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Appendix 1: Types of Arthritis

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“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”
– Margaret Mead, Anthropologist

Seventy years ago, the Arthritis Foundation was founded to help curb “the oldest crippling disease known to man,” which even then was known as “the nation’s leading chronic disease.”

Back then, nearly 8 million Americans suffered directly from arthritis – and at least 30 million, when you counted family members, were “affected by the social and economic consequences” of arthritis.

The Arthritis Foundation and our partners have come a long way in better understanding this life-altering disease of more than 100 types. We’ve offered trusted information, tools and resources, including community connections, to help people navigate the obstacles arthritis throws in their way.

We’ve funded research that led to biologics and other breakthrough interventions, which continue to emerge today. With more knowledge and technology at our disposal than ever before, we’re getting closer to unraveling its mysteries and discovering solutions.

Still, arthritis remains a serious health crisis in the United States – and it’s a global epidemic, too. Recent estimates show that as many as 91 million Americans may have arthritis (37 percent), including a third of those aged 18-64 (Jafarzadeh 2017), plus an estimated 300,000 children.

The Arthritis Foundation’s mission is to ensure that people with arthritis have access to the treatments and health care they need to live full, productive lives. But physical well-being is only one dimension of arthritis. In 2013, the total medical costs and earning losses due to arthritis were equal to more than 1 percent of the U.S. gross domestic product (GDP, about $304 billion).

One of the biggest changes to this edition of Arthritis by the Numbers is continuing to elevate the level of patient involvement. As Kathy Geller, one of our patient partners said: “I have always been most interested in quality of life and functional status. These facts truly tell what life is like living with my arthritis.”

Thanks to suggestions from patient parent partner Robin Soler, we added new information on mental health and fatigue. “Like depression, fatigue is critical,” Robin explained. “My daughter’s greatest issue is that we don’t understand just how tired she is.”
This second annual edition of Arthritis by the Numbers includes more than 300 new and updated observations about arthritis. Each fact has been carefully researched and published in peer-reviewed journals by leaders in the field. Additional arthritis information can be found on arthritis.org and our LiveYes! mobile app (visit the Google Play Store or the iTunes App Store).

Together, we must amplify our voices. Our growing movement is strengthening policies and laws, the health care system and the arthritis community. And we’re accelerating the science that goes along with it. We’ll continue to fight until every person with arthritis can say “yes” to a pain-free life.

“Be the change you wish to see in the world.”
–Mahatma Gandhi, Philosopher
ABOUT 54.4 MILLION ADULTS IN THE U.S. HAVE DOCTOR-DIAGNOSED ARTHRITIS.

(Barbour – MMWR (66) 2017)
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) and related conditions. People of all ages, genders and races have arthritis, the leading cause of disability in the United States. We don’t know the true number of people with arthritis because many people don’t seek treatment until their symptoms become severe. Conservative estimates only include those who report they have doctor-diagnosed arthritis, indicating that about 54 million adults and almost 300,000 children “officially” have arthritis or another type of rheumatic disease. A recent study says as many as 91 million Americans may really have arthritis – when you add together those who are officially diagnosed plus those who report obvious symptoms but haven’t been diagnosed. While researchers try to find more accurate ways to estimate the prevalence of this disease and the burdens it causes, we do know that it is more common among women and that the number of people of all ages with arthritis is increasing.

Common arthritis joint symptoms include swelling, pain, stiffness and decreased range of motion. Symptoms may come and go, and can be mild, moderate or severe. They may stay about the same for years but may progress or get worse over time. Severe arthritis can result in chronic pain, inability to do daily activities and make it difficult to walk or climb stairs. Arthritis can cause permanent joint changes.

