If excessive uric acid builds up, it can form needle-like crystals that deposit in the tissue. When released into the joint, these crystals trigger intense inflammation and an acute attack of arthritis, usually of a single joint such as the knee or big toe. The joint pain can appear suddenly, with severe episodes of pain, tenderness, redness, warmth and swelling. The pain may last hours or weeks and make it difficult to perform daily activities. The attack can also be associated with fever.

About

8.3 Million
people in the U.S.
have gout

While most forms of arthritis affect women more than men, gout is the exception. Gout is more common in men. Men are nearly 3 times more likely to develop gout, compared with women, and black males are most commonly affected.¹ Gout is unusual in pre-menopausal women, but can be found in post-menopausal women.² Gout incidence increases with age in both men and women, with the most significant age related increase noticed in post-menopausal women.¹ Gout is associated with metabolic syndrome; obesity, hypertension and diabetes are other features of the metabolic syndrome.

Despite the pain and challenges gout causes patients, there are effective therapies to lower uric acid in the body, either by reducing the production of uric acid or increasing its elimination by the kidney. These therapies can lessen the accumulation of uric acid deposits, which are called tophi. A tophus can be visible as a bump or

nodule frequently near the elbow, or they can occur in other locations including the fingers. Lowering uric acid can also promote the dissolution of the uric acid in the tophus. Unfortunately, many patients do not receive effective therapy to lower uric acid. Inadequate adherence to can also impair a program of prevention.

In addition to the use of drugs to lower uric acid, 95% of gout patients say there are things a person can do to make their arthritis better (source: 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation). Lifestyle factors, such as eating a rich diet high in certain high-purine foods (like red meats or shellfish), being overweight or obese, and excessive alcohol use can contribute to the development of gout.

Prevalence

Gout is one of the most common rheumatologic diseases and is the most common cause of inflammatory arthritis among adults in the U.S.³ About 3.9% of adults in the nation, or 8.3 million individuals, have gout. The prevalence of gout increases with age and peaks at more than 12% in people over 80 years old.⁴

Comorbidities related to metabolic syndrome, such as diabetes, obesity and high blood pressure, are believed to play a role in the rising prevalence of gout.^{4,5} The National Health and Nutrition Examination Survey data from 2007-2008 reported that, among gout patients, more than half also had high blood pressure (74%), stage two or greater chronic kidney disease (71%), and/or were obese (52.3%). Additionally, about 1 in 4 patients had diabetes (26%), and 1 in 10 or more had experienced heart attack (14%) and/or stroke (10%).⁶

Weight is one of the most important and potentially controllable factors related to gout's prevalence numbers. In the U.S., the prevalence of gout is only seen in 1-2% of people of normal weight. Prevalence increases as body mass index (BMI, a weight to height ratio that can indicate body fat) increases. In people who are overweight (BMI 25.0-29.9), prevalence is 3%. In people who are obese (BMI 30 and over), prevalence rises from 4-7% as BMI increases.⁷ And while obesity is not only a risk factor for developing gout, it is also associated with an earlier age of gout onset.⁸

Gout in Women

The onset of gout occurs at a later age in women – usually after menopause. Women are more likely to have comorbidities such as hypertension or renal insufficiency, and they use diuretics more often. Because gout is a rare disease in women before menopause and it can have an unusual way of manifesting itself, it is very important to recognize the symptoms. Health care providers should consider gout especially in post-menopausal female patients with hypertension, diuretic use, renal insufficiency, and arthritis in one or more joints. Women may more often have other joints involved than just one toe, and the gout recurs less often than in men.⁹

Health Burdens

Once patients are diagnosed, acute gout may be treated with nonsteroidal anti-inflammatory drugs, corticosteroids or colchicine. After an initial gout attack, chances are high that more will occur. About 2 in 3 (60%) patients experience a recurrent gout flare within a year of an initial event and about 4 in 5 (78%) experience a recurrent flare within two years.¹⁰

Sometimes, an acute attack of gout is related to a situation like dietary indiscretion and too much alcohol and may not recur. In other patients, gout attacks occur regularly, signaling the need for drug therapy to decrease uric acid in the body. Some of the approved drugs used to treat gout include allopurinol and febuxostat (Uloric), which inhibit the enzyme xanthine oxidase and can reduce uric acid production. Another drug, probenecid, also can lower uric acid by increasing the excretion of uric acid in the urine. Although this agent was used commonly in the past, its effects are limited in patients with chronic kidney disease. Increasing uric acid in the urine can also increase the risk of kidney stones.

Because gout can be related to BMI, patients should focus on diet and exercise to help reduce the likelihood of flares. To avoid high levels of uric acid in the blood, patients should avoid or limit consumption of certain purine-rich proteins (like red meat, wild game, organ meats and shellfish, and some large saltwater fish), alcoholic drinks (especially beer) and beverages sweetened with high-fructose corn syrup. Eating more vegetables and low-fat or nonfat dairy products, as well as purine-rich nuts, oatmeal, asparagus, legumes and mushrooms do not seem to increase risk of gout flares.¹¹

Pain associated with acute gout has been described as intolerable, resulting in a feeling of desperation for the attack to end and a sense of helplessness.¹² Severe foot pain, impairment and disability were observed in a study among patients with acute gout. Gout flares frequently result in patients being unable to bear weight and being bedbound for the duration of the acute attack.¹³ As gout progresses, advanced gout is associated with joint damage, impaired mobility and reduced health-related quality of life, as well as an increased risk of death, primarily due to cardiovascular disease.^{5, 14}

The financial burden of gout can be measured in direct (medical) and indirect (loss of wages/productivity) terms. In 2012, the combined estimate of annual direct and indirect costs of gout patient care totaled more than \$6 billion. This included \$4 billion in direct costs and \$2.6 billion in indirect costs.¹⁵ These numbers have been increasing.

Work/Employment Impact

Poorly controlled gout leads to absences from work, health care use and reduced social participation.³ Compared to workers without gout, employees with this condition used significantly more sick leave, short-term disability and workers' compensation benefits.¹⁶

In 2012, the cost of gout patient care totaled more than

\$6 billion 

- these numbers are increasing.

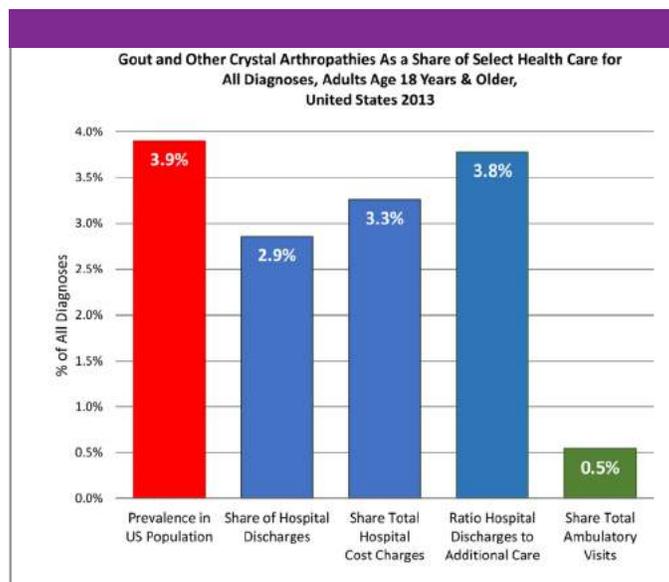
Consider this example: the U.S. labor force consisted of 155 million persons in July 2012. If gout was present in 2% of workers (3.1 million persons), and each missed five days per year because of gout, the yearly loss of wages/productivity amounts to \$833 per worker (based on 2010 data), or an overall national loss of \$2.6 billion.¹⁵

On an individual level, the yearly loss of wages/productivity increases as gout progresses to a more advanced stage. The number of workdays missed increases as the number of yearly gout flares increases.¹⁷

Medical/Cost Burden

Patients with gout have higher than average medical costs and health care utilization than patients without gout.¹⁸ The increased costs of gout are generally associated with poorly controlled disease and are largely modifiable. Gout is a metabolic disease that can be improved with proper diet, exercise and medication. Substantial resources could be spared by closing the gap between doctor recommendations and patient practice.¹⁹ Medication adherence is important for a program of prevention to reduce frequency of gout and reduce the likelihood of permanent joint damage.

By 2013, gout accounted for about 7 million doctor visits in the U.S. at an annual cost of nearly \$1 billion.²⁰ While comorbid conditions may account for some of the elevated resource use among gout patients, gout-related health care utilization increases with the severity of gout.²¹ Health care utilization can be estimated using two main sources: hospital and outpatient (or ambulatory) care.



Note: Accessed from USBJ Burden of Musculoskeletal Diseases in the United States.²³

From 2006 to 2012, the rate of emergency department (ED) visits for gout in adults increased 14% from 75.0 to 85.4 per 100,000. The rate increased 29% for those aged 45 to 54. Emergency department charges increased 80%, from \$156 million to \$281 million.²²

From 2009 to 2012, the number and cost of ED visits with gout as the primary diagnosis rose.

- In 2009, there were 180,789 ED visits, costing a total of \$195 million.
- In 2010, there were 201,044 ED visits, costing \$239 million.
- In 2012, there were 205,152 ED visits, costing \$287 million.²²

In 2013, more than 850,000 hospitalization for gout represented 2.9% of hospital visits for all conditions. Patients with gout were more likely to be discharged to short-term or home health care than other diagnoses.²³

Those numbers are increasing. By 2016, nearly 8% of all emergency department visits for gout resulted in hospitalization, with a median inpatient stay approaching three days.²⁴

The number of outpatient (or ambulatory) visits for gout has also increased. From 1993 to 2009, the frequency of outpatient visits for gout increased 3 times, with the most significant increase after 2003.²⁵

During the six-year period from 2002 to 2008 there were a total of 50.1 million gout-related ambulatory visits in the U.S. This averaged out to about 7.2 million visits per year, costing about \$1 billion annually.²⁰

In 2013 there were about 5.3 million outpatient visits for gout. Almost three quarters of these visits were for men (72%) and half were for those who were 65 years or older (50%).²³

What the Numbers Mean , Craig's Story: Words of Wisdom About Living With Gout and OA

Meet Craig Buhr, who is challenged by gout and osteoarthritis (OA). Following, in his own words, are his thoughts about the statistics he reviewed in this edition of Arthritis by the Numbers – and how they relate to him personally.

Question: How did you get involved with the Arthritis Foundation's mission to stop arthritis?

Craig: I first noticed joint pain when I was 42. I was diagnosed with osteoarthritis, having enlarged knuckles and other typical symptoms. I thought arthritis was just a part of aging. My pain intensified over the next years, causing difficulty in walking and maintaining an active work and home lifestyle. As a detail-oriented engineer, I did research to better understand this disease. I learned so much from the Arthritis Foundation's books, Arthritis Today magazine and information online.

Question: How do the statistics you reviewed apply to what you were going through?

Craig: There's a correlation between gout and OA, shown by comorbid biomarkers. I didn't know that before reading about it through the Arthritis Foundation. If I had, I would have posed more specific questions to my doctor earlier or modified my diet sooner as a preventive measure.

Question: What changes have you made in your life?

Craig: Excess weight has a severe and detrimental effect on joint longevity. I ramped up my cardio-based fast-walking and cross-trained with weights on alternating days. I was able to lose 37 pounds in just over a year. I participated in the Arthritis Foundation's Jingle Bell Run for the first time and recorded my best overall personal pace. I've been able to contain my gout flares. Conquering OA, which is a sinister and progressive disease that slowly degenerates joints, has been more challenging. But wraps, braces and heating packs have helped.

Question: What's your advice to someone newly diagnosed with arthritis?

Craig: Equip yourself with knowledge from the Arthritis Foundation. Seek medical assistance promptly. Talk with others going through this. Adjust your lifestyle to mitigate the long-term impact of OA, gout and other joint diseases. Expect rough spots. Get some rest. Volunteer to help others dealing with this. Research is constantly learning more about these debilitating diseases, so keep the faith and take care.

Question: What would you like arthritis researchers and health care experts to focus on?

Craig: I'd like to learn more about when it might be appropriate to get a joint replacement. How long do I put up with discomfort and loss of mobility before I consider that? We all desire the best quality of life, whatever stage of life. We want to function and remain active members of society.



“Excess weight has a severe and detrimental effect on joint longevity. I ramped up my cardio-based fast-walking and cross-trained with weights on alternating days.” - Craig Buhr

SECTION 4: AUTOIMMUNE AND INFLAMMATORY ARTHRITIS



A RELATED GROUP OF RHEUMATOID DISEASES

The normal immune system is protective and plays a key role in the defense against infection by bacteria and viruses, and even the emergence of cancerous cells. The immune system can also respond to injury and promote healing and repair. But the immune system can go awry, mistakenly attacking body tissues with intense inflammation, causing arthritis. Inflammation can damage any organ or organ system. During the disease course of some forms of inflammatory arthritis, inflammation can occur in other tissues and organs such as the skin, eyes and kidney. Inflammatory conditions can be termed autoimmune if there is evidence of abnormal reactivity to tissues in the body. This reactivity can be determined by blood tests for antibodies called autoantibodies.

Because there currently are no cures for these diseases, the goal of treatment is to reduce inflammation and pain, improve function, and prevent further joint and organ damage. Increasingly, with current therapy, remission is possible for many patients, providing a strong rationale for early diagnosis and treatment.

There are many types of joint diseases that fall into the category of inflammatory and autoimmune arthritis. This section presents the facts for some of the most common diseases in this group:

- Connective tissue diseases with multi-system organ involvement, including **systemic lupus erythematosus (SLE or lupus)**, **Sjögren's syndrome** and **scleroderma (systemic sclerosis)**, are also referred to as rheumatic or connective tissue disorders. These conditions can be considered as autoimmune if there is evidence of immune reactivity to normal components of the body, usually demonstrated by the presence of abnormal antibodies or autoantibodies in the blood. In the rheumatic diseases, antibodies to components of the cell nucleus are common. In these conditions, there can be inflammation and damage of multiple organ systems, including joints.¹
- **Rheumatoid arthritis (RA)** has a main manifestation of arthritis, but RA can affect multiple systems including lungs, heart, vessels, eyes and others.
- **Spondyloarthritis (SpA)** is an umbrella term for diseases primarily involving the sacroiliac as well as the joints, ligaments and tendons in the spine or axial skeleton. Ankylosing spondylitis is the most common form of SpA, and this term is used when there is evidence of sacroiliac involvement by X-rays. Some forms of psoriatic arthritis (PsA) also involve the spine. SpA is associated with inflammation of other tissues and organs such as the eye and gastrointestinal tract.

Women are
2 to 3 times
more likely to be affected by
autoimmune forms of arthritis as men.

Women are 2 to 3 times as likely to be affected by autoimmune forms of arthritis as men.² It is estimated that 1 in 12 women, compared to 1 in 20 men, will develop such diseases during their lifetime.³ But why are women more likely to be affected?

New Research Contributes to Understanding Why Someone Develops Autoimmune Disease

What causes the immune system to go awry? We know a lot, but we don't have all the answers. Research has looked at different suspected causes of autoimmune diseases – both genetic and environmental. Most likely there are multiple reasons for this to happen. The National Institutes of Health states that autoimmune

diseases are “individually rare, collectively common.” In 2012, these diseases were estimated to affect more than 23.5 million Americans (more than 7% of the population), with the prevalence rising. Of the more than 80 autoimmune diseases, rheumatoid arthritis and lupus are listed as two of the top five most common autoimmune diseases (this list also includes type 1 diabetes, multiple sclerosis and celiac disease).^{4,5} According to the American Autoimmune Related Diseases Association (AARDA), the number of people being diagnosed with autoimmune diseases is increasing at a rapid, epidemic rate. AARDA estimates that about 50 million Americans (20% of the population or 1 in 5) suffer from autoimmune diseases, with 75% of those being women. This has serious implications for the government and health care professionals. If this trend

continues, the number of patients with autoimmune forms of arthritis and other rheumatological diseases will increase significantly – far outpacing the current rheumatology health care workforce.⁶

Genetic and Epigenetic Implications

This area of investigation goes to whether disease is inherited from family through DNA or if there is an environmental piece. Many genes are now associated with the development of arthritis and other rheumatic diseases. In general, these genes involve the regulation of the immune system and likely evolved to help the immune system fight against major infections such as malaria or the plague. When present in certain combinations, these genes can lead to a predisposition to autoimmunity.

Epigenetics looks at the ways that genes and the environment interact and affect the structure of DNA and the effects on gene expression. [Dr. James Jarvis](#), another Arthritis Foundation-funded investigator, explained that cells can sense the environment and respond by modifying the structure of DNA, changing which genes are turned on or off. So, even subtle changes in which genes are turned on or off can disrupt the timing and coordination of cell processes, leading to chronic inflammation. This can affect the offspring for generations. For instance, it has been shown with mice that a traumatic event associated with certain smells can cause cowering in response to the smell for several generations of mice (even in the offspring that are only exposed to the smell and no trauma). Or, as Dr. Jarvis explained, “The Mohawk nation has a saying that the harms inflicted on the Mother can be felt for at least seven generations.”

Microbiome Implications

Scientists have been studying the relationship of bacteria in the mouth, lungs and intestines and the development of different autoimmune diseases. These bacteria are an ordinary part of the body and are known as the microbiome. In fact, there are more bacterial cells in the body than human cells. It is increasingly recognized that bacteria in the digestive tract can play an important role in the immune system and protection against pathogens. [Dr. Jose Scher](#), an Arthritis Foundation-funded investigator, explained, “In a healthy individual, there is a balance in the diversity of bacteria. It makes us question whether certain bacteria are triggering the body to produce an immune response.”

Stress Implications

A 2018 paper suggested that stressful life events may play a role in the development of autoimmune disorders. The paper explained how psychological stress, stressful events, chronic stress and the body’s mechanisms to cope with stress can set up a cycle of continued activation of the immune system through the nervous system. The nervous system sets up a fight or flight reaction within the endocrine and immune system, which after a time, the body doesn’t shut down. This pattern has been implicated in conditions of chronic inflammation such as RA, lupus and juvenile idiopathic arthritis (JIA) in children.⁷

The role of stress is echoed in the discussion about adverse childhood experiences (ACEs). Studies have shown that the number of ACEs a child experiences, if not mitigated with positive experiences or protective factors, can lead to the development of serious chronic health conditions.^{8, 9}

There are many other areas for potential causes of these diseases. Is it just one factor or are there many factors? We don’t know. The data we’ve collected so far depends on the questions that scientists are asking – how the problem is defined for a specific study. If the question hasn’t been asked, the information isn’t there – yet. This is why patient input and the Live Yes! Arthritis Network are so important. Patients have different questions and observations about their diseases. This may lead to new pathways to explore as we look for cures together.



Living With RA – Bonnie’s Story

Bonnie Simpson Mason, MD, faces the conference room in a power pose, hands on hips, and the medical students rise from their seats to copy her stance. Poised and confident, genial but firm, she shares her tips for success.

“Be an initiator. Be a problem-solver. Be resourceful. Be that person who’s there early, who stays late, who’s always enthusiastic,” she tells the students.

Dr. Mason herself is all of that. Those attributes helped her become an orthopedic surgeon – an African American woman in a highly competitive, male-dominated field. And when rheumatoid arthritis (RA) made it too difficult to continue, those qualities helped her continue to succeed in another career. Dr. Mason, 48, runs Nth Dimensions, a nonprofit organization she created to provide mentoring, scholarships and research opportunities for women and minority students seeking to enter competitive medical and surgical specialties.

She also helps physicians learn the business of medicine through her company, Beyond the Exam Room, and is a visiting professor at the University of Texas Medical Branch in Galveston and the University of Louisville School of Medicine in Kentucky. Her husband, Thomas Mason, MD, the chief medical officer in health information technology with the U.S. Department of Health and Human Services, is a steadfast support as she balances a demanding work schedule with family life (they have two preteen sons) and dealing with RA.

As she pursued a residency in orthopedic surgery, Dr. Mason held herself to the standards and expectations she now imparts to her students – being prepared, always learning and networking. She became one of only two women in an orthopedic surgery residency at Howard University in Washington, DC. And when she became chief resident, she was determined not to show signs of weakness, even when she began to feel ill.

She was very active, and like other residents, she worked 100 to 120 hours a week. When she developed pain in her feet, she simply switched from heels to flats. But then came gastrointestinal upset. One day, she had searing pain in her shoulder, which she chalked up to performing a total hip replacement. She blamed pain in her hip to climbing too many stairs. But other symptoms followed – weakness, fatigue and a burning sensation in her hands. A concerned friend insisted she go to the emergency room, where she was referred to a rheumatologist who diagnosed RA.

Eventually, she gained control of her RA with corticosteroids and disease-modifying antirheumatic drugs. She still struggles with fatigue, but her RA is well controlled and she keeps herself healthy with daily exercise, stress management, naps, lots of juiced vegetables and listening to her body.

At the end of her residency, Dr. Mason won a prestigious hand surgery fellowship at Columbia University, which she had to turn down due to RA. She performed surgery for three years before pain in her right elbow became too intense; she can’t fully extend that arm. Losing her career as a surgeon was a blow.

“I voluntarily sought out therapy from a mental health perspective because it was a grieving process,” she says. “Never once did I doubt or question or say to myself that I went through all this orthopedic training for nothing. I knew there had to be a bigger reason why.”

She poured her energy into Nth Dimensions. In 2015, Dr. Mason received the Diversity Award from the American Academy of Orthopaedic Surgeons. She’s working now to build an endowment to ensure Nth Dimensions’ future and its impact. For Dr. Mason, RA turned out to be enabling, not disabling.

“He told me I had the most intense case of rheumatoid arthritis that he had ever seen.” - Bonnie Simpson Mason, MD

RHEUMATOID ARTHRITIS

Rheumatoid arthritis (RA) is an autoimmune disease in which the body’s immune system mistakenly attacks the joints. This creates inflammation that causes the tissue that lines the inside of joints to thicken, resulting in swelling and pain in and around the joints.

If inflammation goes unchecked, it can damage cartilage, a shock-absorbing tissue that covers the ends of bones in a joint and makes joint motion smooth. The inflammation can also affect the bones themselves in a process called erosion. Over time, there is loss of cartilage and the joint spacing between bones can become smaller. Joints can become loose, unstable, painful and lose their mobility. Irreversible joint deformity can occur, so doctors recommend early diagnosis and aggressive treatment to control RA.

RA most commonly affects the joints of the hands, feet, wrists, elbows, knees and ankles, and is usually symmetrical. Because RA can also affect other body systems, such as the cardiovascular or respiratory system, it is called a systemic disease, meaning it affects the entire body.

Patients with RA commonly produce antibodies to modified proteins known as citrullinated proteins. These antibodies, called ACPAs or antibodies to citrullinated proteins, occur in about 80% of patients. ACPAs are also called anti-CCP or antibodies to cyclic citrullinated peptide. Other antibodies include rheumatoid factor (RF), which is directed to the immunoglobulin molecules. Determination of ACPAs and RFs is important in diagnosis. Despite the many challenges of this disease, 87% of RA patients are optimistic and say they have access to a good health care team for their arthritis (source: 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation). Current therapy can produce remission in a significant number of patients.

Prevalence

Prevalence is increasing. In 2005, RA was estimated to affect 1.3 million adults in the U.S.¹ By 2007, an estimated 1.5 million U.S. adults had rheumatoid arthritis.²

Globally, the prevalence of RA is estimated to be between 0.5 to 1% in developed countries. Prevalence in the U.S. falls into the low range of developed countries at 0.6% of the population.³

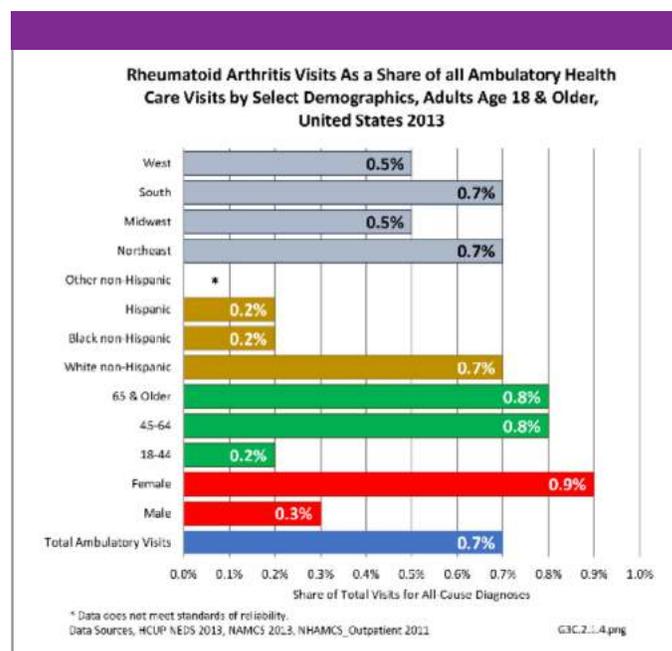
Health Burdens

In 2011, RA was diagnosed in 6.4 million ambulatory (non-hospital) visits. Among these visits, females, non-Hispanic whites and those age 45 and above represented the largest populations who sought health care for this disease.⁴

Comorbidities like heart and lung diseases, depression and anxiety, and bone fracture risks affect RA patients to varying extents. Mortality hazards are 60-70% higher in patients with RA compared with those in the general population. The overall survival gap between patients with RA and those without RA has not been closing over the past decades.⁵ A 2007 study found greater mortality rates in RA patients compared to adults without the disease. RA patients had increased risk of death rates due to cardiovascular disease (31%), pulmonary fibrosis (4%) and lymphoma (2.3%).⁶ However, more recent studies have shown the survival gap related to cardiovascular disease has improved in RA patients as compared to adults without RA.⁷

Diabetes can affect RA patients, depending on the severity of both diseases. From 1987 to 2012, patients with RA were hospitalized at a greater rate for diabetes mellitus than were people without RA.⁸

Patients with RA, regardless of age, are at high risk of falls as well as fall-related injuries and fractures. RA patients are at increased risk of osteoporotic fractures. The risk of non-spinal fractures is increased in RA patients who are treated with opioids. Risks of fracture associated with opioid use were more than 6 times higher between the first



Note: Accessed from USBJ Burden of Musculoskeletal Diseases in the United States.⁴

and third week of treatment. Clinicians caring for vulnerable adult patients with RA should carefully consider the risk of fractures associated with use of these medications, especially during the initial period of treatment.⁹

Menopausal status is associated with worsening functional decline in women with RA. Pre-menopausal women had less functional decline. The use of hormonal replacement therapy, having a pregnancy and having a longer length of reproductive life were associated with less decline.¹⁰

Psychiatric disorders in RA are common, particularly depression. About 16.8% of RA patients suffer from depression, which is significantly greater compared with that of the general population.¹¹ From 1987 to 2012, men with RA were hospitalized for depression at a greater rate than were men without RA.⁸

At least half of patients with RA have one or more additional comorbidities already at the time of RA diagnosis.^{12, 13}

Medical/Cost Burdens

From 1987 to 2012 in Olmsted County, Minnesota, patients with RA were hospitalized at a greater rate than were patients without RA. The increased rate of hospitalization was found in both sexes, all age groups, all calendar years studied, and throughout disease duration.⁸

However, since 2012, mortality rates attributable to RA have declined globally. Population aging combined with the fall in RA mortality may lead to an increase in the economic burden of the disease that should be taken into consideration in policy making.¹⁴

According to the 2013 Health Care Cost and Utilization Project (HCUP) Nationwide Inpatient Sample, RA is identified more often as a comorbidity in hospital discharge records than as the primary discharge disease. During this year, about 61% of discharges listed RA as a comorbidity on hospital admitting documents.⁴

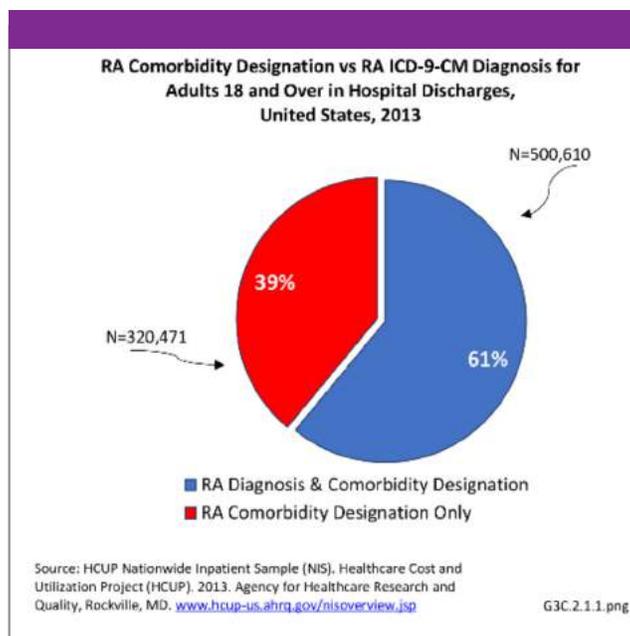
Based on 2005 U.S. Medicare/Medicaid data, total annual societal costs of RA (direct, indirect and intangible) increased to \$39.2 billion. The direct (\$8.4 billion) and indirect (\$10.9 billion) costs to RA patients translate to a total annual cost of \$19.3 billion. Intangible costs included (\$10.3 billion) quality-of-life deterioration and (\$9.6 billion) premature mortality. From a stakeholder perspective, 33% of the total cost was allocated to employers, 28% to patients, 20% to the government, and 19% to caregivers.¹⁵

A 2009 study found that almost half (43.6%) of RA patients had problems paying medical and drug bills after insurance payments. Almost 10% reported a severe or great burden, being unable to purchase all the medications or care they needed because of out-of-pocket medical expenses. This burden was substantially greater for patients over 65 years of age (11.8%) compared with those at or older than 65 (5.3%).¹⁶

Work/Employment Impact

The lost productivity associated with RA is substantial. The indirect cost of RA due to lost productivity has been estimated to be nearly 3 times greater than the costs associated with treating the disease.¹⁷ Because of its progressive nature, many individuals report missing work or choose not to work because of disease-related disabilities.

- About 20-70% of individuals who were working at diagnosis were disabled after seven to 10 years.¹⁸ A 2010 study found that about one-fourth to one-half of all patients with RA become unable to work within 10 to 20 years of follow-up.¹⁹
- Among those who did miss work, employees with RA missed more days than employees without the disease. In 2015, estimated national indirect costs of RA-related absenteeism from work were \$252 million annually.²⁰
- Globally, of 291 conditions studied, RA was ranked as the 42nd highest contributor to disability.²¹



Note: Accessed from USBJI Burden of Musculoskeletal Diseases in the United States⁴

What the Numbers Mean , Eileen's Story: Words of Wisdom About Living With RA

Meet Eileen Schneider, who is a registered nurse and has a passion for patient advocacy. Following, in her own words, is her story about living with rheumatoid arthritis (RA) and how the statistics she reviewed in this edition of Arthritis by the Numbers relate to her personally.

Question: How do some of the RA statistics you read about affect you?

Eileen: They're a reminder to me that this disease affects many people in many ways. Over the years, I've learned that a person doesn't just have RA, because the disease affects other parts of the body, too. The numbers reinforce that RA is more than a physical disease and can also affect behavioral health. RA is difficult to cope with, and as the statistics reveal, depression is particularly common.

I seem to be an outlier when it comes to the impact RA can have on work. I have maintained full-time employment since I was diagnosed and have never had to call in sick because of my RA. I've had some surgeries on my joints, but even then, I was able to return to work promptly while recovering. There have been days when I haven't felt well, but I've learned that keeping myself busy has been a helpful coping strategy.

The cost burdens of living with RA are real. I have decent medical insurance, but prescriptions, copays and lab work are all costly. I had significant financial hardship from hand and wrist surgeries, and it took quite a while to pay off the out-of-pocket expenses. The benefits were terrific, but the financial strain increased stress.

Question: What changes has your arthritis made to the way you live?

Eileen: There have been significant changes. One of the biggest challenges was accepting that I could no longer be as independent as before. I grew up taking care of myself and figuring things out on my own. When I was diagnosed at age 27, I wasn't ready to give up that independence. Over time, I realized I no longer had a choice and had to ask for help if I needed it. That was a tough transition.

One of the biggest changes I had to make was in my line of work. I was in the prime of my nursing career when diagnosed. My rheumatologist told me that bedside nursing care would no longer be possible. I knew he was right, but it made me so sad. I could no longer open syringes, help turn a patient over, safely help someone walk who was weak. I became a nurse educator and have worked in the same hospital for 35 years in a variety of nurse-related roles. RA has made me a better nurse because I have greater understanding of those with chronic conditions.

Question: What advice would you give to a newly diagnosed patient or parent/caregiver?

Eileen: Be patient with yourself. It takes a while to learn to live with it. Over time, you will find the balance between living with RA, but not letting it consume you. Some days, I hardly think about it at all; other days, I think about it a lot and feel down. I've learned to pay attention to what my body is telling me. I've learned that often when I'm feeling down, it's because of fatigue. My body is telling me to slow down, get more rest. Ask for help and listen to your body. Balance is key.

Question: What are the questions we can't answer yet, but you would like researchers to focus on?

Eileen: When I was first diagnosed, I asked my rheumatologist why I got RA. I didn't know anyone who had it, including family members. He said there is likely a genetic predisposition to RA and that a stressor may trigger it. Is there genetic testing that can be done? What types of stressors may trigger it? If other family members have the same genetic predisposition, why did I get it and others did not? Knowing those answers won't change anything for me, but others may benefit as more research is done into those aspects.



SYSTEMIC LUPUS ERYTHEMATOSUS (SLE OR LUPUS)

Lupus is a chronic, autoimmune disease. People with lupus have an overactive and misdirected immune system. Lupus can affect many parts of the body, including the joints, kidneys, skin, blood, brain and other organs.

Systemic lupus erythematosus (SLE) accounts for about 70% of all lupus cases. While SLE generally is considered the most serious form of lupus, cases range from very mild to severe. SLE affects various parts of the body and can cause joint pain, fatigue, hair loss, photosensitive skin, fever, rash and kidney problems.

In addition to inflammation, patients with lupus experience fatigue, pain, depression, sleep disturbance and trouble with thinking. These problems all impact the quality of life, although their origin is not clear. Furthermore, the severity of disease varies over time and patients often experience flares.

Lupus can sometimes affect the skin without causing problems in other tissues. A condition known as discoid lupus can cause scarring and pigment loss in the skin and can be especially severe in members of the African American population.

The production of antibodies to molecules found in the cell nucleus (antinuclear antibodies or ANA) is an important feature of SLE that is used for diagnosis. While ANAs occur in other diseases, antibodies to DNA and a protein called Sm are specific for SLE. Patient evaluation includes measurement of these antibodies.

Despite the challenges of this disease, SLE patients remain optimistic. According to a 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation, 90% of these patients say they can meet the goals that they set for themselves. Many different therapies to reduce the immune system are available and can prevent progression of certain complications, such as kidney disease.

9 in 10
diagnoses of lupus
are in women
ages 15 and 44.²



Prevalence

Women are affected far more than men – about 4 to 12 women develop lupus for every man affected.¹ Nine in 10 diagnoses of lupus are in women ages 15 and 44.² About 15- 20% of all systemic lupus erythematosus cases develop before the age of 18 years.³

Racial Distribution

Race affects the prevalence of systemic lupus erythematosus as well as the frequency of diagnosis and severity of the disease.

Minority and ethnic groups are affected more than non-Hispanic whites.⁴ Additionally, minority women tend to develop lupus at a younger age, have more serious complications and higher mortality rates.⁵ In the U.S., members of the African American population have particularly severe lupus, including the development of serious kidney disease.

The prevalence (how widespread) and incidence (risk for the disease) of SLE in the American Indian and Alaska native populations are as high as or higher than the rates reported for the African American population. American Indian and Alaska native populations develop SLE at an overall prevalence of 178 per 100,000 people. As with other populations, women are almost twice as likely to develop the disease (271 per 100,000 people).⁶

The prevalence of SLE is higher among Asian, Hispanic and non-Hispanic black populations, and Hispanic whites as compared with non-Hispanic whites in the U.S.⁷

On the east coast, in Manhattan, non-Hispanic black women, Hispanic women and non-Hispanic Asian women are more likely to have SLE than non-Hispanic white women.⁸

On the west coast, in San Francisco County, the disease burden is highest in black women, followed by Hispanic women, Asian women and white women.⁴

In the south, in Georgia, noticeable gender, age and racial disparities in SLE have been demonstrated. The prevalence of SLE is 3 to 4 times higher in African Americans than non-Hispanic whites. Disease onset also occurs at a younger age in the black population.⁹

In the north, in Michigan, SLE prevalence is 2.3 times higher in African Americans than in non-Hispanic whites and 10 times higher in females than in males.¹⁰

International comparison of all race prevalence shows a higher prevalence in the U.S. (52.2 cases per 100,000) compared to the United Kingdom (26.2 cases per 100,000) and Japan (28.4 cases per 100,000).¹¹

Human and Economic Burdens

In the U.S., studies suggest strong associations between ethnicity, socioeconomic status and outcomes of lupus. African Americans, Hispanics and individuals of low socioeconomic status have a higher risk of negative health outcomes.¹²

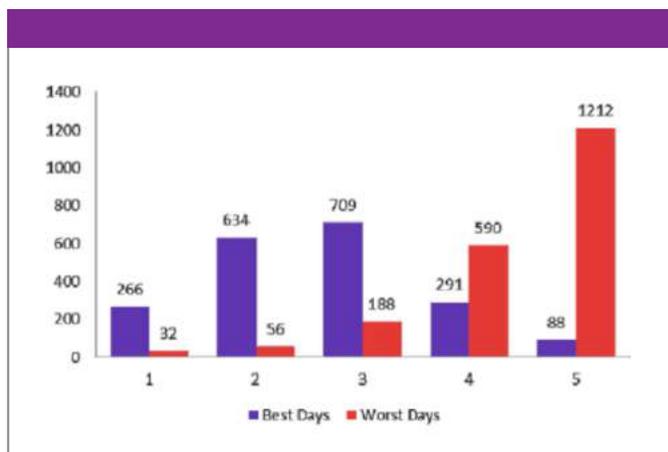
Many people with lupus experience challenges with identity and self-esteem, as well as a decrease in quality of life. These issues may be made worse by the stigma of the disease. Friends, family and coworkers may not understand the impact of the disease, which has many invisible symptoms.¹³

Patients report that treatments have limited effectiveness and are often associated with substantial negative effects. A 2018 lupus survey asked over 2,000 patients to rate the impact of lupus and its symptoms on their daily lives. Respondents indicated that their lupus symptoms are only under moderate control. Most stated that control of their disease was not optimal, as they were experiencing many flares.¹³

An increase in the damaging effects of lupus, disease complications and an increased risk of death may be associated with poor access to health care, late diagnosis, less effective treatment regimens and poor adherence to therapy.¹

Systemic lupus erythematosus patients are likely to have reduced health-related quality of life and are especially bothered by fatigue, pain, stress and depression. Differences in disease presentation, severity and course can often be related to ethnicity, income level, education, health insurance status, level of social support and medication adherence, as well as environmental and occupational factors.¹⁴ Poverty, either current or at some time, plus severity of poverty, is associated with increased disease-related

Comparison of impact of lupus symptoms on best days and worst days.