The following facts describe some of the features common to many forms of arthritis.
General Facts
- There are more than 100 types of arthritis. (CDC 2016)

- Currently, arthritis affects more than one in four adults. (Barbour – MMWR [66] 2017)

- Newer adjusted estimates for 2015 suggest that arthritis prevalence in the U.S. has been substantially underestimated, especially among adults younger than age 65.
  - Based on adjusted estimates, 91.2 million adults either have doctor-diagnosed arthritis and/or report joint symptoms consistent with a diagnosis of arthritis.
  - For people aged 18 to 64, about one in three people (both men and women) have doctor-diagnosed arthritis and/or report joint symptoms consistent with a diagnosis of arthritis.
  - For people over 65, the numbers are much worse:
    - More than one in two men may have arthritis.
    - More than two in three women may have arthritis. (Jafarzadeh 2017)

- By conservative estimates between 2010-2012:
  - Almost 50 percent of adults 65 years or older reported doctor-diagnosed arthritis.
  - Arthritis was more common among women (26 percent) than men (19 percent).
  - About 4 million Hispanic adults had doctor-diagnosed arthritis.
  - About 6 million non-Hispanic blacks had doctor-diagnosed arthritis.
  - Arthritis was more common among adults who are obese than among those who are normal weight or underweight. (Barbour 2013)

- By conservative estimates between 2013 - 2015:
  - About 54.4 million adults in the U.S. (22.7 percent of all adults) had doctor-diagnosed arthritis.
    - 23.7 million (43.5 percent of those with arthritis) had arthritis-attributable activity limitation.
    - There was an increase of about 20 percent in the number of adults with arthritis who reported activity limitations since 2002. (Barbour – MMWR [66] 2017)
  - By 2015, 23.7 million adults reported activity limitation due to their arthritis. (Barbour – MMWR [66] 2017)

  - By conservative estimates by 2040:
    - The number of U.S. adults with doctor-diagnosed arthritis is projected to increase 49 percent to 78.4 million (25.9 percent of all adults).
    - The number of adults with arthritis-attributable activity limitation will increase 52 percent to 34.6 million (11.4 percent of all adults). (Hootman 2016)

  - By conservative estimates between 2002-2014, almost two-thirds (64 percent) of adults with doctor-diagnosed arthritis were younger than 65 years old. (Barbour – MMWR [65] 2016)

Human and Economic Burdens
Health Burdens
- Only 7 percent of all rheumatologists practice in rural areas, where 20 percent of the population lives. (ACR 2013)

- Severe joint pain was higher among women (29 percent) and those who:
  - Had fair or poor health (49 percent),
  - Were obese (32 percent),
  - Had heart disease (34 percent),
  - Had diabetes (40.9 percent), or
  - Had serious psychological distress (56 percent). (Barbour –MMWR [65] 2016)

By new estimates, 1 in 3 people age 18-64 have arthritis. (Jafarzadeh 2017)
• 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 population growth. (Barbour - MMWR [65] 2016)

• In 2014, more than one in four adults with arthritis had severe joint pain (27 percent).
  - Among adults with arthritis, the highest prevalence of adults with severe joint pain was among persons 45 to 64 years old (31 percent). (Barbour - MMWR [65] 2016)

• Almost half of all adults with heart disease (49.3 percent) also have arthritis.
  - More than half (54.5 percent) of adults with arthritis and heart disease have activity limitations. (Barbour – MMWR [66] 2017)

• Physical activity can reduce pain and improve physical function by about 40 percent. (Barbour – MMWR [66] 2017)

• Almost half of all adults with diabetes (47.1 percent) also have arthritis.
  - More than half (54 percent) of adults with arthritis and diabetes have activity limitations. (Barbour – MMWR [66] 2017)

• Obesity affects 36.5 percent of all adults in the U.S., occurs frequently among those with arthritis, and those with both conditions are more likely to
  - have arthritis activity and work limitation,
  - be physically inactive,
  - report depression and anxiety, and
  - have an increased risk of expensive knee replacement. (Barbour 2016)

• Increase in obesity prevalence in older adults with doctor-diagnosed arthritis was not limited to those with poor health characteristics as might be expected, but also occurred among those who reported meeting physical activity recommendations, had very good/excellent health and did not have a disease, diabetes or serious psychological distress. (Barbour 2016)

• About one in three U.S. adults with arthritis, 45 years and older, report having anxiety or depression. (Murphy 2012)

• Anxiety is nearly twice as common as depression among people with arthritis, despite more clinical focus on the latter mental health condition. (Murphy 2012)

• Among people with arthritis:
  - Nearly one in four adults with arthritis also has heart disease,
  - 19 percent also have chronic respiratory conditions, and
  - 16 percent also have diabetes.
  - It’s believed that arthritis likely comes first and results in these other health problems. (Murphy 2009)

• Arthritis is strongly associated with major depression (attributable risk of 18.1 percent), probably through its role in creating functional limitation. (Dunlop 2004)
Employment Impact and Medical Cost Burden

- Arthritis is the leading cause of disability among adults in the U.S. (Barbour 2013)

- Annually, 172 million work days are lost due to arthritis and other rheumatic conditions. (BMUS 2014)

- In 2013, fewer adults with arthritis (77 percent) were able to work compared to adults without the disease (84 percent). (Murphy 2017)

- In 2013, total medical costs and earnings losses due to arthritis were $304 billion (about 1 percent of the U.S. gross domestic product for 2013).
  - Total earnings losses were higher than medical costs. (Murphy 2017)

- In 2013, earnings losses were $164 billion (for adults with arthritis between ages 18 and 65).
  - The average adult with arthritis earned $4,040 less than an adult without the disease. (Murphy 2017)

- In 2013, U.S. adults spent about $140 billion for arthritis-attributable medical costs for 66 million people.
  - The average medical costs per person were $2,117. (Murphy 2017)

- Health care services worldwide will face severe financial pressures in the next 10 to 20 years due to the escalation in the number of people affected by musculoskeletal diseases.
  - By the year 2040, the number of individuals in the United States older than the age of 65 is projected to grow from the current 15 percent of the population to 21 percent.
  - Persons age 85 and older will double from the current, less than 2 percent, to 4 percent. (BMUS 2014)

- In 2010, there were more than 100 million outpatient visits due to arthritis. (BMUS 2014)

- In 2011, there were an estimated 6.7 million hospitalizations due to arthritis. (BMUS 2014)

- In 2011, there were 757,000 knee replacements and 512,000 hip replacements. (BMUS 2014)

IN 2013, TOTAL MEDICAL COSTS AND EARNINGS LOSSES DUE TO ARTHRITIS WERE $304 BILLION (ABOUT 1 PERCENT OF THE U.S. GROSS DOMESTIC PRODUCT FOR 2013).

(Murphy 2017)
IN 2013, TOTAL MEDICAL COSTS AND EARNINGS LOSSES DUE TO ARTHRITIS WERE $304 BILLION (MURPHY 2017)
Section 2:
Osteoarthritis

What is Osteoarthritis?
Osteoarthritis (OA) isn’t just a disease that affects older adults; it’s the most common form of arthritis, affecting more than 30 million Americans. 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. OA is a chronic condition that can affect any joint, but 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. Currently, there is no cure for OA.

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. In the final stages of OA, 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.

The following facts describe some of the features common to OA.
DIAGNOSIS OF OA IN THE ATHLETE IS OFTEN DELAYED AND DIFFICULT BECAUSE OF HIGH TOLERANCE TO PAIN, AS WELL AS THE ATHLETE’S PREFERENCE FOR EXPEDITED RETURN TO PLAY.

(Amoako 2014)
Prevalence

U.S. General Population
- Today an estimated 30.8 million adults have osteoarthritis. (Cisternas 2015)

- Osteoarthritis is the most common cause of disability in adults. (Lawrence 2008)

- In the athlete or young individual, injury, occupational activities, and obesity are the main factors that contribute to the development of osteoarthritis (OA).
  - Diagnosis of OA in the athlete is often delayed and difficult because of high tolerance to pain, as well as the athlete’s preference for expedited return to play. (Amoako 2014)

- Among people younger than age 45, osteoarthritis is more prevalent among men; among those age 45 and older, it is more prevalent among women. (Berger 2011)

- The lifetime risk is of developing symptomatic knee osteoarthritis is 45%. (Murphy 2008)

- The prevalence of symptomatic knee osteoarthritis (OA):
  - increases with each decade of life, with the annual incidence of knee OA being highest between age 55 and 64 years old.
  - has been increasing over the past several decades in the U.S., concurrent with an aging population and the growing obesity epidemic. (Deshpande 2016)