Note: From Lupus: Patient Voices report. A score of 1 indicates minimal impact and a score of 5 indicates high impact. N= 1,988 for best days, N = 2,078 for worst days.¹³

damage throughout the body in patients with SLE.¹⁵ Lack of coordination and communication of patient needs is associated with increased risk of severe infection and diagnosis of additional health conditions. These results suggest that improved health information exchange could positively impact health outcomes for SLE patients.¹⁶

Comorbidities and Health Burdens

Fatigue is the most common symptom affecting quality of life for people with this disease.¹⁷ More than half of surveyed patients ranked fatigue and pain in joints and muscles as having the most impact on well-being.¹³ There is a direct relationship between fatigue in SLE and physical inactivity, poor sleep quality, mood changes, depression, anxiety and cognitive dysfunction (including brain fog).¹⁸ Some degree of cognitive dysfunction is present in up to 80% of patients with SLE.¹⁹

Cognitive dysfunction related to neuropsychiatric symptoms (mental or emotional complications) usually occurs early in the development of SLE.²⁰ Brain abnormalities have been seen in 25% of newly diagnosed SLE patients, suggesting that the brain may be affected extremely early, even before a diagnosis of SLE is made.²¹ In SLE, neuropsychiatric involvement, including depression and anxiety, is associated with a lower quality of life and poor prognosis.²²

Skin involvement and certain types of neurologic activity are predictive of depression. Additionally, the use of higher-dose prednisone (20mg or more daily) is a risk factor for depression in lupus patients.²³

Other symptoms that patients noted as affecting their daily lives include chest and abdominal pain, reduced physical strength, increased susceptibility to infections, organ inflammation, and kidney disease or failure.¹³ Largely related to increased susceptibility to infections and organ inflammation (including kidney disease or failure), SLE patients have 2 to 5 times the risk of death compared with the general population.²⁵ Serious infections are recognized as major causes of morbidity and mortality in patients with lupus, accounting for 13-37% of hospitalizations, 65% of avoidable hospitalizations and one-third of deaths.²⁶

Kidney Involvement

Kidney damage is one of the main causes of morbidity and mortality in patients SLE.²⁷ Some degree of kidney involvement is observed in at least 60% of cases of this disease. Glomerulonephritis (inflammation of the kidney) is seen in 30-50% of unselected patients with SLE at diagnosis.²⁸ Lupus nephritis (kidney disease) is a severe manifestation of the disease, affecting up to 60% of patients.²⁹ During 2000 to 2010, the overall reported prevalence of end-stage kidney disease caused by lupus nephritis increased 56%.³⁰

**SLE patients have
2 to 5 times
the risk of death
compared with the general
population.²⁵**

There is a direct relationship between fatigue in SLE and physical inactivity, obesity, vitamin D deficiency/insufficiency and comorbidities such as fibromyalgia.¹⁸ Observational studies report the prevalence of obesity among adults with SLE at around 28%.²⁴

The prevalence of kidney and cardiovascular damage in SLE is not represented equally among different racial and ethnic groups. It's higher among African Americans than non-Hispanic whites. African Americans with SLE also experience these complications at earlier ages.³¹

Joint Involvement

Joint involvement is a central feature of SLE. It's seen in 70% of children and 90% of adults with the disease.³²

One study showed that about 44% of the hip and knee joints of SLE patients who have corticosteroid treatment display osteonecrosis lesions, a bone disease that results from loss of blood supply to the bone, causing the bone tissue to die and bone to collapse.³³ However, some experts feel this estimate is high.

Pregnancy Impact

Pregnancies in women with lupus are associated with a higher risk of complications, higher health care costs, specific prescribed medications to minimize the danger to the developing fetus and immunosuppressants than healthy women.³⁴ Lupus patients continue their medications during pregnancy, using specific medications to minimize danger to the developing fetus, but still working to control maternal disease.

Maternal outcomes (such as pre-eclampsia, stroke and infection) are more common among women with SLE. By 2016, pregnant women with SLE (16%) were diagnosed with pre-eclampsia almost 3 times more often than those from the general population (5%). Among the pre-SLE women, pre-eclampsia was found in 26% of those with SLE within two years postpartum and 13% in those with SLE within 2 to 5 years postpartum.³⁵

Infant outcomes, such as preterm birth, infection and mortality, were worse among those born to mothers with prevalent SLE and pre-SLE during pregnancy.³⁵

Adverse pregnancy outcomes (APO) occur in almost 1 in 5 (19%) pregnancies in women diagnosed with lupus. Fetal death occurs in 4%, neonatal death occurs in 1% and preterm delivery occurred in 9% of pregnancies. In a 2015 study, about 10% of neonates were small for their gestational age (birthweight was below the fifth percentile). Results of the study also showed that maternal flares and higher disease activity during pregnancy are predictive of APOs.³⁶

The longer a person has been diagnosed with SLE, the less likely they are to be part of the workforce.

About 20% of Americans **with a work disability** have lupus.

Employment/Economic Impact

Systemic lupus erythematosus is one of the leading causes of work disability in the U.S., accounting for about 20% of the more than an estimated 1.5 million Americans with a work disability.³⁷ Patients often have reduced ability to perform work, care for their dependents and engage in other unpaid work. Resulting indirect costs can exceed direct costs by 2 to 4 fold.³⁸

The longer a person has been diagnosed with SLE, the less likely they are to be part of the workforce. Worldwide, about half of SLE patients of working age report being employed.¹⁷ A 2008 study showed that the number of hours a patient worked in a year decreased since the year of diagnosis, from 1,378.2 hours per year to 899.5 hours per year for people with SLE. The mean income of working-age participants decreased from \$24,931 in the year of diagnosis to \$16,272 at the time of the study, representing a loss of \$8,659.³⁹

Symptoms of lupus can have a profound impact on the person's employment, the individual's work, quality of life, self-management, self-efficacy and status in the U.S. workforce. Impacts of lupus are more pronounced among young and middle-aged adults. A 2016 study showed that loss in work hours due to lupus symptoms cost the U.S. nearly \$13 billion annually.³⁷

According to a 2008 longitudinal survey of persons with SLE, in the year of diagnosis, 76.8% of participants were employed, but fewer than half (48.7%) were employed at the end of the study.³⁹ A 2015 study revealed that 15-40% of U.S. lupus patients are unemployed within five years of diagnosis.⁴⁰

A longitudinal study showed, that, of patients employed at diagnosis, more than a third stopped working by 10 years after diagnosis, more than half stopped working by 15 years, and almost three-quarters had stopped working by 25 years after diagnosis. Almost no one made it to normal retirement age.

Medical/Cost Burdens

Both direct medical costs associated with an individual's care and indirect costs such as loss of economic productivity are high.¹⁴ In a study of U.S. Medicaid enrollees between 2000 and 2009, lupus patients had significantly higher health care utilization and higher overall expenditures than patients without lupus. During this decade, lupus patients incurred \$10,984 more total cost per year, with 55% of that being attributed to inpatient care.⁴²

During this decade, most SLE direct costs were related to inpatient care (16-20%), outpatient services (24-56%) and medications (19-30%). Between 2000 and 2010, the mean annual direct costs of SLE patients in the U.S. ranged from \$13,735 to \$20,926. If patients had nephritis, the costs were higher and ranged from \$29,034 to \$62,651. If patients did not have nephritis, the costs were less and ranged from \$12,273 to \$16,575.⁴³

Hospitalization rates for serious infections in SLE patients increased substantially between 1996 and 2011. By 2011, lupus patients were over 12 times more likely to be hospitalized than patients without SLE.²⁶

In 2013, flares were experienced by 97% of SLE patients, with an average of 2.6 flares per patient per year. The cost per flare was highest for severe flares at \$11,716. Patients with at least one severe flare during the follow-up period had an annual cost of \$49,754. Patients with at least one severe flare had more than twice the costs of patients with moderate or mild flares.⁴⁴

Costs continue to rise. A 2016 study showed that the total mean medical costs of SLE were \$51,295 over four years.⁴² However, a 2018 study demonstrated that incorporating multivariate assay panels into the diagnosis process could lead to earlier diagnosis. This would result in a total, four-year direct cost savings of \$2,255,356 (\$2,256 per suspected SLE patient) and a first year savings of \$711 per suspected SLE patient. Identifying patients at a less severe disease state using this method is anticipated to improve patient outcomes.⁴⁵

The longer a person has been diagnosed with SLE, the less likely they are to be part of the workforce.

About 20% of Americans with a work disability have lupus.

Using multivariate assay panels in the SLE diagnosis process may lead to earlier diagnosis, resulting in direct cost savings and improved patient outcomes.

What the Numbers Mean, Liz's Story : Support Networks Help



Meet Liz Morasso, a licensed clinical social worker at UCLA's department of radiation oncology who has volunteered for the Arthritis Foundation since 2002. That's when, at age 16, she was diagnosed with systemic lupus erythematosus (SLE) and rheumatoid arthritis (RA). Over the years, she has immersed herself in leadership roles with the Foundation and speaks nationwide to inspire patients living with chronic illness.

Following, in her own words, is Liz's story about living with these conditions and how the statistics she reviewed in this edition of *Arthritis by the Numbers* relate to her personally.

Question: How do some of the arthritis statistics you read about affect you?

Liz: Being female and having SLE and RA rang true. More adult women are diagnosed with these diseases than men. My symptoms began in middle school, mostly depression and fatigue. I felt isolated, and my emotions and physical state were unpredictable. Even though I was active in afterschool activities, like the swim team, my fatigue was constant, and I started to develop joint and muscle pain.

About a month before my diagnosis, I jokingly told a friend that I felt like I have arthritis. She thought I was kidding – after all, kids don't get arthritis. Not long after that, my Spanish teacher recognized my malar rash. The school nurse found that I had a fever, and my joints, muscles and lymph nodes were swollen and sore. I was referred to a pediatric rheumatologist.

Another fact that stood out to me was the number of patients who develop SLE before the age of 18. In my work with different arthritis groups, I am seeing more and more patients who are teenagers and young adults. The number of patients in this age group is rapidly growing. I hope better access to care and understanding of rheumatic disease will help them experience relief and support like I did.

Question: What changes has your arthritis made to the way you live?

Liz: It can be challenging to explain my disease in a way that others can understand. This disease sometimes still feels like it is something for older people. I thought it was rare for young people to feel the way I felt. Initially, I was afraid to meet others who had RA or lupus.

Question: What advice would you give to a newly diagnosed patient or parent/caregiver?

Liz: The turning point for me was connecting with fellow patients through the Arthritis Foundation. Connecting made me feel validated. The Arthritis Foundation has helped me build my toolbox – forming relationships, sharing information and helping me navigate difficult systems and live the most meaningful life. Connecting helped me feel less isolated and more normal. Being part of this community is important for a variety of reasons. It empowers you and those who love and care about you to find control.

Question: What are the questions we can't answer yet, but you would like researchers to focus on?

Liz: I can't overemphasize the emerging young adult piece in this. Adolescents and young adults want to see themselves represented more in research as a separate category. Young people cope differently and go through complex developmental stages and transitions. That is often missing in the programming and literature they are reading. This group's unique experiences are something the arthritis community should be more mindful of, whether it's research, patient care or policy.

SJÖGREN'S SYNDROME

Sjögren's syndrome is a chronic, autoimmune disease that causes dryness of the eyes, mouth and other body parts. In an autoimmune disease, the immune system mistakenly attacks healthy tissue, leading to inflammation in different tissues or organs. In Sjögren's syndrome, the immune system attacks the normal cells of the glands that produce moisture in the eyes (tears), mouth (saliva) and other parts of the body. This causes inflammation which damages the glands, making them unable to produce moisture.

In addition to affecting the saliva and tear-producing glands, the disease can affect the skin (abnormally dry skin), joints (inflammatory arthritis), lungs, kidneys, blood vessels (purpura, Raynaud's disease), digestive organs (disorders of the esophagus, stomach, intestines, liver and pancreas), the throat and larynx (voice-related disorders), and the nervous system. Problems with dryness are sometimes called sicca symptoms.

Sjögren's syndrome often remains undiagnosed or is misdiagnosed because the cardinal symptoms of dry eyes and dry mouth are common in the population and have multiple potential causes, including certain medications. The disease is classified either as:

- Primary Sjögren's, where the condition exists as an individual rheumatic disease but may also be seen with other autoimmune non-rheumatic and/or non-glandular diseases, such as autoimmune thyroid disease or celiac disease.
- Secondary Sjögren's, where the condition overlaps with another rheumatic disease, such as rheumatoid arthritis (RA), lupus, scleroderma or myositis.

Both primary and secondary Sjögren's syndrome can cause ongoing, unpredictable and severe fatigue.

About 7 in 10 Sjögren's patients say they struggle to cope with this disease on a weekly or more frequent basis. Almost 9 in 10 patients agree that living with this disease makes every day a challenge.¹

Almost

9 in 10 patients

agree that

living with this disease makes every day a challenge.

Prevalence (Primary Sjögren's Syndrome)

Sjögren's syndrome affects more than 4 million people in the United States. About 9 in 10 patients with the condition are women. Most people are 40 years or older when diagnosed. The chances of developing Sjögren's syndrome are greater if a relative has it or another autoimmune disease.²

Primary Sjögren's syndrome is an autoimmune chronic inflammatory disorder affecting about 2 million people in the U.S. (0.2-3.0% of the population).² Although the average age of onset of primary Sjögren's syndrome is usually in patients in their 40s to 50s, it can begin in patients in their 60s or 70s. While this form of autoimmune disease can affect patients of any age, the prevalence of primary Sjögren's syndrome in the elderly population is between 5 to 8 times higher than in younger and middle-aged adults.³

Sjögren's syndrome in juvenile patients is rare but is becoming more evident in this population. As of 2014, only 145 cases of primary juvenile Sjögren's had been reported in recent international pediatric literature. Juvenile-onset Sjögren's syndrome affects 7 times more girls than boys. About 100,000 adult patients (about 5%) indicated they had symptoms before the age of 12, with the average age of onset being 10 years of age.⁴

Comorbidities (Secondary Sjögren's Syndrome)

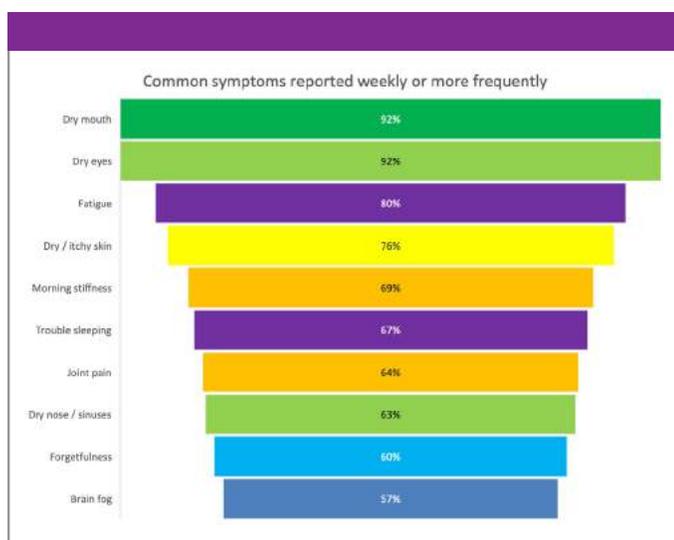
Sjögren's is the most frequent disorder that occurs in conjunction with other autoimmune and rheumatic diseases.⁵ About half of the time, Sjögren's syndrome occurs alone. The other half occurs in the presence of another rheumatic disease, such as RA, lupus or scleroderma.⁶ The most frequent autoimmune diseases observed in Sjögren's syndrome patients are thyroid disease, RA and lupus.⁷

When a Sjögren's patient has another major rheumatic, autoimmune disease, they are often categorized as having secondary Sjögren's. However, this terminology is confusing and often inaccurate in implying that one disease is secondary to or less important than another. For example, patients with Sjögren's syndrome may have clinical and laboratory features which overlap with those of another systemic rheumatic disease when they first present, or they may develop signs and symptoms of another systemic rheumatic disease years after the initial development of Sjögren's syndrome.⁵

Health Burdens

The disease's predominant effects are on the lacrimal (tear) and salivary glands. However, this autoimmune disease can involve many of the body's systems and significantly impact a patient's quality of life. A 2016 survey of nearly 3,000 adult Sjögren's syndrome patients identified the common symptoms that affect them and are frequently experienced with this disease.

Dry eyes from Sjögren's syndrome can cause serious ocular complications that include corneal ulceration and scarring, as well as bacterial corneal and eyelid infections, which require continuous medical care and treatment to prevent declining eyesight and potential blindness.⁸



Note: From Living with Sjögren's poll.¹

Dry mouth caused by reduced saliva production from Sjögren's syndrome can increase the incidence of oral infections, cavities and other dental problems due to the loss of the lubricating, buffering and antimicrobial capacities of saliva.⁸ Saliva plays several critical roles in digestion. It helps moisturize food so that it can easily be swallowed. Saliva also contains an enzyme that breaks down starches, digesting some food before it enters the stomach. Saliva also contains bicarbonate, which helps neutralize acid that may be present in the esophagus and may help prevent or lessen the effects of acid reflux. Chronic stomach upset caused by acid reflux can contribute to tooth erosion – again, saliva helps neutralize the acid.

Sjögren's syndrome affects exocrine glands (glands that produce and secrete substances onto cell surfaces). Examples of exocrine glands include sweat, mammary

and mucous producing glands, to name a few. The liver and pancreas are also exocrine glands. Sjögren's, by damaging exocrine glands, may affect any part of the body that depends on the fluids produced by these glands, including the gastrointestinal system – from the mouth, esophagus and bowel to the liver and pancreas. Indigestion (including upset stomach, heartburn, acid reflux and nausea) is found in up to 23% of Sjögren's syndrome patients.⁹ Sjögren's syndrome patients are prone to develop a type of reflux where acidic gastric contents move into the upper part of the esophagus and windpipe, causing local symptoms and changes in the voice and/or vocal cord tissues.⁸ Individuals with Sjögren's syndrome may experience voice disorders and specific voice-related symptoms (frequent throat-clearing, throat soreness, difficulty projecting and vocal discomfort) that are associated with reduced quality of life.¹⁰

Patients may have rare pancreatic involvement that includes pancreatitis and pancreatic insufficiency. Abnormal liver tests are found in up to 49% of Sjögren's syndrome patients, but they are usually mild.⁹

Sjögren's syndrome can also affect other moisture-producing glands in the larynx (hoarseness), trachea (cough), skin (pruritus) and possibly the genital area (vaginal dryness that can lead to dyspareunia). Up to 75% of patients with primary Sjögren's syndrome may have clinically apparent involvement of organs apart from the moisture-producing glands, including the skin (abnormally dry skin), joints (inflammatory arthritis), lungs, kidneys, blood vessels (purpura, Raynaud's disease), digestive system and nerves (peripheral neuropathy).¹¹ Autoimmune thyroid disease has been observed in 45% of Sjögren's syndrome patients.¹²

The prevalence of fatigue among patients with Sjögren's syndrome may be as high as 65-70%.¹³ Fatigue related to Sjögren's syndrome has been reported to be continuously present and patients say they never feel refreshed. Some patients reported disturbed sleep caused by increasing stiffness and aching. Others sleep so deeply that they did not notice the stiffness until they woke up, but even then, they can still feel tired. Patients with fatigue related to primary Sjögren's syndrome feel a lack of vitality, but fatigue also varied during the day and from day-to-day in an unpredictable and uncontrollable way.¹⁴ According to patients, those with severe dryness also have severe fatigue.¹

Fatigue caused by Sjögren's doesn't always lead to sleep at night. Poor sleep or sleep disturbances can be caused by many things, including medications taken to treat comorbidities and stress, anxiety, and depression. Sjögren's patients report that dry eyes (eye lids sticking to the eye), dry mouth (the tongue sticking to the roof or side of the mouth) and dry throat (which can result in coughing) wake them. Others report that drinking fluids too close to bed to moisturize their dry throat can result in multiple trips to the bathroom. In a 2012 study, Sjögren's patients were found to be twice as likely to experience obstructive sleep apnea (when your throat muscles relax during sleep and block the airway) and hypopneas (abnormally slow or shallow breathing due to partial blockage of the airway) compared to healthy people.¹⁵ Whatever the cause of poor sleep/sleep disturbances, the fatigue that Sjögren's patients experience can lead to a low in moods with more worry and pain.¹⁶ This, in turn, can lead to additional stress, anxiety and depression, which exacerbates insomnia and related issues that cause poor sleep.