- There are 14 million individuals in the U.S. who have symptomatic knee osteoarthritis.
  - Nearly 2 million people under the age of 45 have symptomatic knee osteoarthritis.
  - The overall number of people in the U.S. with symptomatic knee OA is nearly identical between those age 45 to 64 years and those age 65 or older (about 6 million in each age group).
  - About 1 in 5 people who have symptomatic knee OA identify as a racial/ethnic minority, and that number is expected to rise. (Deshpande 2016)

- The prevalence of symptomatic knee osteoarthritis (OA) in patients age 45 and older has been estimated between:
  - 5.9 and 13.5 percent in men and
  - 7.2 and 18.7 percent in women. (AAOS 2013)

- In people age 55 and younger, the prevalence of knee osteoarthritis in men is lower compared to women. (Heidari 2011)

- About 13 percent of women and 10 percent of men age 60 and older have symptomatic knee osteoarthritis. (Zhang 2010)

- More than half of all individuals with diagnosed symptomatic knee osteoarthritis (OA) have had sufficient progression of OA that would make them eligible for knee replacement. (Deshpande 2016)

- More than half of all people with symptomatic knee osteoarthritis (OA) are younger than age 65 and will live for three decades or more after diagnosis. For these people, there is substantially more time for greater disability to occur. (Deshpande 2016)

- About 40% of U.S. adults are likely to develop symptomatic osteoarthritis (OA) in at least one hand by age 85. (Qin 2017)

- The risk of developing symptomatic hand osteoarthritis by age 85 differs across sex, race and body mass index.
  - Women are nearly twice as likely as men (47% versus 25%) to develop it.
  - Caucasians are more likely to develop it than African Americans (41% versus 29%).
  - Obese people are at greater risk than non-obese people (47% versus 36%). (Qin 2017)

- The lifetime risk is of developing symptomatic hip osteoarthritis is 25%. (Murphy 2008)

U.S. Military
- One of every three military veterans in the United States lives with arthritis. (Murphy 2014)

- A study of combat-injured soldiers found that osteoarthritis was the most common cause of disability and separation from military service. (Rivera 2012)
- About 94.4 percent of osteoarthritis cases in military service members are attributable to combat injury. (Rivera 2012)

- The rate of osteoarthritis in military service members is:
  - 26 percent higher than the general population aged 20 to 24.
  - Twice as high as the general population aged 40 and older. (Cameron 2011)

- For service members age 25 and older:
  - The overall rate of osteoarthritis (OA) was higher among black, non-Hispanics than other racial/ethnic group members.
  - The rate of shoulder OA was higher among men than women. (Williams 2016)

- Among service members age 30 and older:
  - Women had higher rates of OA of the knee and pelvic region/thigh than men. (Williams 2016)

- Knee injuries remain the most prevalent worldwide, with 700,000 cases annually in the U.S. and accounting for 12.5 percent of post-traumatic osteoarthritis cases. (Gage 2012)

- Hip and knee osteoarthritis represent a substantial cause of disability worldwide and are responsible for approximately 17 million years lived with disability globally. (Cross 2014)

### Global

- Osteoarthritis ranks fifth among all forms of disability worldwide. (Murray 2012)

- Osteoarthritis (OA) is the most common articular disease of the developed world and a leading cause of chronic disability, mostly because of knee OA and/or hip OA. (Grazio 2009)

- Osteoarthritis is thought to be the most prevalent of all musculo-skeletal pathologies, affecting an estimated 10 percent of the world’s population over the age of 60. (Pereira 2011)

- The prevalence of osteoarthritis (OA) increases with age, up to 80 percent in people over age 65 in high-income countries. (Fernandes 2013)

- As the world’s population continues to age, it is estimated that degenerative joint disease disorders such as osteoarthritis will impact at least 130 million individuals around the globe by the year 2050. (Maiese 2016)

- Adolescents and young adults with anterior cruciate ligament injuries are prone to develop osteoarthritis before they reach age 40. (Oiestad 2010)

### Human and Economic Burdens

#### Health Burdens

- Advanced age, obesity, genetics, gender, bone density, trauma and a poor level of physical activity can lead to the onset and progression of osteoarthritis. (Gabay 2016)