Patients with fatigue related to Sjogren's Syndrome feel a lack of vitality, but fatigue also varied during the day and from day-to-day in an unpredictable and uncontrollable way.

Many Sjögren's patients experience brain fog – a fluctuating mild memory loss that is not appropriate for a patient's age. However, brain fog can be caused by different factors, including poor sleep/sleep disturbances, and should be evaluated by a health care provider.¹⁷ Brain fog is often experienced as problems with memory or difficulty focusing, processing information or numbers, paying attention and feeling not mentally lucid. It is not progressive, and thus, not an early manifestation of dementia. Brain fog generally is a different type of dementia than Alzheimer's disease and is not likely to lead to placement in a nursing home for chronic care.¹⁸

Neurological issues seem to affect about 20% of patients with primary Sjögren's syndrome. It is not uncommon for issues to occur before other signs and diagnosis of this disease.¹⁹ Sjögren's can cause nerve damage (peripheral neuropathy), leading to burning and numbness in the extremities and sometimes other areas of the body, including the face and torso. This damage often affects only sensory nerve fibers but can involve both sensory and motor nerves and lead to mild weakness of the extremities. Some patients can have involvement of their autonomic nervous system, leading to alterations in the regulation of heartbeat, breathing and movement of food through the digestive tract. Symptoms include lightheadedness when standing, increased or decreased sweating and feeling full after eating a small meal.²⁰

Central nervous system involvement in Sjögren's patients may resemble multiple sclerosis. Neuromyelitis optica is an autoimmune disease that mimics multiple sclerosis, affect the brain and spinal cord, and is associated with Sjogren's syndrome. Sjogren's patients may also have an increased number of white matter lesions on MRI scans of their brain. These may resemble those that define multiple sclerosis, but are atypical in location and form, are not associated with neurologic deficits and may relate more to age and cardiovascular risk factors rather than the underlying Sjogren's. Patients with primary Sjögren's syndrome have an increased risk of developing non-Hodgkin B cell lymphoma, with a recent study showing a cumulative risk at 15 years after diagnosis of almost 10%.²¹ The increased risk of developing non-Hodgkin B cell lymphoma is higher than that of patients with RA and lupus who also have an increased risk of developing non-Hodgkin lymphoma.²²

Similar to patients with other autoimmune forms of arthritis, high blood pressure and high cholesterol are more common in primary Sjogren's syndrome patients. These patients also have an increased risk of cerebrovascular events (such as strokes and aneurysms) and heart attack.²³

Sleep disruption can interfere with work performance. A Swedish study showed that at 2 years after diagnosis, work disability affected **41% of patients.**

Secondary Sjögren's Syndrome With Rheumatoid Arthritis

RA patients with secondary Sjögren's syndrome may experience more serious comorbidities. Up to 31% of patients with RA meet the diagnostic criteria for secondary Sjögren's syndrome. However, while about 30-50% of RA patients may have dry eye or dry mouth, they do not meet the full criteria for secondary Sjögren's syndrome diagnosis.

Secondary Sjögren's patients have significantly longer disease duration and higher disease activity, which might be associated with the higher incidence of anemia. The incidence of anemia is higher in secondary Sjögren's syndrome patients with RA than in patients with

only RA or in primary Sjögren's syndrome patients. The incidence of coronary heart disease and cardiovascular events is also higher for secondary Sjögren's syndrome patients than for patients with RA alone. Interstitial lung disease, a common lung complication associated with RA, was also more likely to be found in RA patients with secondary Sjögren's syndrome.²⁴

Secondary Sjögren's Syndrome With Lupus

Sjögren's syndrome patients with lupus are more often older white women with photosensitivity, oral ulcers, Raynaud's phenomenon and antibodies commonly found in patients with autoimmune diseases (anti-Ro antibodies and anti-La antibodies). These patients have a lower frequency of renal disease and antibodies commonly found in lupus patients (anti-dsDNA antibodies and anti-RNP antibodies) than lupus patients without Sjögren's.²⁵

Juvenile-onset Sjögren's Syndrome

Sjögren's syndrome symptoms may be different in juvenile patients than in adults. Juvenile-onset patients show recurring gland (parotid) swelling and fewer dry eye/dry mouth symptoms.⁴ Disease-related antibodies may be found in the blood that indicate Sjögren's syndrome in some juvenile patients who don't have dry eye or dry mouth symptoms. These patients are diagnosed with subclinical SS.²⁶

Work/Employment Impact

Sleep disruption from Sjögren's can interfere with occupational performance and lead to daytime fatigue. Patients report an impact on, and a relationship between, sleep and other Sjögren's symptoms. Sleep disturbances make other symptoms feel worse – which affects sleep, creating a vicious cycle. Comorbidities (additional chronic health issues) contribute to sleep difficulties, making all symptoms worse, which results in further sleep problems. Poor sleep limits the ability to participate and perform daily activities – improvements in sleep may positively influence symptoms and improve participation.¹⁶

Work disability, including sick leave and disability pension, is significantly higher among patients with primary Sjögren's syndrome than in the general population. Work disability is only a part of the indirect costs that could be underestimated in primary Sjögren's syndrome because most patients are female, and are more likely to be engaged in unpaid and under-recognized activities that are of value to society (like housework, caring for children or parents, or voluntary activities).²⁷

A study in Sweden showed that at the time of diagnosis, 16% of patients with primary Sjögren's syndrome were already receiving a disability pension and 10% were on sick leave. After the diagnosis, there was a steady increase in work disability, initially including sick leave, then including disability pension. At two years after diagnosis, 41% were receiving a disability pension.²⁸

Medical/Cost Burdens

Patients report that living with Sjögren's adds a significant financial impact to their life. In a 2016 survey, patients said they spent the most on dental care, followed by prescription medications and health care appointments/copayments.¹

Another 2016 study that detailed direct costs of primary Sjögren's syndrome based on claims database information from 10,000 patients in the U.S. found that annual health care costs in the year following diagnosis increased by 40% to \$20,416 per person.²⁹ An earlier study showed that Secondary Sjögren's syndrome patients require more therapy during treatment and incur higher hospitalization costs due to the higher incidence of anemia.²⁴

SCLERODERMA

Scleroderma, which means hard skin, affects about 300,000 Americans. Scleroderma involves the buildup of scar-like tissue in the skin in a process called fibrosis, but it can also affect the cells in the walls of the small arteries. Patients with scleroderma often show evidence of autoimmunity as indicated by the production of characteristic autoantibodies. Scleroderma may occur in two forms – localized scleroderma (which affects mainly the skin) and systemic sclerosis (which affects many parts of the body).

Systemic sclerosis tends to be the more severe form of this disease, but fewer people are affected by it. Systemic sclerosis may be classified as either limited or diffuse.

- Limited scleroderma affects the skin on the face, fingers and hands, and lower arms and legs. For many people, the first symptoms of systemic sclerosis are Raynaud’s phenomenon and puffy fingers, which can begin several years before other symptoms. In Raynaud’s phenomenon, the blood vessels, especially of the fingers, show abnormal reactivity to the cold. The blood vessels narrow, and the finger can blanch (appear white). However, some people experience severe Raynaud’s phenomenon, gastrointestinal problems or serious effects on the lungs.
- Diffuse scleroderma presents with widespread skin thickening. It may affect any part of the body, especially the hands, arms, thighs, chest, abdomen and face. Itching, decreased flexibility and pain can also occur. Diffuse scleroderma may affect the blood vessels, heart, joints, muscles, esophagus, intestines and lungs. The severity of internal organ involvement varies. Kidney problems may lead to high blood pressure, and if untreated, kidney failure. Lung damage is the leading cause of death with this condition.

The cause of scleroderma is unknown. However, it is believed to be an autoimmune disease, meaning it occurs when the body’s immune system mistakenly attacks its own cells and tissues. Scientists know that people with scleroderma overproduce collagen, a key component of connective tissue. Too much collagen causes the skin to thicken and may cause internal organs to function abnormally.

Prevalence

Scleroderma does not occur randomly in the population. There are groups who are at greater risks. The highest reported prevalence of scleroderma in the U.S. has been reported in a Choctaw Indian group in Oklahoma.¹ Women are affected 4.6 times more often than men. Scleroderma also occurs more frequently and is diagnosed at a younger age in African Americans than in the white population.²

The prevalence of scleroderma in the U.S. seems to be stable, with 240 cases per million adults. Most adults with systemic scleroderma are diagnosed between the ages of 30 to 50.²

Localized scleroderma (LS) has several subtypes. Plaque morphea, the most common adult subtype, occurs in about 60% of adults with LS.³

Health Burdens

Patients with diffuse scleroderma are about 5 to 8 times more likely to die compared to people of the same age or gender of the general population.² Survival is strongly dependent on the degree of internal organ involvement. The average 10-year survival rate for adults is now 70-80%.⁴ Progressive pulmonary fibrosis, pulmonary hypertension, severe gastrointestinal involvement and scleroderma heart disease are the main causes of death.⁵

Scleroderma does not occur randomly in the population. Groups who are at greater risks include the Choctaw Indian group in Oklahoma, African Americans, and women.

The presence of pulmonary arterial hypertension (PAH) in connective tissue disease patients accounts for up to 30% of all cases of PAH, with most cases found in scleroderma patients.⁶ In PAH, the blood vessels to the lung are affected, putting strain on the heart. PAH is estimated to occur in 10-15% of adults with scleroderma.⁷ The presence of PAH in scleroderma patients has a detrimental impact of survival.⁸

Mild renal (kidney) problems are not uncommon in systemic sclerosis. Scleroderma-related renal crisis occurs in about 15% of adult patients.⁹

Economic Burdens

A 1997 US study of costs for scleroderma showed the annual direct (medical) and indirect (non-medical and productivity) costs of scleroderma in the U.S. were \$1.5 billion (about \$2.3 billion in 2017 dollars).¹⁰

A 2008 Canadian study of costs for systemic sclerosis showed the average direct cost per patient was \$5,038 per year. The average indirect costs, the value of potential productivity loss related to paid labor, was estimated at \$5,345 per patient per year. The cost of lost productivity related to unpaid labor contributed another \$8,070 per patient annually. In that year, the average total annual cost was estimated at \$18,453 per patient. Total annual costs were strongly associated with younger age, greater disease severity and poorer health status.¹¹

A 2010 European study showed that the average yearly direct medical, non-medical and indirect (work productivity loss-related) costs were higher for systemic sclerosis patients than for RA and/or psoriatic arthritis patients.¹²

A 2012 study showed that the average annual medical costs in the U.S. for systemic sclerosis patients were more than 3 times higher than costs for patients without systemic sclerosis. Patients with serious disease complications from lung disease, gastrointestinal bleeding or renal disease experience the highest costs.¹³

SPONDYLOARTHRITIS

Spondyloarthritis (SpA) is a broad term for inflammatory diseases that involve the sacroiliac joints as well as the joints, ligaments and tendons primarily of the spine; peripheral joints such as hips and ankles can be affected. The involvement of the sacroiliac joints is a key feature. If there is evidence of erosion or fusion of these joints in a person with back pain, the condition is known as radiographic spondyloarthritis or ankylosing spondyloarthritis. If there are no X-ray findings, the condition is known as non-radiographic spondyloarthritis.

Under the traditional SpA classification system, the most common of these diseases is ankylosing spondylitis (AS). Others include reactive arthritis, some forms of psoriatic arthritis and enteropathic arthritis, which is associated with the inflammatory bowel disease.

Patients with SpA have symptoms of inflammatory back diseases. These symptoms include pain and stiffness of the back (especially in the morning), improvement with exercise and a response to nonsteroidal anti-inflammatory drugs. SpA can also be associated with enthesitis, which is an inflammation of the enthesis (the places where ligaments attach to bone).

SpA can be associated with psoriasis and inflammatory bowel disease. Another important association relates to the eye. Uveitis commonly occurs in patients with this condition.

Uveitis commonly
occurs in patients with
Spondyloarthritis

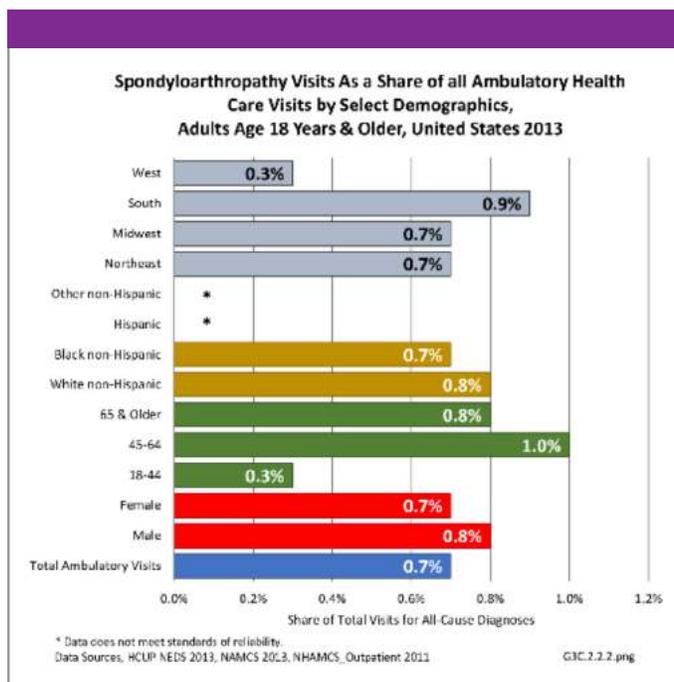


A newer SpA classification system recognizes two broader categories that encompass the full range of SpA: axial spondyloarthritis and peripheral spondyloarthritis.

- Axial spondyloarthritis affects the back and/or pelvis. It may or may not include inflammatory changes seen on x-ray that occur to the sacroiliac joints (the joints linking the spine to the pelvis). Patients with radiographic changes of the sacroiliac joints are considered to have ankylosing spondylitis. Patients with symptoms of inflammatory back pain without X-ray changes of the sacroiliac joints have a condition called non-radiographic SpA. Because these patients do not have findings of sacroiliitis, they may be given other diagnoses. The Centers for Disease Control and Prevention estimates that at least 2.7 million U.S. adults have this form of arthritis.
- Peripheral spondyloarthritis causes inflammation in joints outside the back or sacroiliac joints, including those in the hands, wrists, elbows, shoulders, knees, ankles, feet, fingers and toes. Almost all people with psoriatic arthritis have this category of arthritis at some point in their disease.

Many people with SpA have both axial and peripheral SpA, while others only have one form. Enthesitis such as Achilles tendonitis can be a sign of SpA.

Regardless of which form of SpA a patient may have, joint inflammation often comes and goes and is accompanied by fatigue. Other problems can occur along with SpA, including osteoporosis, pain and redness of the eye, inflammation of the aortic heart valve, intestinal inflammation and psoriasis.



Note: Accessed from USBJI Burden of Musculoskeletal Diseases in the United States.³

Despite the challenges of this disease, spondylitis patients remain optimistic. According to a 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation, 90% of these patients say they can think of many ways to get the things in life that are important to them.

General Prevalence

Spondyloarthritis (SpA) is a group of interrelated diseases with different rates of prevalence. The overall prevalence of SpA in the U.S. ranges between 0.9-1.4%. The two most common forms of spondyloarthritis are ankylosing spondylitis (up to 1.7% prevalence) and psoriatic arthritis (up to 0.4% prevalence).¹

The axial spondyloarthritis (AxSpA – those forms that affect primarily the back and/or pelvis) prevalence may be similar to that reported for RA. The overall number of people with AxSpA in the U.S. ranges between an estimated 1.7 million and 2.7 million persons.²

In 2011, spondyloarthritis accounted for 0.7% of ambulatory (non-hospital) diagnostic visits. Among these visits, males were more likely to receive care

for SpA than females, non-Hispanic whites were only slightly more likely to receive care for any of these diseases than non-Hispanic blacks, and those age 45 and above represented the largest populations who sought health care for this disease.³

Living With AS – Daniel’s Story

Nothing holds Daniel Ortman back. Not the arthritis that has challenged him for two decades. Not the major brain surgery he endured nine years ago, nor any of the other obstacles he and his family have faced along the way.

In 2018, Dan vowed to cross the finish line of his Ellicott City, Maryland, Jingle Bell Run for the very first time. And he made it!

“It was surreal,” reflects Daniel. “I was starting to tire out after the first mile. But I said, ‘I’m going to keep going and get to the other side.’ And when I got to the end, I said, ‘I’m not disabled anymore. I can do anything!’”

Daniel was diagnosed with arthritis at age 11, at first with ankylosing spondylitis and later with psoriatic arthritis. His arthritis was very aggressive. Finding and keeping an effective treatment proved difficult and took a heavy toll on his body. He had to use a wheelchair or walker for long periods and required assistance with many of the things most people take for granted. Daniel’s worst arthritis flare occurred after the biologic he was on failed, causing excruciating pain that prevented him from enjoying something as simple as sitting down for a family dinner.

In 2011, the last time Daniel was physically able to participate in the Jingle Bell Run, he got halfway through the 5K course, but couldn’t keep going and had to be helped to an awaiting car. Now 30, Daniel believes his sister, Theresa, who passed away unexpectedly a year ago, helped him make it over the finish line last year.

“Theresa inspired me and so many others, so I dedicated my fundraising campaign in her memory.” Daniel and his team, Dan’s Fans, set their goal at \$20,000 and brought in more than twice that amount, thanks to a matching gift.

At the Arthritis Foundation’s Conference of Champions in November, Daniel had the pleasure of seeing his father, Michael Ortman, receive the organization’s highest honor, the Charles B. Harding Award for Distinguished Service. Michael has been thoroughly engaged with our cause ever since Daniel was first diagnosed, including two years serving as the Foundation’s board of directors’ chair.

Today, things are looking up for Daniel. He’s pursuing his career in brain training, working to help others with disabilities, both mentally and physically, covering a wide range of disorders. He also works with those struggling with rehabilitation from arthritis. In addition, he’s got an active social life.