- Current therapies, including pain management, improved nutrition and regular programs for exercise, do not lead to the resolution of osteoarthritis. (Maiese 2016)

- Osteoarthritis is linked to increased rates of comorbidity (e.g., obesity, diabetes and heart disease). (Suri 2012)

- In the U.S., about 65 percent of patients with osteoarthritis are prescribed NSAIDs, making them one of the most widely used drugs in this patient population. (Gore 2012)

- Women, particularly those 55 and older, tend to have more severe osteoarthritis in the knee but not in other sites. (Srikanth 2005)

- A greater proportion of individuals with osteoarthritis are reported to have depression (12.4 percent), as compared to individuals without the disease. (Gore 2011)

- Five common athletic injuries have been identified as placing patients at greater risk of developing post-traumatic osteoarthritis:
  - anterior cruciate ligament ruptures
  - meniscus tears (the second most common structure damaged in athletes)
  - shoulder dislocation
  - patellar dislocation
  - ankle instability (the most commonly injured joint in the body). (Whittaker 2015)
1 in 3 military veterans in the U.S. lives with arthritis

(CDC 2014)
Economic Burdens

- Costs of short-term disability, workers’ compensation and absenteeism are much higher among persons with osteoarthritis. (Berger 2011)

- Earning losses due to OA cost an estimated $80 billion per year between 2008 and 2011. (OAA 2014)

- A study in 2012 demonstrated that osteoarthritis was the highest cause of work loss and affected more than 20 million individuals, costing the U.S. economy more than $100 billion annually. (Sandell 2012)

- It has been estimated that the costs due to absenteeism from osteoarthritis alone are at least $11.6 billion due to an estimated three lost workdays per year. (Kolzarz 2010)

- Employed individuals with evidence of osteoarthritis (OA) have much higher health care costs over a single year than those of similar age and gender without evidence of OA. (Berger 2011)

- Osteoarthritis consumes a tremendous amount of medical resources and causes considerable disability. (Rivera 2012)

- Osteoarthritis accounts for more than 25 percent of all arthritis-related health care visits. (AAOS 2008)

- During fiscal year 2011, the Medicare program reimbursed U.S. hospitals:
  - $3.5 billion for total knee arthroplasty (the program’s largest expenditure for a single procedure)
  - $3.4 billion for heart failure
  - $2.0 billion for coronary intervention with drug-eluting stents
  - $3.2 billion for spinal fusion. (Culler 2015)

- Over 1 million total joint arthroplasties, at a cost of $18.8 billion, were performed in the United States in 2012. (CDC-Table 105 2015)

- By 2013, knee osteoarthritis contributed more than $27 billion in health care expenditures annually. (Losina 2015)

- In 2010, each total knee arthroplasty revision surgery was associated with total costs of $49,360. (Bozic 2010)

- In 2013, each primary total knee arthroplasty (TKA) cost an average of $20,293 and each revision TKA cost an average of $26,388. (Losina 2015)

- Compared with nonsurgical treatments, total hip arthroplasty increased average annual productivity of patients by $9,503. (Koenig 2016)

- 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. (Koenig 2016)

- Hip osteoarthritis 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. (Murphy 2012)

- A recent study found infection was the most common surgical cause of readmission after shoulder arthroplasty and that these readmissions incurred an average hospital cost of $11,000. (Schaier 2014)

Knee, Hip, and Shoulder OA Burden

- With the lifetime risk of symptomatic hip osteoarthritis (OA) estimated at 25.3 percent, conditions that can lead to OA must be addressed to reduce the quality of life lost, caused by disability and functional limitations, and their corresponding economic impact. (Murphy 2010)
Knee osteoarthritis is frequently accompanied by comorbidities that contribute to decreased quality of life:
- obesity or being overweight (90 percent)
- hypertension (40 percent)
- depression (30 percent)
- diabetes (15 percent). (Hunter 2011)

Opioids do not appear to be cost-effective in osteoarthritis patients without comorbidities, principally because of their negative impact on pain relief after total knee arthroplasty. (Rose 2016)

The most severe fracture that can result from osteoarthritis involves the hip, which requires hospitalization and leads to permanent disability in 50 percent of individuals and fatality in another 20 percent. (Maiese 2016)