“I get to go out and socialize with people,” he says. “There are a lot of pleasures all around me. I enjoy all my waking hours and have fun.”

Daniel says he considers arthritis a gift and a chance to see the world differently.



“You’re only disabled if you let yourself be disabled,” he maintains. “Arthritis is an opportunity to live an awesome life. You have to just take on the world and go with the good stuff.” - Daniel Ortman

ANKYLOSING SPONDYLITIS

Prevalence

Unlike most other forms of arthritis, AS occurs twice as often in men than women. Symptoms tend to present at an earlier age, with about 80% of patients showing symptoms at or before age 30 and about 5% of patients showing symptoms at age 45 or older.⁴

Ankylosing spondylitis is more common in non-Hispanic whites than other races. The chances of developing ankylosing spondylitis is 5 to 16 times greater if a parent, child or sibling has the disease. The prevalence is typically associated with the presence of the human leukocyte antigen (HLA) B27 gene. About 90% of North American non-Hispanic whites with AS carry the HLA B27 gene.⁵

There are differences with AS and non-radiographic SpA. With non-radiographic SpA, the frequency of HLA B27 is lower, although the number of women affected is greater than that of AS.

Although rare, juvenile AS can begin in childhood. Children and adolescents with this disease tend to have more peripheral arthritis than adults. Their arthritis typically involves lower extremity joints (knees, feet, etc.) and does not necessarily involve joints on both sides of the body.⁶ Juvenile AS can be mistakenly diagnosed as other forms of juvenile arthritis due to common symptoms like uveitis, diarrhea, and pulmonary and heart disease. Ineffective treatment of this childhood disease results in disease progression to the typical adult form of AS.⁷

Human and Economic Burdens

There is no known cure for AS. The goals of treatment are to reduce pain and stiffness, slow progression of the disease, prevent deformity, maintain posture and preserve function.⁵

Ankylosing spondylitis is a chronic inflammatory form of spondyloarthritis that often results in lower back pain early in the disease. This can eventually lead to new bone formation that fuses the bones in the spine. Fusing of the back's bones in AS patients results in impaired spinal mobility. For many AS patients, the fusing begins at the sacroiliac joints and progresses up from the lumbar spine to the neck. Fusion can occur at any part of the spine, sometimes the bone fusion may skip some joints but continue to move up.⁴

Ankylosing spondylitis is responsible for 4-5% of patients with chronic low back pain. AS can be systemic, affecting more than just the back and sacroiliac joints. Some patients have dactylitis (sausage digit), Achilles tendinitis and plantar fasciitis. About 20-40% of AS patients have eye involvement (uveitis or conjunctivitis). Comorbidities such as cardiovascular disease, lung disease (including decreased chest expansion), colitis and inflammatory bowel disease, spinal cord compression and cauda equina syndrome, osteoporosis (compression fractures possible with minimal trauma), and fatigue and malaise are also seen.⁵ Cardiovascular disease is not uncommon – patients with AS are at a 30-50% increased risk of incident cardiovascular events.⁸

Back pain may improve with exercise, but pain increases with rest. All patients with AS should have physical therapy to improve mobility and physical functioning. Nonsteroidal anti-inflammatory drugs (NSAIDs) are nearly always used in conjunction with physical therapy.⁴ Physical therapy and supervised exercise programs have been found to be better than at-home versions for treatment of AS. Patient education programs can increase understanding and compliance with the physical therapy and exercise. Patients should be encouraged to quit smoking, as it is associated with poorer health outcomes.⁹

Five anti-TNF drugs are approved for treating AS: adalimumab, etanercept, golimumab, infliximab and certolizumab. Secukinumab is an anti-IL-17 biological agent and is also approved. A 2015 study showed that AS patients who used anti-TNF drugs for up to 24 weeks had improvement in pain, function and inflammation as measured by morning stiffness, overall well-being (about 40%), partial remission (10-44%) and/or slight improvement in spinal inflammation, as measured by MRI.¹⁰

While surgical intervention is rare, total hip replacement is the most common surgery for patients with ankylosing spondylitis.¹¹

Work disability affects 10-20% of patients with AS. Lost income and lost productivity due to work disability represent major economic difficulties to both families and society.¹²

Living With PsA – Meg’s Story

Meg Maley isn’t one to let an opportunity slip by or negativity dim her joy. If you have any doubt about her optimism, just check the tattoo on her foot – Always Yes. That attitude, and maybe her infectious smile, landed her a spot on the CBS reality TV show “Big Brother” in 2015, which changed the course of her life.



But despite her buoyant outlook, always yes isn’t always easy. Meg, 29, has psoriatic arthritis (PsA), which causes persistent joint pain, bouts of fatigue and vision problems that make it impossible to drive some days. “It’s hard for people to understand, because normally I’m very outgoing,” says Meg. “I have a big personality, and I like to be really active.”

Diagnosed when she was about 12 years old, Meg hid her PsA from even her closest friends. As she got older, she came to see it as something she had to deal with, but not something that would define her, so she kept the painful details to herself.

“Big Brother’s” casting people found her in New York. “My life super changed at that point,” she says with a laugh. But appearing on “Big Brother” revealed her reality to viewers. She performed poorly in physical competitions, and viewers who watched the 24-hour live-stream online noticed other details: She took pills, she walked funny sometimes, she has knee scars and she always hit the hot tub early in the morning before anyone was up. Social media began to buzz about it. “They put together that I had some sort of autoimmune disease,” Meg says. “They didn’t know what it was, but they knew it was something of the sort.”

After the show ended, she decided to go public about her psoriatic arthritis – on her terms. “I didn’t want people to think I wasn’t cool about it or proud of it; I just didn’t want that to be the first thing people saw in me,” she says.

She and her friend Andrea Boehlke (a “Survivor” alumna) started co-hosting their annual Reality Takeover, a fundraiser in New York and Los Angeles benefitting the Arthritis Foundation. This year, she joined Advocates on Capitol Hill and is speaking at the Arthritis Foundation’s JA Conference.

She’s found that sharing her story brings an outpouring of support from the arthritis community, including high school students and parents of kids with juvenile arthritis. She’s not as self-conscious now about having to take breaks or ask for help – or about wearing what she wants. “My psoriasis is something that I’ve struggled with because I am the girl who wears short skirts and crop tops,” she says. “But honestly, I found the people who matter don’t care and the people who care don’t matter.”

“Be proactive! Don’t be afraid to tell your doctor about your concerns. In the past, I would never call my doctor and say I’m in pain. But you should do that, because they can help.” - Meg Maley

PSORIATIC ARTHRITIS (PSA)

Psoriasis is a skin disease that causes itchy, scaly rashes and crumbling nails. In the U.S., psoriasis remains a common, inflammatory disease, affecting 7.4 million adults. Its prevalence has remained stable since the mid-2000s.¹³ Not everyone who has psoriasis also develops psoriatic arthritis (PsA) – fewer than 4 in 10 of these patients also develop PsA. Once it starts, PsA can lead to joint pain, stiffness and swelling. It may result in permanent joint and tissue damage if not treated early and aggressively.

The disease may lay dormant in the body until triggered by some outside influence, such as a common throat infection. Yet for the most part, these patients remain optimistic. According to a 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation, 96% of PsA patients say that even when others get discouraged, they know they can find a way to solve the problem.

Prevalence

Psoriatic arthritis occurs in 6-41% of psoriasis patients.¹⁴ The presence of psoriasis and inflammatory arthritis, with the absence of positive serological tests for rheumatoid arthritis, are the hallmarks of PsA. Most people with PsA (60-70%) are diagnosed with psoriasis first. In 15-20% of PsA patients, arthritis precedes the onset of psoriasis.¹⁵

Psoriatic arthritis has a higher prevalence in patients with more extensive skin disease and a prevalence as high as 30% in dermatology clinics (where patients tend to have more extensive/severe psoriasis). Psoriasis frequency ranges from 1-3% in non-Hispanic white populations.¹⁴

Psoriatic arthritis may not be appropriately diagnosed in psoriasis patients, which may be due to under recognition of PsA symptoms and a lack of effective screening tools.¹⁶ In seven European and North American countries, almost a third of patients with psoriasis seen in dermatology centers had PsA as determined by rheumatologists. Of the patients given the diagnosis of PsA in this study, 41% had not received a previous PsA diagnosis, suggesting underdiagnosis of patients in dermatologic practices of this potentially debilitating disorder.¹⁷ Patients with psoriasis may also have osteoarthritis, which can complicate the diagnosis.

Health Burdens

No curative treatments exist for this disease, but current treatments (particularly with biological drugs) may significantly reduce symptoms, improve joint function and prevent future complications. The main goals of treatment are to achieve clinical remission, inhibit or prevent structural joint damage, and improve patients' quality of life.¹⁸

Skin symptoms of psoriasis can precede the joint symptoms of psoriatic arthritis by between eight to 10 years.¹⁹ Patients with PsA experience pain, swelling and joint tenderness, which reduce functioning in daily activities and impaired quality of life.²⁰ In a 2016 study, patients with PsA report a substantial impact of disease on physical function. One-third of surveyed PsA patients report missing work because of their disease and an impact on their ability to work full time. Over half of patients report receiving no treatment or topical therapy only, leaving joints

No curative treatments exist for this disease, but current treatments (particularly with biological drugs) may significantly reduce symptoms, improve joint function and prevent future complications.

untreated. Patients report they are less likely to follow treatment guidelines due to perceived lack of efficacy and concerns about long-term safety.¹⁹

Psoriatic nail involvement and patient weight may be predictors for PsA outcomes. Nail involvement occurs more often and is more severe in patients with PsA than with psoriasis alone. Nail involvement in psoriasis patients may predict the development of PsA.¹⁹ Severe psoriasis is more common among patients with PsA than psoriasis patients without PsA.²¹ Patients with PsA and psoriasis tend to be heavier than unaffected individuals and patients with RA.²² Obesity has been found to predict worse outcome and poor response to treatment in patients with psoriasis and PsA.²³

Both psoriasis and PsA are like other systemic inflammatory conditions in that they are linked to an increased risk of developing cardiovascular diseases.²⁴

A 2014 study found that about two-thirds of people with psoriasis and/or PsA say their disease makes them feel angry, frustrated and/or helpless. More than half say psoriasis interferes with their ability to enjoy life.²⁵

Two 2014 studies estimated that depression and anxiety affect more than 30% of psoriasis patients. Low self-esteem, social anxiety, embarrassment due to disease stigmata or absence from work due to painful arthritis may partly explain the psychosocial impact of psoriasis.^{25, 26} Additionally, about 88% of family members reported the same levels of depression and anxiety as those with psoriasis.²⁵ A 2015 study estimated that levels of depression may be higher, stating that depression or insomnia affects between 20-50% of patients with psoriasis or PsA.²⁷

According to a 2014 study, 55% of patients with moderate-to-severe psoriasis and 41% of patients with PsA are not being treated with the established standards of care.²⁸ Patients with psoriatic arthritis who did not seek treatment in the previous 12 months said they did not think it would help, suggesting that education about the availability of effective treatments is needed.¹⁹

According to a 2014 study

41% of patients with moderate-to-severe PsA are **not being treated with the established standards of care.**²⁸

Economic Burdens

Psoriatic disease is an expensive condition. A 2013 study found that, although roughly 91% of patients with psoriasis or PsA were covered by insurance, the majority spent more than \$2500 per year in out-of-pocket costs for their disease.²⁹ A 2015 study estimated the U.S. economic burden of psoriatic disease is up to \$135 billion a year.³⁰

What the Numbers Mean, Karen's Story: Take Care of Yourself

Meet Karen Lomas, 65, who works full-time as a nurse. Following, in her own words, is Karen's story about living with psoriatic arthritis (PsA), which she was diagnosed with several years ago, and how the statistics she reviewed in this edition of Arthritis by the Numbers relate to her personally.

Question: What do the statistics you reviewed mean to you and adjustments you've had to make?

Karen: I have been a member of the Arthritis Foundation since reading Arthritis Today magazine in my rheumatologist's office years ago. I've taken part in local Jingle Bell Run and Walk to Cure Arthritis events. I was very surprised at the number of patients who have been diagnosed with, not just PsA, but all forms of arthritis. I expected the number of people with osteoarthritis to be high, but I had no idea the numbers were so high for other forms of arthritis.

Question: What changes has your arthritis made to the way you live your life?

Karen: That depends on a day-by-day basis, on how well the medications are working. On some days, I have a hard time watching my grandchildren because my hands hurt. Nursing can be physically demanding. While I work full time in the surgical department, I don't work in surgery because I have a hard time hanging IV bags, and it's not easy to get on my hands and knees when needed.

I am getting closer to retirement age and am concerned about Medicare coverage. Because I currently have health care coverage through my employer, I can give myself shots at home once a week. Medicare won't pay for that, and many places won't take secondary supplemental insurance cards for this treatment option, so you must pay out-of-pocket and wait to get reimbursed.

This medicine is not cheap. Medicare will pay for infusions of the drug, but that requires you to come into a clinic up to eight hours weekly, which would be a real burden. I plan to work longer, even though my arthritis makes me feel more fatigued. It's less of a burden than trying to pay for medication on a fixed income.

Question: What advice would you give to a newly diagnosed patient or parent/caregiver?

Karen: Take care of yourself and be informed. The more you can educate yourself and understand your disease, the better. Working on diet is a good thing – find out about anti-inflammatory diets. Arthritis Today magazine and the Arthritis Foundation website have a lot of helpful information.

There is a shortage of rheumatologists, especially in rural areas. Be careful, because some well-meaning, but ill-informed, primary care doctors may prescribe ineffective or bad treatments, like steroid shots. Long-term steroid use can be harmful.

Question: What are the questions we can't answer yet, but you would like researchers to focus on?

Karen: I would like to see researchers develop a pill instead of using shots or infusions, especially for squeamish patients. I would also like to see researchers focus on incorporating more natural, homeopathic treatments.

I thank the Arthritis Foundation for the opportunity to be involved. The Foundation allows me to give what I can and to help other patients. I want us to be more visible to others. Maybe focus on more celebrity spokespeople who have different forms of arthritis.



Living With Fibromyalgia – Renee’s Story

For most of her life, doctors and family members told Renee Cafaro that her pain was all in her head. “No one understood how I could be involved in so many activities one day and unable to walk the next,” she says. “I was accused of making up my pain.”

Renee, a young fashion magazine editor now living in New York City, has been in chronic pain since she was 11. Her mom would take her to the pediatrician, where everyone agreed she was experiencing growing pains. Renee recalls struggling to walk and experiencing searing pain all over her body, but she was exhausted from being told nothing was wrong with her. In college, Renee could no longer ignore that something wasn’t right.

“I couldn’t get up to my bunk in my dorm room,” says Renee. “I needed help getting up the stairs, which got me in trouble because the resident assistants thought I was drinking when I was dead sober and just couldn’t walk without assistance.”

When Renee was unable to walk to class, she asked her university for help. They refused to provide resources because she didn’t have a visible disability. Renee eventually had to leave school during her senior year because she could no longer manage her classes and responsibilities with her pain.

For years, Renee didn’t know what was wrong with her or how to describe what she was going through. She had countless tests and was often told she was crazy. With the help of her sister, Renee was diagnosed with fibromyalgia in 2003. Then in 2008 a rheumatologist diagnosed her with seronegative RA. “That was an extremely good day because I finally knew what was going on with me, what I was up against and what I could do about it.”

“Having arthritis and fibromyalgia feels like I light up like a pinball machine with pain all over my body. It’s a searing, burning, constant pain,” says Renee. “It’s so much pain you can barely see straight, and you certainly can’t sleep. A lot of times you’re forced to say no to doing things because you’re in so much pain. Or, you go to things that you can’t miss, and you just grit your teeth and try to put on a brave face. You don’t want to burden anyone with your suffering.”



“The Arthritis Foundation has given me the strength, courage and positive mental state to cope – more than access to any doctors or medical resources. Their arthritis community is what has helped me the most. I’ve been told I’m crazy for most of my life, but here I’ve met so many other people who have my same story.” - Renee Cafaro

SECTION 5: FIBROMYALGIA

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WHAT IS FIBROMYALGIA?

Fibromyalgia is a condition associated with widespread bodily pain, which is experienced in different parts of the body at different times. The pain can be chronic and is amplified, often occurring in the absence of a usual painful stimulus. This pain, along with other symptoms such as fatigue, non-refreshed sleep, memory problems and mood changes, can all strongly impact the quality of life for these patients. Fibromyalgia is not a single disease, but a constellation of symptoms that can be managed by a variety of pharmacologic and non-pharmacologic approaches.

Fibromyalgia is not a form of arthritis because it does not directly inflame or damage joints; rather, it is considered an arthritis-related condition. It is often found as a comorbid condition in people who have different forms of arthritis like osteoarthritis, rheumatoid arthritis, lupus and inflammatory bowel diseases.

Fibromyalgia affects more than 3.7 million Americans. The majority are women between the ages of 40 and 75, but it also affects men, young women and children, especially adolescent females. It sometimes occurs in more than one member of the same family, suggesting that hereditary factors may influence the development of this conditions.

While the challenges of this disease are difficult to deal with, 92% of fibromyalgia patients say they actively seek out information on their illness, according to the 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation.

Prevalence

The prevalence of fibromyalgia is similar in different countries, cultures and ethnic groups. There is no evidence that fibromyalgia has a higher prevalence in industrialized countries and cultures. It can develop at any age, including in childhood.¹

Fibromyalgia is present in as much as 2-8% of the population and is characterized by widespread pain, often accompanied by fatigue, memory problems and sleep disturbances.² Fibromyalgia remains undiagnosed in 3 of 4 of people with the disorder.³ While more women are diagnosed with fibromyalgia than men, the gap is closing. Based on newer diagnostic criteria, twice as many women are diagnosed with fibromyalgia than men, which contrasts with the older 1990 criteria where the female-to-male ratio was 9:1.⁴

Health Burdens and Disease Triggers

Fibromyalgia is a centralized pain state because the processing of pain occurs in the brain and central nervous system. In this condition, pain is experienced in different body regions at different times, although it is usually widespread.⁵ Fibromyalgia may occur with other chronic pain conditions like osteoarthritis, rheumatoid arthritis and lupus. About 10-30% of patients with these diseases also meet the criteria for fibromyalgia.⁶ Magnetic resonance imaging (MRI) of brain response has shown that brain activation in fibromyalgia patients is increased and they experience amplified pain (allodynia) for a stimulus that people without fibromyalgia perceive as touch.⁷ Patients with fibromyalgia may have imbalances or altered activity of various neurotransmitters mediating pain transmission, which may affect mood, memory, fatigue and sleep.²

Twin studies suggest that half of the risk of developing fibromyalgia and related conditions such as irritable bowel syndrome and headache is genetic, and half is environmental.⁸ Environmental triggers range from physical stressors to infection to traumatic life events. Environmental factors most likely to trigger fibromyalgia include stressors involving acute pain that would last for a few weeks.⁹ Fibromyalgia can be triggered by infections like Epstein-Barr virus, Lyme disease, Q fever and viral hepatitis.⁹ Fibromyalgia can be triggered by trauma like motor vehicle collisions.¹⁰ Psychological stress has also been shown to trigger fibromyalgia. Fibromyalgia can be triggered by deployment to war.¹¹ There is also evidence for a relationship to posttraumatic stress disorders which can be associated with sexual abuse.