Although many patients eventually require total knee arthroplasty, they spend an average of 13 years exhausting pain-relieving drugs before undergoing surgery. (Losina 2015)

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 individuals age 45 to 64. (Losina 2012)

It’s estimated that 54 percent of knee osteoarthritis (OA) patients will receive total knee replacement over their lifetime under current guidelines; the current trend suggests that there may be a 29 percent increase in lifetime direct medical costs attributable to this procedure among knee OA patients. (Losina 2015)

By the end stages of osteoarthritis, total knee arthroplasty is often necessary to address the degradation of the joint and the associated symptoms that severely limit day-to-day function. (Hochberg 2012)

Coupled with increasing knee osteoarthritis 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. (London 2011)

By 2012, surgery for end-stage knee osteoarthritis was performed on 658,000 Americans annually. (Bhandari 2012)

Hip and knee osteoarthritis causes the greatest burden in terms of pain, stiffness and disability, leading to the need for prosthetic joint replacement in the most severe cases. (Litwic 2013)

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 osteoarthritis-related health care resource utilization and costs after they recovered from surgery. (Pasquale 2015)

More than 55,000 revision surgeries were performed in 2010 in the U.S., with 48 percent of them in patients under age 65.

- 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. (Bhandari 2012)
- In anterior cruciate ligament ruptures, approximately 50 percent of those affected develop post-traumatic osteoarthritis five to 15 years after injury (treated and with surgery). (Whittaker 2015)
- By 2030, nearly two in three total knee arthroplasty revision patients will be under 65 years. (Kurtz 2009)
- More than 719,000 total knee arthroplasties were performed in 2010 in the U.S. (HCUP 2010)
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. (Babovic 2013)

Across all patients, primary total hip arthroplasty is projected to grow by 75 percent between 2010 and 2020. (Kurtz 2014)

The number of total hip arthroplasties performed on patients 18 to 64 years old has increased by 91 percent between 2003 and 2013. (HCUP 2015)

One study projected that more than 50 percent of total hip arthroplasties will be performed in patients younger than 65 by 2030. (Kurtz 2009)

Infection is a devastating complication after shoulder arthroscopy or arthroplasty that can lead to substantial morbidity. Recent studies have reported a rate of infection of 0.27 percent after shoulder arthroscopies and up to 15 percent of shoulder arthroplasties. (Werner 2016)

Most shoulder prosthetic infections are diagnosed after patients are discharged. (Poulsides 2012)

The 90-day readmission rate for shoulder arthroplasty has been reported to be as high as 6 percent; these rates have been reported to be increasing. (Matsen 2015)

The rate of revision for failed shoulder arthroplasty per 100,000 population has grown by 400 percent over the last two decades; revisions now have been reported to account for up to 10 percent of all shoulder arthroplasties. (Matsen 2015)

Factors associated with the risks of longer lengths of hospital stay, readmission within 90 days and revision surgery:
- Advancing age was associated with longer lengths of stay and more frequent readmission, but with fewer surgical revisions.
- Women, African-Americans and Medicaid patients had longer lengths of stay.
- Patients who underwent arthroplasty for fracture-related problems had longer lengths of stay.
- Patients who underwent arthroplasty for traumatic arthritis and osteoarthritis had shorter lengths of stay but more revision surgeries.
- Facilities with the highest case volumes had longer lengths of stay and higher 90-day readmission rates. (Matsen 2015)

Global Burden
- In developed nations, osteoarthritis is one of the 10 most common disabilities in older individuals, especially those who remain active in the workforce. (Palmer 2015)

The total number of years lived with disability worldwide caused by knee and hip osteoarthritis (OA) increased by 60.2 percent between 1990 and 2010, and by 26.2 percent per 1,000 people. This means OA has moved up from 15th to 11th in the list of the most frequent causes of disability. (Vos 2013)

Australia
- More than half of the 1.8 million Australians with osteoarthritis were between 25 and 64 years old. (Ackerman 2015)

An increasing incidence of sports injuries could result in an increasingly larger future burden of osteoarthritis in the population, with a corresponding increase in health service delivery and musculoskeletal ill-health burden in future years. (Finch 2015)
- 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. (Ackerman 2015)