Patients developing fibromyalgia commonly have lifelong histories of chronic pain throughout their body – regional or widespread musculoskeletal pain occurs in about 30% of patients.¹ Fibromyalgia patients are likely to have

a history of headaches, temporomandibular joint (TMJ) disorder, chronic fatigue, irritable bowel syndrome and other functional gastrointestinal disorders, interstitial cystitis/painful bladder syndrome, dysmenorrhea and/or endometriosis, and other regional pain syndromes (especially back and neck pain).¹²

Living with fibromyalgia also has a significant emotional impact, with depression and anxiety being common comorbidities.¹³ Fibromyalgia symptoms can result in significant functional impairment and a negative impact on patients' quality of life. Fibromyalgia patients report difficulties in establishing and maintaining physical and emotional relationships with others, adjusting personal expectations of what they can complete and goals they can achieve, dealing with mood disturbances, such as anxiety and depression, and starting or continuing education or a career.¹⁴

Patients often have difficulty adjusting to living with fibromyalgia and sometimes feel a sense of loss of identity. Patients also sometimes feel isolated from health care providers because they perceived they had to convince doctors they have a real condition to be taken seriously.¹⁵ Patients have characterized living with fibromyalgia as having to manage two major burdens. The most obvious burden is pain, which can be ever-present and overwhelming. The second, less obvious burden, is invisibility – being doubted by others because the symptoms of fibromyalgia are subjective and not seen by others.¹⁶

Economic Burdens

There are substantial direct (medical) and indirect (lost productivity and wages) costs associated with this disease. Medically, on average, it often takes more than two years and about four consultations with different specialists to be diagnosed with this disease.¹⁷ Fibromyalgia can represent a substantial economic burden for both the patient and the health care system, with increased costs for prescription medications, lost productivity and short-term disability. Fibromyalgia symptoms can affect a patient's ability to work, frequently resulting in missed workdays, reduction in hours and having to change jobs.¹⁸

Currently Recommended Treatments

Many patients who have fibromyalgia (or related syndromes) and are seen in routine clinical practice may respond well to simple interventions like stress reduction, improved sleep patterns, and increased activity and exercise.² The importance of behavioral therapies should be emphasized, as should the normalization of sleep patterns and institution of exercise therapy. Patients should understand that these treatments often will be more effective than pharmacological treatments.¹⁹

Management should take the form of a graduated approach with the aim of improving health-related quality of life. It should focus first on non-pharmacological modalities, but if there is lack of effect, there should be individualized treatment based on patient need. Experts give a strong recommendation for the use of exercise, particularly given its effect on pain, physical function and well-being. Exercise is also easily available and is associated with low cost and low safety concerns.²⁰ Aerobic exercise has been associated with improvements in pain and physical functioning.²¹ Resistance training can also result in significant improvement in pain and function.²² Land and aquatic exercise appear equally effective in improvement in pain and function.²³

Three drugs have been approved for the treatment of fibromyalgia, pregabalin (*Lyrica*) duloxetine (*Cymbalta*) and milnacipran (*Savella*). These drugs have other actions and have been used to treat conditions such as depression.

JUVENILE-ONSET FIBROMYALGIA

Fibromyalgia is often thought of as a condition that affects adults, but it can occur in kids, too. No matter what age it occurs, fibromyalgia can cause widespread musculoskeletal pain accompanied by sleep and mood issues and fatigue. Scientists are not sure what causes fibromyalgia, but it is seen more often in girls and women, in people

with a family history of fibromyalgia, and/or in people with a rheumatic disease (like rheumatoid arthritis or lupus). Mothers of children with juvenile-onset fibromyalgia (JFM) are 4 times as likely to have fibromyalgia than mothers of healthy children.²⁴

Whether it appears in children or adults, symptoms gradually accumulate over time with no single triggering event. However, sometimes symptoms begin after a physical trauma, surgery, infection or significant psychological stress.

In kids with fibromyalgia, symptoms may include the following.

- Widespread diffuse pain is often described as a constant, dull ache that has lasted for at least three months. To be considered widespread, the pain must occur above and below the waist on both sides of the body.
- Frequent headaches occur in most patients with fibromyalgia.
- Continuing sleep disturbances often mean kids take more than an hour to fall asleep. Many have difficulty staying asleep and wake up during the night.
- Constant, unrelenting fatigue is common, even after sleeping for long periods of time. Sleep is often disrupted by pain. Kids with fibromyalgia may have other sleep disorders, like restless legs syndrome or sleep apnea.
- Kids with fibromyalgia may also have pain or cramping in the lower abdomen, may feel like they have brain fog, and experience depression and anxiety.²⁵

Prevalence

Fibromyalgia can develop at any age, including in childhood.¹ JFM occurs most commonly in adolescent girls.^{26, 27}

As with many diseases, it is difficult to tell the true numbers of children affected by JFM. However, a few studies have attempted to estimate its prevalence. A 2014 study estimated that about 2-6% of school children are affected by JFM.²⁷ A 2019 review of studies is more conservative, stating that between 1-2% of school children are affected by JFM. By this estimate, over 1 million school-aged children in the U.S. may have been affected by chronic widespread pain in 2018.²⁸ Despite the potentially large population of school children affected by this condition, not everyone seeks specialized medical care as reflected by the fact that only about 7-15% of referrals to pediatric rheumatology clinics are due to JFM.²⁷

Health Burdens

JFM is associated with considerable difficulty in physical, social and emotional functioning.²⁹ Early symptoms of JFM may be confused with growing pains. Growing pains tend to occur in younger children (pre-teens), mainly at night. JFM symptoms tend to occur during adolescence and are chronic throughout the day. This uncertainty, combined with the fact that all the symptoms of JFM don't appear at once, may delay diagnosis and appropriate treatments for two or more years.²⁷

European studies in the 1990s suggested that about 70% of school-aged children who had JFM symptoms no longer met the criteria for the disease after two years.^{27, 30} However, more recent studies in the past decade show that most JFM patients seen in pediatric specialty care (greater than 80%) continued to report pain and other disease-related symptoms (such as fatigue and sleep difficulty) into their early 20's. About half of those diagnosed with JFM in adolescence went on to meet full criteria for adult fibromyalgia in early adulthood. Over the years, pain symptoms tend to slightly decrease in severity, perhaps reflecting an adaptation to living with pain. Persistence of this disease into early adulthood is associated with significant impairment of physical functioning and lower perceived health status, particularly for those who have mood difficulties.^{27, 31}

Mental Health Impact

Depression, anxiety and attentional disorders are common mental health conditions in JFM patients.³² When compared to adults with fibromyalgia, adolescents with the disease had higher rates of current anxiety disorders. By comparison, adolescents had lower rates of depressive disorders than adults.³³ The lifetime prevalence of major depression is estimated to be 26% in children with JFM and 61.5% in adults with fibromyalgia.³⁴

School and Social Impact

School absenteeism is a risk factor for school dropout and multiple economic, marital, social and psychiatric problems in adulthood. School absenteeism is common, with adolescents missing an average of three school days per month. Several patients are unable to attend regular school at all and are homeschooled due to the symptoms of juvenile-onset fibromyalgia.³⁵

JFM patients have been shown to be absent about 3 times more often than the average student (27 verses nine days).³² While pain intensity and pain duration are not significantly related to school functioning, depression is significantly associated with impairment of school functioning, including school attendance.³⁵

Adolescents with JFM are seen by their classmates (and themselves) as being isolated, more emotionally sensitive than their healthy peers and have fewer friendships.³⁵ They are more likely to report childhood trauma, including physical or sexual abuse, than healthy peers.^{33, 36}

Currently Recommended Treatments

Early intervention for young people with JFM is important to avoid long-term negative effects on quality of life, mood and functioning into adult years.²⁷ Less invasive interventions are recommended for initial treatment and have been found to be effective in improving coping, daily functioning and mood. A randomized clinical trial showed that cognitive behavioral therapy is effective in reducing disability and reducing depressive symptoms in JFM.³⁷ Another study showed that mindfulness-based stress reduction (MBSR) was also useful in reducing JFM pain and disability.³⁸

Research shows that multi-disciplinary treatments that include psychological coping, skills training and physical exercise are effective recommended treatments for JFM.^{39, 40} Newer studies show that specialized exercise programs tailored for patients with JFM are well tolerated and effective in reducing pain and improving function.^{37, 41} No randomized studies have shown the efficacy of complementary and alternative medicine treatment in JFM, although the use of adult data modified for children, in therapies deemed safe, may be considered. These interventions include increased exercise, mind-body therapies (like yoga, tai chi, etc.), omega 3 fatty acid supplementation and massage therapy.⁴²

SECTION 6: JUVENILE ARTHRITIS



Juvenile arthritis (JA), also known as pediatric rheumatic disease, is an umbrella term used to describe the many autoimmune and inflammatory conditions or pediatric rheumatic diseases that can develop in children under the age of 16.

Although the various types of juvenile arthritis share many common symptoms, like pain, joint swelling, redness and warmth, each type of JA is distinct and has its own special concerns and symptoms.

Some types of JA affect the musculoskeletal system, but joint symptoms may be minor or nonexistent. Juvenile arthritis can also involve the eyes, skin, muscles and gastrointestinal tract. This section presents the facts for some of the most common diseases in this group.

Juvenile idiopathic arthritis (JIA) is considered the most common form of childhood arthritis. JIA includes six subtypes.

Juvenile-onset systemic lupus erythematosus (SLE or Lupus) can affect nearly every organ system in the body, including the skin, joints, kidneys, heart, lungs and central nervous system.

Juvenile-onset scleroderma, which literally means hard skin, describes a group of conditions that causes the skin to tighten and harden. It is the third most frequent childhood rheumatic condition after JIA and systemic lupus erythematosus.

Juvenile myositis (JM), including juvenile dermatomyositis (JDM) and juvenile polymyositis (JPM), is a group of rare and life-threatening autoimmune diseases in which the body's immune system attacks its own cells and tissues. Weak muscles, with or without skin rash, are the main symptoms of this disease.

JA patients and their families, regardless of the form of JA they experience, face many physical, emotional, mental and economic challenges. Some of these challenges are described in the following pages.

One of the unmet needs described by parents includes finding help for the significant mental health challenges faced by children with JA. Despite indications for a need, there are no existing guidelines or standard practices for mental health screening and intervention for depression, anxiety and suicidal ideation for JA in context of pediatric rheumatology care. Because mild symptoms of depression may be overlooked as part of normal adolescent development, parents and health care providers should watch for persistent mild or subthreshold depression symptoms which can be a predictor of development of major depression and suicidal behavior in later adulthood. These symptoms should be evaluated. Studies have shown that patients with depression symptoms visit their primary care doctors about 60% less frequently than those without symptoms. This may suggest that depressed young patients and their potentially depressed caregivers may exhibit negative coping styles and social withdrawal, which may make symptoms of the disease worse.¹

Encouraging healthy self-care choices can help patients and their families deal with some of the physical challenges. While it's difficult for kids to deal with the health challenges of their disease, they are empowering themselves by making healthier life choices. According to a 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation, 89% of these patients have started eating more healthfully to improve their arthritis health.

The following pages contain facts from studies that have already been completed. [Learn more about current and ongoing Arthritis Foundation-funded research taking place with our partners at the Childhood Arthritis and Rheumatology Research Alliance \(CARRA\).](#)

Living With JA – Sophie’s Story



Sophie Sherman is a rising high school senior from Brookline, Massachusetts. When she was 11, her parents started to notice that she wasn’t acting like herself. Instead of spending time with her friends after school, she would take four-hour-long naps on the living room sofa. Instead of asking for seconds on pasta night, she would barely touch her plate. It seemed like everything she did, be it physical or mental, consumed every ounce of her energy.

The breaking point came during a family vacation in the summer of 2012. Sophie woke up to immense pain in her back that was completely debilitating. She was immobilized, unable to move from her bed. She didn’t know what was happening. Though she was frightened, the most alarming moment occurred a couple months later when her new rheumatologist diagnosed her with psoriatic arthritis (PsA).

Sophie was confused by the diagnosis. Being only 11 at the time, she had no idea what the disease meant. Despite countless explanations from countless professionals, the only information that truly stuck was the fact that she was going to have to get weekly treatment in the form of a daunting needle.

In the beginning, Sophie had to try oral medications, which only made her sicker. When she started on a biologic, it was like a miracle. She had spent months feeling sluggish, in pain and immobile. The very day after her first biologic injection, she sprinted entire laps around the beach. In just 24 hours, Sophie had gone from a girl who could barely function to one who could keep up with her little brothers as they played together in the ocean’s waves. In that moment, she didn’t care about a weekly needle; it was simply an unlucky price to pay to regain mobility, energy and happiness.

Sophie thought this is how it would now be. She was a student in high school and thought her days of joint pain and mental exhaustion were behind her. Nevertheless, after two years on her miracle medication, she started developing immunity to the injections. Her doctors told her that she needed to switch to another medication that would better control her arthritis. The simple switch, however, cost her a part of her life.

The new medicine needed approval from Sophie’s insurance company, and as she waited, her arthritis went unchecked. She started a new medication that didn’t work, but because of step therapy, she had to wait three months before she could increase the dosage. Then, Sophie would have to wait yet another three months before the medication was considered a failure. During this process, Sophie was in pain and exhausted.

She started noticing it was hard to keep up with the other girls on her crew team and paying attention in class was difficult. Some days, she would have trouble buttoning her jacket and typing on her laptop. The brain fog and joint pain caused by arthritis had returned. Sophie’s grades started slipping and she began distancing herself from friends. She even quit the crew team she had been part of for two years.

Each time Sophie started a new medication, it stopped being effective in a matter of weeks. She had no option but to repeat the arduous process of switching to another biologic. It was step therapy protocol to test Sophie on different injections, but in the meantime, she was truly miserable.

Now 17 and a senior in high school, Sophie has been on five different biologics. The long transitions between medications meant Sophie faced more physical pain and mental exhaustion. Her current medication has been working, but she fears that it will become ineffective and she’ll have to endure step-therapy protocols again.

“I want to make the most of the last moments I have at home and with my classmates, making my final year one for the books,” she says. “Step therapy could get in the way of my goal. It is imperative that these protocols be reformed to improve quality of life for thousands of patients like me.”

JUVENILE IDIOPATHIC ARTHRITIS (JIA)

The term juvenile idiopathic arthritis (JIA) has replaced the older terms juvenile rheumatoid arthritis (JRA, used in the U.S.) and juvenile chronic arthritis (JCA, used in Europe). However, JIA is more inclusive than the older terms and includes what was previously called JRA or JCA and other idiopathic forms of childhood arthritis. It is the most common form of JA. There are several JIA categories.

Systemic JIA (formerly called Still's disease) causes inflammation in one or more joints and is often accompanied by a high-spiking fever that lasts at least two weeks and a skin rash. About 10% of children with JIA will have this form.

Oligoarticular JIA causes arthritis in four or fewer joints, typically the large ones (knees, ankles and elbows). Children with this type of JIA are more likely to get uveitis (chronic eye inflammation) than those with other forms of JA. Persistent oligoarticular JIA is diagnosed when four or fewer joints are affected for longer than six months. When five or more joints are affected within six months of symptoms beginning, extended oligoarticular JIA is diagnosed.

Polyarticular JIA causes inflammation in five or more joints, often the small joints of the fingers and hands, but any joint can be affected, including weight-bearing joints and the jaw. About 25% of children with JIA will have this form. This category most closely resembles adult rheumatoid arthritis. Polyarticular JIA can be either seropositive, meaning the rheumatoid factor (RF) is positive, or seronegative, meaning the patient is RF negative.

Juvenile psoriatic arthritis involves arthritis that usually occurs in combination with a skin disorder called psoriasis. The psoriasis may begin many years before any joint symptoms become apparent.

Enthesitis-related JIA is a separate category of JIA. It can be characterized by enthesitis, which is tenderness where the bone meets a tendon, ligament or other connective tissue. The tenderness may be associated with joint inflammation and most often affects the hips, knees and feet. It can also occur without tenderness. This form of arthritis may also be characterized by inflammation in the sacroiliac joints and other spine joints. This form is sometimes called spondyloarthritis or ankylosing spondyloarthritis. Patients with this form of arthritis may be positive for a blood test called HLA-B27. Some patients may also develop acute uveitis.

Undifferentiated arthritis describes juvenile arthritis that does not fit into any of the other types or involves features of two or more subtypes.

Prevalence

Juvenile idiopathic arthritis (JIA) has been identified all over the world in nearly all races and ethnicities with an average prevalence rate of 1 to 2 per 1,000 children.¹ JIA appears to be more common in non-Hispanic white populations and less common in non-Hispanic black and Asian populations in the U.S.²

More girls than boys are affected by JIA.³ The girl-to-boy ratios of children affected range from 2-1 to 3-1, depending on the JIA category.²

Genetic and environmental factors predispose children to developing JIA. Data from family and twin studies suggest that susceptibility to juvenile idiopathic arthritis (JIA) may be inherited. While siblings of JIA patients are 12 times more likely than the general population to develop JIA and first cousins are 6 times more likely than the general population to develop this disease, the overall risk is low because JIA is considered to be a rare disease with a low prevalence rate. However, children with JIA and their family members are at increased risk of autoimmune disorders in general.^{4, 5}

Living With JIA – Laniese’s Story

For as long as Laniese Penner can remember, friends, classmates and complete strangers have been encouraging her to buck up and push through what they think is just a little stiffness and soreness. They don’t know what she experiences as a teenager living with arthritis.

As a young child, Laniese competed in gymnastics. For several years, she complained about ankle and wrist pain. Her mom thought it was from landing poorly and the stress of tumbling. But pain took over. Eventually, Laniese had to drop out of gymnastics. Then she was forced to quit piano lessons because it hurt to press the keys. During a vacation, she couldn’t keep up with her family for even a quarter of a mile on their annual hike. Laniese became very sick and was diagnosed with JIA at age 9, just after starting the fourth grade.



“When I was first diagnosed, my friends told me their grandma had the same thing I did and didn’t understand why I had to miss so much school,” says Laniese. “I felt so alone, like no one else my age knew what I was experiencing.”

“At first, I just wanted to fit in. I would show up to school with so much joint pain. Kids would ask me if I was okay. I’d tell them I was fine and that nothing was wrong. Today, I want every child with arthritis to know that they should never hide their pain. It’s not something to be ashamed of, and it certainly doesn’t define you.”

Laniese wants the world to know that arthritis is more than a little hurting or pain. “People don’t understand what arthritis is,” she says. “It’s not like having a twisted ankle that will heal in two weeks. It’s constant and never goes away. Some days, the pain makes me so exhausted that I could sleep for a week and still be tired.”