- While direct health care costs are often reported, indirect health care costs may be eight times greater than direct costs, indicating that the true burden of osteoarthritis is underestimated. (Finch 2015)

- The cost of arthritic disease in Australia is estimated to be $24 billion per annum, affecting one in eight adults. (Finch 2015)

- In Australia, 13 percent of primary total hip replacements and 7 percent of primary total knee replacements are undertaken in people under age 55. (Ackerman 2015)

- People undergoing total joint replacement are 26 percent more likely to have cardiovascular disease than people without osteoarthritis. (Finch 2015)

**United Kingdom**

- Knee replacements are being performed much more frequently. There were more than 80,000 primary procedures in 2011 and increasing by around 3 percent annually. (Wills 2015)

- Knee replacements are being performed much more frequently. There were more than 80,000 primary procedures in 2011 and increasing by around 3 percent annually. (Wills 2015)

- Since 2006, the majority of knee replacement patients were obese (body mass index of 35 or greater) and this proportion is growing.
  - In 2006, 15 percent of patients were obese.
  - In 2013, 21 percent of patients were obese. (Wills 2015)

- There are around 5,000 (6 percent) revisions out of 88,000 total procedures in England each year. (Wills 2015)

- 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. (Wills 2015)

**Spain**

- In Spain, deprived areas have higher rates osteoarthritis (OA; hand, hip, knee). OA patients in the most deprived areas were younger, had fewer women, and a higher percentage of obese, smokers and high-risk alcohol residents. (Reyes 2015)

- 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. (Reyes 2015)

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**OSTEOARTHRITIS ACCOUNTS FOR MORE THAN 25 PERCENT OF ALL ARTHRITIS-RELATED HEALTH CARE VISITS.**

(Vollenhoven 2009)
Section 3: Autoimmune and Inflammatory Arthritis

A Related Group of Rheumatoid Diseases
A healthy immune system is protective. It generates internal inflammation to get rid of infection and prevent disease. But the immune system can go awry, mistakenly attacking the joints with uncontrolled inflammation, causing joint erosion and damage to internal organs, eyes and other parts of the body.

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

• Diseases commonly involving multi-system organ involvement including: rheumatoid arthritis (RA), systemic lupus erythematosus (SLE or lupus), Sjögren’s syndrome, and scleroderma (systemic sclerosis)

• spondyloarthritis (SpA), an umbrella term for diseases primarily involving the joints, ligaments, and tendons that includes: ankylosing spondylitis and psoriatic arthritis (PsA).

The goal of treatment for these diseases is to reduce pain, improve function and prevent further joint damage.
IN 2015, ESTIMATED NATIONAL INDIRECT COSTS OF RA-RELATED ABSENTEEISM FROM WORK WERE $252 MILLION ANNUALLY. (Gunnarsson 2015)
**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, the elastic tissue that covers the ends of bones in a joint, as well as the bones themselves. 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 body systems, such as the cardiovascular or respiratory system, it is called a systemic disease, meaning “entire body.”

The following facts describe some of the features common to RA.

**Prevalence**

- In 2005, rheumatoid arthritis was estimated to affect 1.3 million adults in the U.S., representing 0.6 percent of the population. *(Helmick 2008)*

- By 2007, an estimated 1.5 million adults had rheumatoid arthritis. *(Myasoedova 2010)*

- The prevalence of rheumatoid arthritis is approximately 0.5 percent to 1 percent in developed countries and 0.6 percent in the U.S. population. *(Gabriel 2009)*

- Women are two to three times as likely to be affected as men. *(Vollenhoven 2009)*

- One in 12 women and 1 in 20 men will develop an inflammatory autoimmune rheumatic disease during their lifetime. *(Crawson 2011)*

**Human and Economic Burdens**

**Health Burdens**

- Mortality hazards are 60-70 percent higher in patients with rheumatoid arthritis (RA) compared with those in the general population.