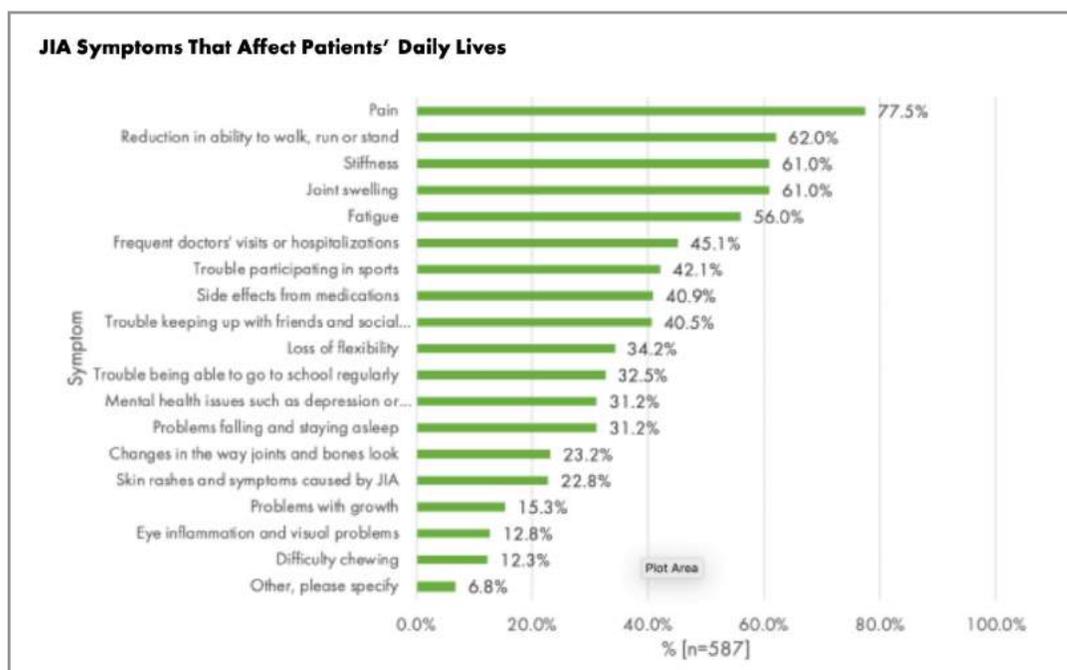
This past school year was one of her worst years with arthritis. She developed a sinus infection and missed a lot of school. People don’t realize one of the complications of arthritis is having a weaker immune system. Her body was trying to fight the sinus infection and arthritis at the same time.

“People think arthritis is just a little pain - but you’re having surgeries and a hip replacement at age 16. That’s not normal and shouldn’t be happening,” she explains.

“You can be stronger than your disease. People want to put you in a box and tell you what you can’t do. But you can show the world you can play varsity basketball, run cross-country, be student council president, become valedictorian, receive a perfect score in music class, tell your congressman your story and much more. I am stronger than arthritis, and I’m just getting started.” - Laniese Penner

Health Burdens

A lot is unknown about the health burdens of JIA. Doctors are actively researching this to better understand how the disease impacts daily life and how best to support patients with the disease. While there is no cure, JIA patients can go into remission. Patients, parents and health care providers may use different criteria to determine if a disease is in remission. Patients and parents may feel the disease is in remission if patients have no swelling or pain (or less or tolerable pain), report a lack of stiffness (especially in the morning), are able to participate in activities, sleep better, have more energy, and are feeling more capable or independent. Doctors use joint examination, blood tests, feedback from the patient about pain and other symptoms, eye exams, physical examinations, and imaging (including MRI and ultrasound) to determine disease remission.⁶



Note: From the Arthritis Foundation-CARRA Externally-led Juvenile Idiopathic Arthritis Patient Focused Drug Development Meeting Report⁷

A 2018 survey of almost 600 patients and parents asked which JIA disease symptoms affected their daily lives. Pain, reduction in physical abilities, stiffness, joint swelling and fatigue were rated as symptoms that had the largest effects. More than a third of respondents stated that pain (37%) and fatigue (34%) are symptoms that may persist even with current therapies.⁷

Many children with JIA who are managed with contemporary treatments attain inactive disease within two years of diagnosis and some can discontinue treatment. The probability of attaining remission within five years of diagnosis is about 50%, except for children with polyarthritis.⁸

Nearly half of children with JIA have recurrent or ongoing disease activity on entry into adulthood. These children have active arthritis with progressive joint damage, in addition to continued exposure to chronic arthritis treatments and decreased health-related quality of life.⁹

In the 1980s, the disease modifying anti-rheumatic drug (DMARD), methotrexate, opened an era of disease suppression treatments that resulted in significant improvements in patient outcomes for this disease. With the approval of biologic response modifiers, or biologics, in the late 1990s, more powerful therapies that target specific components of the immune system became available. Some therapies have been approved for adults and are awaiting approval for use in children. The table below lists the therapies available or being tested for JIA in 2019.⁷

Biologics and Small-Molecule Targeted Therapies for Arthritis

Methotrexate continues to be one of the most common medications used to treat this disease. It is an effective, relatively safe and low-cost treatment for children with JIA, but its use is often limited by significant side effects.¹⁰ Among children taking methotrexate, a greater proportion of girls compared to boys reported symptoms of intolerance such as nausea and/or effects on the liver.⁹

A serious comorbidity of this disease is JIA-associated uveitis (JIA-U), which can lead to ocular complications and permanent vision loss. About 10-25% of the children in the U.S. with JIA develop uveitis within the first four years of their arthritis diagnosis.¹¹

<p>TNF Inhibitors</p> <ul style="list-style-type: none"> • Infliximab (Remicade) • Etanercept (Enbrel)* • Adalimumab (Humira)* • Golimumab (Simponi)** • Certolizumab (Cimzia)** <p>Inhibitor of CD28-B7 (T cell co-stimulation signal)</p> <ul style="list-style-type: none"> • Abatacept (Orencia)* <p>IL-6 Inhibitors</p> <ul style="list-style-type: none"> • Tocilizumab (Actemra)* • Sarilumab (Kevzara)** <p>B cell Inhibitor</p> <ul style="list-style-type: none"> • Rituximab (Rituxan) 	<p>IL-1 Inhibitors</p> <ul style="list-style-type: none"> • Anakinra (Kineret)** • Canakinumab (Ilaris)* • Rilonacept (Arcalyst) <p>IL-17 Inhibitors</p> <ul style="list-style-type: none"> • Secukinumab (Cosentyx)** • Ixekizumab (Taltz) <p>IL-12/23 Inhibitor</p> <ul style="list-style-type: none"> • Ustekinumab (Stelara) <p>JAK Inhibitors (Small Molecule)</p> <ul style="list-style-type: none"> • Tofacitinib (Xeljanz)** • Baricitinib (Olumiant)** <p>Phosphodiesterase Inhibitor (Small Molecule)</p> <ul style="list-style-type: none"> • Apremilast (Otezla)
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* FDA Approved for JIA.
** Currently in clinical trial for FDA approval in JIA.

Note: From the Arthritis Foundation-CARRA Externally-led Juvenile Idiopathic Arthritis Patient Focused Drug Development Meeting Report⁷

Patients with JIA have a poorer health-related quality of life (HRQL) compared to peers in good physical health. The areas of HRQL most affected JIA are overall health, physical functioning, role social limitation (physical) and bodily pain/discomfort.¹² HRQOL in children who are newly diagnosed with JIA can vary, even with excellent symptom control. Strong predictors of HRQOL include the child’s perception of social support, their perceived difficulty with the treatment regimen and missed school.¹³

As with most other forms of arthritis, fatigue is common in patients with JIA, even when they reach adulthood. Fatigue is significantly more common in patients with JIA compared to the general population.¹⁴ The consequences of JIA-induced fatigue are important, as they hamper children’s performance at school and can impact their social life, sports and hobbies.¹⁵

Mental Health Impact

Studies have found that the increased length of illness was linked with a higher incidence of psychiatric disorders. The presence of psychiatric disorders was related to considerable difficulties with learning, peer relationships and leisure activities.¹⁶

It has been found that there are higher rates of depression in children with JIA as compared to those without, but there is no significant difference in rates of depression when JIA patients become adults.¹⁷ However, clinical

classification of disease activity and severity has not been directly linked to depression and trait-anxiety in children with JIA. What has been observed is that self-efficacy corresponds with less pain and somatic complaints.¹⁸ This suggests that early recognition of psychiatric illness and management might improve the outcome in children with JIA.¹⁶

School and Social Impact

A 2008 study showed that adolescents with JIA spent a greater percentage of time in bed and less time on moderate to vigorous physical activity than their peers. Only 23% of the JIA patients met public health guidelines on physical activity, compared with 66% in healthy peers.¹⁹

A more recent 2016 study showed that school functioning among teenagers with primary pain conditions (unrelated to a specific disease) and those with JIA have poorer school functioning and school quality of life, missed more school days and made more visits to the nurses than healthy peers. While school function scores were not accounted for by pain intensity, pain frequency or time since pain onset, pain intensity did emerge as a predictor of school-related quality of life.²⁰

Another study found that JIA category, severity at presentation and time elapsed was not associated with educational and occupational accomplishment. Despite JIA and the different associated challenges, researchers have found that young adults are similar to their healthy peers as they transition to adulthood. Even with health challenges, young adults with JIA and healthy peers are comparable in terms of family background, scholastic and occupational self-concept, and academic competence. The percentage of high school graduates and those working, those planning for further studies or seeking employment are equivalent in young adults with JIA and healthy peers.²¹

Economic Burdens

Economic burdens from this disease include direct (medical) and indirect costs (absenteeism and lost productivity for parents). A child with JIA may incur high medical costs due to frequent visits to physicians and therapists to manage the disease.²² There is higher inpatient health care utilization in children with JIA compared to those without JIA. The higher inpatient health care utilization is due to joint surgery, non-joint surgery and hospitalizations.¹⁷

One study of primarily male workers' use of sick leave between 2000 and 2009, found parents who had a child with juvenile idiopathic arthritis (JIA) lost an average of \$4,589.37 due to missed work, compared to \$2,986.08 for parents who had no children with JIA.²³

A 2015 U.S. study reported that more than half (53%) of the parents of children with JIA reported an increase in the number of missed work hours for the period covering the year before and the year after their child's diagnosis. Parents of children without JIA were 64% less likely to experience work-time loss than parents of a child with JIA. Parents of a child with JIA were 2.78 times more likely to report work-time loss than parents having no children with JIA. Only 32% of the parents of children without JIA reported a work-time loss.²⁴

A 2015 study in Europe showed a remarkable increase in annual health care costs for JIA patients due to the inclusion of non-professional caregiver costs, a wider use of biologics and longer hospital stays.²³

What the Numbers Mean, Soler Family Story: I Know Just Enough to Know I Don't Know Enough

Among patient partners who reviewed Arthritis by the Numbers – a collection of verified arthritis facts and figures – was the Soler family of Georgia. Robin Soler has been active with the Arthritis Foundation ever since her younger daughter, Isabela, was diagnosed with juvenile idiopathic arthritis (JIA). At the time she was one of the youngest children in the state to be diagnosed with JIA at just 12 months old.

Over the past 15 years, mother and daughter have seen about 50 different doctors and scores of other medical experts. Isabela has taken at least 20 different types of prescription drugs – consuming more than 15,000 pills in her lifetime, not including antibiotics and other normal childhood drugs. She has missed countless parties and playdates, and one recent semester had to skip 7th period 21 times for doctor's appointments.

Isabela's mother, Robin, is a developmental psychologist and senior scientist at the Centers for Disease Control and Prevention in Atlanta. Robin has had her own personal experience with arthritis, diagnosed with fibromyalgia when she was 26, though her chronic pain goes back to her mid-teens.



After reviewing arthritis statistics we've collected, Robin's main takeaway: "I am happy to know there is information out there, but I'm concerned about the pictures the numbers paint for parents. We and our children need to be hopeful."

Grim Picture Can Be Better

Robin says the evidence on children with arthritis is sad, dismal and frustrating because the disease manifests itself in so many ways. "Are common solutions possible for the masses?" she wonders. "Or maybe each child is so unique and the quest for a more common solution is impossible. I don't know. I know just enough to know I don't know enough."

"As a scientist," Robin continues, "I think we need a comprehensive science agenda to pull together what we know, what we need to know and what we need to know first. Then we need to translate that for parents in a compassionate and responsible way."

Currently, Isabela, now 17, copes with several conditions: polyarticular arthritis, fibromyalgia, uveitis in medicated remission, amplified pain syndrome, clinical depression, generalized anxiety disorder and chronic fatigue. She says she doesn't remember not having arthritis. "I've had to form my day around arthritis," Isabela says. "I've had to go on many medications, each with their own side effects and problems. I've had to try different diets. I try to push through at school. I already miss school enough for doctor's appointments. If I left school each time I was in pain, then I would never be at school."

Her older sister, Elena, 21, remembers watching Isabela drag herself around the floor because she couldn't crawl or walk. "My sister's diagnosis has been followed by countless pills, shots and blood tests," says Elena. "Bela is my inspiration. Even before she could walk, she was a fighter. She's my hero and my reason to be inspired."

JUVENILE-ONSET SYSTEMIC LUPUS ERYTHEMATOSUS (LUPUS)

Lupus is an autoimmune disease. In autoimmune diseases, the immune system turns against the body it's designed to protect for unknown reasons. Lupus can affect nearly every organ system in the body, including the skin, joints, kidneys, heart, lungs and central nervous system. Most often, when people speak of childhood lupus, they are referring to systemic lupus erythematosus (SLE).

SLE is often characterized by periods of illness and remission. There are many symptoms associated with lupus. It can affect the joints, skin, brain, lungs, kidneys and blood vessels. It affects different organ systems in different ways. The organs affected can also differ from patient to patient. Children and teens with SLE may have fatigue, pain or swelling in joints, skin rashes, fevers, hair loss, mouth sores or skin color changes due to the cold (Raynaud's phenomenon). Fatigue is one of the most prominent and life-affecting symptoms.

Prevalence

Juvenile-onset SLE is very rare. It is diagnosed in about 3 to 9 cases for every 100,000 children.¹ About 15-20% of all SLE cases develop before the age of 18 years.² Most juvenile-onset SLE begins around puberty.³ Juvenile-onset SLE is very rare before age 5.⁴ Although uncommon, this disease has been diagnosed in children younger than 2 years old.⁵

While more commonly diagnosed in girls, the ratio of girl to boy with this disease changes with age. During the first decade of life, there are 4 girls diagnosed for every 3 boys. During the second decade of life, 4 girls are diagnosed for every 1 boy.⁶

Juvenile-onset SLE is more common in young people of color. It is diagnosed more often in Asian, non-Hispanic black, Hispanic and native American children than non-Hispanic white children.⁷ In non-Hispanic white children, juvenile-onset SLE is 10 to 15 times less common than JIA and type 1 diabetes.⁸ However, in Asian children, juvenile-onset SLE is as common as JIA.⁹

Health Burdens

Diagnosis of SLE in adolescence is not always obvious since the clinical and blood test results commonly seen in these patients may mimic other medical conditions frequently seen in this age group.¹⁰ The diagnosis should be made by a clinician with expertise in rheumatology.

Pediatric patients with SLE typically have more severe disease than their adult counterparts.¹¹ They often have serious organ damage (like kidneys) at diagnosis and over the course of the disease. They often have an increased need for longer-term immunosuppressive treatment.⁶ However, since 1990, about 92-95% of patients with SLE survive at least 10 years after diagnosis.¹²

The American College of Rheumatology (ACR) recognizes the following symptoms in children with SLE. They do not always present with all the symptoms, but often have several of the symptoms¹³:

- **Fever, fatigue, weight loss**
- **Joint involvement**
 - Arthritis occurs in about 60-90% of patients with juvenile SLE. The arthritis is like that seen in JIA. However, the arthritis is almost always non-erosive and non-deforming.¹⁴
- **Skin involvement**
 - The malar, or butterfly rash, is seen in 60-90% of children with systemic lupus erythematosus. The rash is usually on the cheeks and often extends over the bridge of the nose. It can also affect the chin and ears.
 - Rashes are triggered by the sun (photosensitive) in more than a third of patients. Sun exposure may cause a systemic flare of lupus affecting other organs.¹⁴
 - Sores in the mouth or nose

- **Kidney involvement**
 - Kidney disease (nephritis) occurs in over 40% of all juvenile SLE patients.^{10,14} More than 90% of those who have nephritis develop it.¹⁵
 - Kidney involvement causes kidney dysfunction leading to protein and/or blood in the urine. It can also cause high blood pressure affecting the cardiovascular system and brain (like stroke and heart disease). It can have adverse effects on the bones during growth and development. Treatment usually consists of high-dose steroids and other immunosuppression. In severe cases, the inflammation can cause kidney failure, requiring dialysis or transplantation.¹²
 - Juvenile-onset SLE is associated with a greater risk of developing nephritis than adults who develop lupus.⁶
- **Circulatory system involvement**
 - Patients can develop fluid around the heart or lungs.
 - Problems with the blood can occur, including anemia or easy bruising, low platelets and low white blood cell numbers.
- **Immune system impact**
 - These patients, in general, are immunocompromised due to immune dysfunction of the disease and due to the frequent use of high dose corticosteroids and other immunosuppressive treatment.¹⁴ Because of this, the following recommendations for vaccinations should be followed:
 - No live-attenuated vaccines should be given to these patients while receiving systemic immunosuppressive drugs. For those who have not had chickenpox or had prior vaccination, live-attenuated vaccine is recommended at least four weeks before the start of immunosuppression.
 - Vaccination using killed and recombinant forms of vaccines are recommended at their usual administration time. A yearly influenza vaccine (killed injectable, not live-attenuated nasal mist) is also strongly recommended. Meningococcal and pneumococcal vaccinations are recommended.¹⁶
- **Nervous system involvement**
 - There are 19 syndromes affecting the nervous system (also called neuropsychiatric lupus) as defined by ACR. Up to 65% of these patients develop one or more of the distinct syndromes. Up to 85% of these patients with neuropsychiatric lupus will develop it within the first two years of diagnosis.¹⁷

The most common forms of neuropsychiatric lupus seen in these patients include:¹⁴

- headache that can be mild to debilitating
- mood disorders, including depression and anxiety
- cognitive dysfunction, including difficulties with memory and concentration that can lead to declining school performance
- psychosis, which includes visual and auditory hallucinations
- seizures, which are frequently seen with other neuropsychiatric SLE syndromes and are rarely isolated
- brain vascular disease, which may cause stroke

Mental Health Impact

It is important to keep in mind that 1 in 3 young people with lupus experience symptoms of depression and/or anxiety. One study showed that 1 in 6 young people with lupus experience thoughts of suicide, which is higher than their healthy peers. Even with these serious statistics on the mental health of these young patients, an estimated 75% of youth with lupus have not had a mental health evaluation.¹⁸

The increased prevalence of depression and anxiety in juvenile SLE is complex and has been attributed to several factors. Sometimes these disorders are part of neuropsychiatric lupus. More commonly, depression and anxiety are related to the psychological stress of dealing with chronic illness during adolescence, the effects of steroids on the central nervous system and body changes due to increased weight gain and acne that can be caused by medications. There are also heredity and environmental factors to consider. It is important to address depression and anxiety because these disorders are associated with inferior disease control, medication adherence, quality of life and transition to adult care.^{19, 20, 21, 22}

School and Social Impact

Cognitive dysfunction is one of the 19 neuropsychiatric syndromes of SLE defined by ACR. The prevalence of cognitive dysfunction in this population ranges from 20-95%, depending on the tests used for diagnosis. The areas that are most typically affected are executive functioning (mental flexibility), psychomotor functioning (physical skills that require mental coordination) and fine-motor speed.²³

Cognitive dysfunction may have a substantial impact on learning, academic success and later employment for children and adolescents with lupus. One study found that more than a third of young lupus patients report that the disease has negatively interfered with their education.¹⁴ However, it's important to keep in mind that while children and teens with SLE may demonstrate poorer academic performance than healthy peers, this may also be linked to missed school time due to disease severity and treatment intensity.²⁴

JUVENILE-ONSET SCLERODERMA

Scleroderma, which literally means hard skin, describes a group of conditions that causes the skin to tighten and harden. There are two basic forms, localized scleroderma and systemic sclerosis.

Localized scleroderma is primarily a skin disease and is the type seen more commonly in children. Localized juvenile scleroderma can damage the skin, muscle, bones and joints, depending on the type. It is unlikely to cause damage to internal organs. Systemic sclerosis affects the entire body. It causes internal organ damage and may be severe.

Prevalence

Juvenile-onset scleroderma is a rare disease that can occur at any age and in any race, but it is more common in girls. However, it is the third most frequent rheumatic condition in childhood after juvenile idiopathic arthritis (JIA) and systemic lupus erythematosus (SLE). It is estimated that 10% of all patients with scleroderma develop the disease before the age of 8.¹

The clinical presentation of scleroderma differs between adults and children. Children typically have either juvenile localized scleroderma or juvenile systemic sclerosis.² Juvenile localized scleroderma is the most frequent form of scleroderma in childhood, but it can occasionally progress into the systemic form.¹ About 1 to 3 new cases of localized scleroderma are diagnosed per 100,000 children each year.³ Localized scleroderma (LS) has several subtypes. Linear scleroderma, the most common pediatric subtype, occurs in about 50-60% of children with this form of the disease.⁴

Less than 5% of all juvenile-onset scleroderma patients have systemic sclerosis.⁵ About 1 new case of systemic sclerosis is diagnosed per 100,000 children each year,⁶ with about 4 times as many girls diagnosed as boys.⁷

Health Burdens

Juvenile Localized Scleroderma

The potential complications of localized scleroderma may be related to which parts of the skin are affected. About 50% of children with linear scleroderma of the extremities have orthopedic complications. About 40% of children with linear scleroderma of the head have neurologic or ocular symptoms.

A small percentage of children with linear scleroderma have Raynaud's syndrome (about 2.1%), and less than 2% of children with linear scleroderma have gastrointestinal, respiratory or renal symptoms.⁸

Juvenile Systemic Scleroderma

Internal organ involvement in pediatric systemic sclerosis patients (in decreasing frequency) includes most of the major systems of the body. Gastrointestinal (occurs in about half of pediatric systemic sclerosis patients), pulmonary (lungs), musculoskeletal, cardiac, renal (kidney) and neurological systems all have the potential to be affected.⁷

Compared to adult-onset systemic sclerosis, muscle and skeletal involvement is more common in pediatric systemic sclerosis. About 30-50% of pediatric systemic sclerosis patients experience inflammatory arthritis.⁵

Despite all the potential organ involvement in systemic sclerosis, children have a more favorable long-term prognosis due to a lower frequency of severe organ involvement. A few predictors to long-term outcomes may be heart and lung involvement. Although infrequent, cardiac involvement is the major cause of scleroderma-related deaths in children with systemic sclerosis.⁵ Annual cardiovascular screening for patients with juvenile sclerosis is important to reduce the cardiovascular and pulmonary complications of pulmonary arterial hypertension.²

Pulmonary involvement in pediatric systemic sclerosis patients ranges from 30-70% and includes interstitial lung disease, pulmonary arterial hypertension and abnormal lung function tests.⁹ Pulmonary arterial hypertension is estimated to occur in about 7% of children with systemic scleroderma.¹⁰

Mild renal (kidney) problems are not uncommon in systemic sclerosis. Scleroderma-related renal crisis is less common in children than adults. It occurs in less than 15% of pediatric patients.⁵

JUVENILE MYOSITIS (JM)

Juvenile dermatomyositis (JDM) and juvenile polymyositis (JPM) are two different forms of idiopathic inflammatory myopathy, which, together in children, is called juvenile myositis (JM). While this disease can occur at any age, it usually appears in children and adolescents between the ages of 5 and 15 and in adults between the ages of 40 and 60.

JM involves weakness of the muscles closest to the center of the body like the muscles of the hips and thighs, upper arms and neck. People with this disease may find it difficult to perform everyday tasks like climbing stairs, getting out of a chair or lifting items above their head. In some cases, it may make swallowing or breathing difficult.

Both JDM and JPM cause weakness in muscle used for movement. However, in JDM, a reddish or purplish skin rash on the eyelids and knuckles develops. There is no rash with JPM.

In JM, the muscle weakness develops gradually over a period of weeks to months or even years. Other symptoms include joint pain and general tiredness (fatigue). All age and ethnic groups are affected. Roughly 1 in 5 children also have joint symptoms, but they are likely to be mild. Remission is possible, but a minority of children with JDM may have a more chronic disease course.

Prevalence

In childhood, JDM occurs far more frequently than JPM, whereas in adults, the ratio is more equal.¹ JDM is the most common idiopathic inflammatory myopathy of childhood, accounting for about 85% of cases.²

Girls are up to 5 times more likely than boys to be affected by JDM.³ JDM occurs in 2 to 4 cases per million children each year in the U.S. The average JDM disease onset is age 7.⁴ It is found in patients of all ethnic and racial backgrounds and its distribution appears to be comparable to population demographics in the U.S.⁵

JPM occurs less frequently and accounts for only 3-6% of childhood idiopathic inflammatory myopathies.²

Health Burdens

Juvenile Myositis

Despite considerable advances in the management of JM, it is still associated with significant morbidity and mortality, representing major long-term medical, social and economic burdens on patients, their families and health care systems.⁶ These problems may continue into adulthood.

Of JM patients followed between 1993-2002, damage was present in 79% of the patients for almost seven years (82 months) after diagnosis, which most commonly included joint problems, weakness and scarring of the skin.¹

Cardiac issues in JM patients may be associated with elevated inflammatory markers, active disease and decreased heart muscle function.⁷ JM patients may be at increased risk of cardiovascular disease in adult life.⁸

Juvenile Dermatomyositis

JDM is characterized by muscle weakness and a characteristic skin rash, but other organ systems, such as the heart, lungs, joints and gastrointestinal tract, may also be affected.⁹

Up to 30% of JDM patients may develop calcinosis (which is associated with worse functional outcomes) or skin or gastrointestinal ulceration (which are associated with a severe course of illness).¹⁰

Due to improvements in treatments, 99% of patients with JDM are expected to survive.⁶ Aggressive treatment of JDM aimed at achieving rapid, complete control of muscle weakness and inflammation appears to improve outcomes and reduce disease-related complications. In a 2009 study, medication-free remission was attained within an average of 38 months in more than one-half of the children (28-49%) whose disease was treated with this approach.¹¹

According to a 2017 study, minority race and lower family income was found to be associated with worse morbidity and outcomes in patients with JDM in a group of North American children.¹² The minority children had worse physical function, more disease activity and lower quality of life scores. Additionally, patients with lower family income were found to have worse physical function, more disease activity, more weakness and lower quality of life scores. Non-Hispanic black patients were more likely to have calcinosis.

CONCLUSION



We hope you have spent time reading the patient stories contained in this 2020 edition of Arthritis by the Numbers. The numbers show that the number of individuals affected by arthritis is increasing. This means the costs and other burdens to them, and society at large, continues to grow. Our patient stories put a face to how these numbers affect real people. Taken together, this document reminds us that arthritis, while told by numbers, is a story of real people. For these people, and for our society, these burdens and these costs can only be reduced by accelerating our investment in research.

Throughout 2019, we've collected patient data through the Arthritis Foundation Live Yes! Insights assessments to learn more about how arthritis affects patients and what are the greatest needs related to treatment and daily living. Learn more about these results in the First Look report.

Our patient data highlights the invisibility of the disease. Despite their outward resilience, arthritis patients have tremendous, unmet needs. Based on what we learned from the first look at year one of the Live Yes! Insights assessments, the Arthritis Foundation has developed a bold agenda for making new investments in science, advocacy, programming and product development to pioneer new ways to address these unmet needs.

The First Look report identifies key populations in our community for which an aggressive research agenda will address the issues raised by the Live Yes! Arthritis Network. By empowering human connections through this network, both online and across the country, we are connecting patients to a powerful community of support that is facing these challenges head-on, together.

Patients reinforced what we already knew: arthritis is painful, and it prevents people from leading active, healthy lifestyles. Patient responses showed us that all patients (100% of over 18,000 assessments) reported pain during the past seven days, with an average pain score of five on a 10-point scale. This is persistent pain, ignorable for only short periods of time. Beyond the intensity of pain, this study documents the magnitude of its impact on life.

- **More than 9 in 10 patients reported that pain interfered with their daily activities.**
- **More than 4 in 5 reported difficulty in doing chores such as vacuuming or yardwork.**
- **About 4 in 5 patients report trouble going up and down stairs.**
- **About 7 in 10 report issues with sleep.**
- **About 2 in 3 patients report feeling some level of depression or anxiety.**
- **Almost 7 in 10 say they have trouble participating in all family activities they want to do.**
- **More than 7 in 10 say they have trouble performing all their usual work activities (including work at home).**

We will continue to drive a research agenda that helps patients live fuller, more pain-free lives. At the national level, new initiatives in osteoarthritis, the most common form of arthritis, will define the research agenda in 2020.

Our data focus us, as well, on continued progress in understanding and improving how health care is delivered and developing new therapeutic strategies across arthritic conditions.



While most patients felt being able to talk to a professional to answer health questions is important, patients told us:

- **About 3 in 10 patients were not able to talk to a professional to answer health questions.**
- **About 4 in 10 do not feel they get the help they need.**

In 2020, the Arthritis Foundation is committing to advocacy efforts that support better access to health care providers, new treatments, and empowering individual people with arthritis with education and self-management opportunities. At the national level, we will continue to drive new research initiatives that improve how care is delivered.

We continue to advance our understanding of arthritis. By investing in additional scientific discoveries and supportive policies, we remain confident in the ability of the Arthritis Foundation and the world's largest arthritis patient network to conquer this life-altering disease, together.

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APPENDIX 1

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TYPES OF ARTHRITIS

The following is a list of arthritis and related conditions considered to be types of arthritis. For more information about each type of arthritis, visit arthritis.org.

Adult-onset Still's Disease	Myositis
Ankylosing Spondylitis	Osteoarthritis (OA)
Back Pain	Osteoporosis
Behçet's Disease	Paget's Disease
Bursitis	Palindromic Rheumatism
Calcium Pyrophosphate Deposition Disease (CPPD)	Patellofemoral Pain Syndrome
Carpal Tunnel Syndrome	Pediatric Rheumatic Diseases
Chondromalacia Patella	Pediatric SLE
Chronic Fatigue Syndrome	Polymyalgia Rheumatica
Complex Regional Pain Syndrome	Pseudogout
Cryopyrin-Associated Periodic Syndromes	Psoriatic Arthritis (PsA)
Degenerative Disc Disease	Raynaud's Phenomenon
Developmental-Dysplasia of Hip	Reactive Arthritis
Ehlers-Danlos	Reflex Sympathetic Dystrophy
Familial Mediterranean Fever	Reiter's Syndrome
Fibromyalgia	Rheumatic Fever
Fifth Disease	Rheumatoid Arthritis (RA)
Giant Cell Arteritis	Rheumatism
Gout	Scleroderma
Hemochromatosis	Sjögren's Syndrome
Infectious Arthritis	Spinal Stenosis
Inflammatory Arthritis	Spondyloarthritis (SpA)
Inflammatory Bowel Disease	Systemic Juvenile Idiopathic Arthritis (sJIA)
Juvenile Dermatomyositis (JD)	Systemic Lupus Erythematosus (SLE)
Juvenile Idiopathic Arthritis (JIA)	Systemic Lupus Erythematosus (SLE) in Children & Teens
Juvenile Scleroderma	Systemic Sclerosis
Kawasaki Disease	Tendinitis
Lupus	Temporal Arteritis
Lupus in Children & Teens	Vasculitis
Lyme Disease	Wegener's Granulomatosis

APPENDIX 2



ARTHRITIS FOUNDATION-FUNDED RESEARCH

The story told through the statistics presented in Arthritis by the Numbers has gaps in knowledge that have been exposed by both patients and researchers. That doesn't stop us from continuing to ask questions and look for answers that are important to patients and will eventually lead to a cure. We have included some of our patient reviewer stories in this edition. Another piece of the story comes from the donor-supported research our investigators have done to help find information to fill some of the gaps.

Our History

We have an impressive research history. The Arthritis and Rheumatism Foundation, organized in 1948, became the Arthritis Foundation in 1964. Since its inception, the Foundation has supported research that strives to improve the lives of people with arthritis. As the timeline shows, the time between discovery of a new drug or biologic and its approval for use may take decades.

1949 – First Grant

The Foundation began its professional education program by granting funds to support the Seventh International Congress on Rheumatic Diseases, sponsored by the International League Against Rheumatism, held in New York City in 1949. One of the highlights of the Congress was a presentation of the effects of cortisone and adrenocorticotropin (ACTH) on patients with rheumatoid arthritis (RA). This was the first presentation on cortisone given at an international meeting of doctors and scientists whose main interest was the study and treatment of rheumatic diseases.



1978 – Identification of Lyme Disease

The guidance of an astute mother, Polly Murray, brought Lyme disease to the attention of the Arthritis Foundation and scientists when she recognized an abnormal number of kids with pediatric arthritis in her community, including her son. Without this patient involvement, the discoveries that led to better understanding and treatments for this disease may have taken longer.

In the mid-1970s, Lyme disease was recognized as a distinct disease when a cluster of cases originally thought to be juvenile rheumatoid arthritis was identified in three towns in Connecticut. Two of the towns, Lyme and Old Lyme, gave the disease its name. The ensuing work, funded through the Arthritis Foundation, led to recognition of infectious nature of the disease.



1982 – Foundation-funded Study on Methotrexate

Researchers first developed Methotrexate in the 1940s as a treatment for several forms of cancer. In the 1950s and 60s, doctors began using an older form of this drug at lower doses to treat psoriasis, psoriatic arthritis and RA. The older form of this drug was hard to manufacture, so a newer form was created. The newer form of this drug has been part of RA treatment for at least three decades.

For some of this time, the rheumatology community was hostile to using an anti-cancer treatment for RA, and doctors were reluctant to submit their clinical study results due to fear of rejection from professional journals. However, in the early 1980s, researchers began to publish their results. In the 1980s, the Arthritis Foundation was behind the earliest clinical trials that set the stage for methotrexate to become a mainstay of treatment for RA. An Arthritis Foundation-funded study on low dose methotrexate in rheumatoid arthritis patients (K. Steinsson, et al) was published in the Journal of Rheumatology in late 1982. This study, along with other similar studies, provided data that led to the drug's approval for treating arthritis.



In 1988, methotrexate won FDA approval for treating RA, and it soon became the treatment of choice for people with this condition and other forms of inflammatory arthritis.

1983 – Identification of IL-1

Only a handful of foundations can draw a direct connection between their work and FDA approved therapies. Using his Foundation research grant in the early 1980s, Dr. Bill Arend studied the role of interleukin (IL)-1 protein in rheumatoid arthritis – which ushered in the biologic era that led to the development of etanercept (Enbrel), anakinra (Kineret) and secukinumab (Cosentyx). These biologics owe their inventions to milestone discoveries funded by the Arthritis Foundation.

**1998****Enbrel (etanercept) Approved TNF Inhibitor**

Enbrel is a biologic that treats autoimmune diseases by acting as a tumor necrosis factor (TNF) inhibitor. TNF-alpha is one of the main regulators of immune (inflammatory) responses in the body. Autoimmune diseases are caused by overactive immune responses. Enbrel inhibits the immune response caused by TNF-alpha. It is used to treat ankylosing spondylitis, juvenile idiopathic arthritis, psoriasis, psoriatic arthritis and rheumatoid arthritis.

North American Rheumatoid Arthritis Consortium (NARAC) Forms

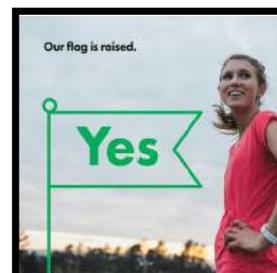
This is a group of researchers across the U.S. who conduct research on the genetics of rheumatoid arthritis. Sponsored by the National Institutes of Health and the Arthritis Foundation, NARAC maintains a database and serum and DNA repository that serves as a resource for the entire scientific community to allow for comprehensive analysis of genetic susceptibility to RA.

**2000****Kineret (anakinra) Approved**

Kineret is a biologic that is used to treat rheumatoid arthritis. It is a slightly modified version of interleukin (IL)-1 that acts to inhibit immune responses.

Childhood Arthritis and Rheumatology Research Alliance (CARRA) Forms

The Childhood Arthritis & Rheumatology Research Alliance (CARRA) is an organization of pediatric rheumatologists committed to advancing the health and quality of life of children living with rheumatic disease. With financial support from the Arthritis Foundation, the American College of Rheumatology (ACR) and others, CARRA's network of pediatric rheumatology research centers provides an accessible point of entry for patients and families across the United States and Canada to participate in research studies and trials of new therapies.

**2015 – Cosentyx (secukinumab) Approved by FDA**

This biologic binds to the protein interleukin (IL)-17A and inhibits the immune response. Cosentyx was approved for treating ankylosing spondylitis and psoriatic arthritis and was awarded the 2016 Prix Galien USA Award for Best Biotechnology Product. Prix Galien awards are the pharmaceutical industry's equivalent of a Nobel Prize, given for innovative medical research.

2017 – Launch of Four (ongoing) Scientific Initiatives

The Arthritis Foundation is currently supporting its scientific initiatives program to provide funding that goes to the development and rollout of four specific initiatives.

Advancing Osteoarthritis Treatments

Affecting more than 30 million Americans, Osteoarthritis remains a huge issue and a serious condition. We are determined to find out more about this devastating disease and aid in the development of new and novel treatments.

Cultivating a New Generation of Rheumatologists

The growing shortage of rheumatologists, specialists devoted to diagnosis and therapy of rheumatic diseases, creates more barriers to care and negatively impacts a patient’s quality of life. Creating incentives, like our fellowship program, will increase the number of medical students choosing rheumatology.

Conquering Childhood Arthritis

The Arthritis Foundation partners with the Childhood Arthritis and Rheumatology Research Alliance (CARRA) to not only fund research for disease treatment options, but also to activate large-scale patient engagement to compare the effectiveness of different treatments both in the short and long-term.



Collaborating with Patients for Better Health

Real, patient-centered care is vital in ensuring better health outcomes. Our digital data exchange will enable patients to record symptoms, problems and challenges in real time, with results sent directly to their doctor. Communication between visits will enrich the care plan produced by both the doctor and the patient.

2018 – Launch of Live Yes! Arthritis Network

The Arthritis Foundation created the Live Yes! Arthritis Network to better connect patients, families and caregivers to a strong network of support to empower people living with arthritis to manage stress, live life with less pain and take control of their health care by becoming more active in their care.

The network built upon our existing resources and programs and launched new, online community, topic-driven forums. The Live Yes! Arthritis Network also offers local, peer-led support groups that provide connections, education and empowerment to adults living with arthritis and parents/guardians of children living with arthritis.



2019 – Launch of Live Yes! Patient Reported Outcomes (PRO) Insights Assessments and A Mandate for Action, A First Look Report

By providing people with arthritis life-changing resources and connections, the Live Yes! Arthritis Network aims to make positive impact in three domains: physical health, emotional and social health, and experience of care.

The Live Yes! Insights assessments are patient reported data that measure these three domains of living with arthritis:

- Physical health questions ask patients about fatigue, physical function, pain and sleep.
- Emotional and social health questions ask about companionship, anxiety, depression, hope, support and social roles/activities.
- Experience of care asks questions about self-advocacy and shared decision making as a partner with health care providers.

The First Look Report summarizes the results from nearly 20,000 responses collected during the first year of this program to create a clearer picture of what it is like to live with arthritis.



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