- The survival gap between patients with RA and those without RA appears to be only widening. *(Mikuls 2010)*

- A 2007 study found that excess mortality in rheumatoid arthritis has been seen in
  - cardiovascular disease (31 percent),
  - pulmonary fibrosis (4 percent), and
  - lymphoma (2.3 percent). *(Young 2007)*

- Psychiatric disorders in rheumatoid arthritis (RA) are common, particularly depression.

  - About 16.8 percent of RA patients suffer from depression
  - that is significantly greater compared with that of the general population. *(Matcham 2013)*

- For those with rheumatoid arthritis (RA) from 1987 to 2012:

  - Men with RA were hospitalized for depression at a greater rate than were men without RA.

  - Patients with RA were hospitalized at a greater rate for diabetes mellitus than were people without RA. *(Michel 2015)*

**Work/Employment Impact**

- The lost productivity associated with rheumatoid arthritis is substantial.

  - Because of its progressive nature, many individuals report missing work or choose not to work because of disease-related disabilities.

  - Approximately 20 percent to 70 percent of individuals who were working at the inception of their rheumatoid arthritis were disabled after seven to 10 years. *(Burton 2006)*
- The indirect cost of rheumatoid arthritis due to lost productivity has been estimated to be nearly three times greater than the costs associated with treating the disease. (Agarwal 2011)

- A 2010 study found that about one-fourth to one-half of all patients with rheumatoid arthritis become unable to work within 10 to 20 years of follow-up. (Mikuls 2010)

- Among those who did miss work, employees with rheumatoid arthritis (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. (Gunnarsson 2015)

**Medical/Cost Burdens**

- Mortality rates attributable to rheumatoid arthritis (RA) have declined globally. Population aging combined with fall in RA mortality may lead to an increase in the economic burden of disease that should be taken into consideration in policy-making. (Kiadaliri 2017)

- From 1987 to 2012 in Olmsted County, Minnesota

  - Patients with rheumatoid arthritis (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. (Michet 2015)

- There were 323,649 hospitalizations for rheumatoid arthritis (RA) between 1993 and 2011.

  - During this time, the annual hospitalization rate for patients with a principle discharge diagnosis of RA declined from 13.9 to 4.6 per 100,000 US adults. (Lim 2016)

- Based on 2005 U.S. Medicare/Medicaid data, total annual societal costs of rheumatoid arthritis (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. (Birnbaum 2010)

- A 2009 study found that

  - Almost half (43.6 percent) of rheumatoid arthritis patients had problems paying medical and drug bills after insurance payments.
  
  - About 9.0 percent 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 <65 years of age (11.8 percent) compared with those ≥65 years (5.3 percent). (Wolfe 2009)

**WOMEN ARE TWO TO THREE TIMES AS LIKELY TO BE AFFECTED BY RA AS MEN.**

(Wollenhoven 2009)
Systemic Lupus Erythematosus (SLE or Lupus)

Lupus is a chronic, autoimmune disease. People with lupus have an overactive and misdirected immune system. Lupus is systemic, meaning that it affects a wide part of the body, including the joints, kidneys, skin, blood, brain and other organs.

Systemic lupus erythematosus (SLE) accounts for about 70 percent 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, sensitivity to light, fever, rash and kidney problems.

The following facts describe some of the features common to SLE.

**Prevalence**
- About 15 to 20 percent of all systemic lupus erythematosus cases develops before the age of 18 years. (Weiss 2012)

- Geographic and racial distribution — both geography and race affect the prevalence of systemic lupus erythematosus and of frequency and severity of the disease.
  - The disease appears to be more common in urban than rural areas. (Chakravarty 2007)

- The prevalence (how widespread) and incidence (risk for the disease) of systemic lupus erythematosus (SLE) in the U.S. American Indian and Alaska native populations are as high as or higher than the rates reported for the African American population. (Ferucci 2014)

- For U.S. American Indian and Alaska native populations
  - The prevalence is
    - Overall, 178 per 100,000 people have SLE.
    - Women are almost twice as likely to have SLE (271 per 100,000 people).
  - The incidence is
    - The overall risk is 7.4 cases per 100,000 per year.
    - Among women is 10.4 cases per 100,000 per year. (Ferucci 2014)

- The prevalence of systemic lupus erythematosus is
  - higher in the U.S. among Asians, African Americans, African Caribbeans, and Hispanic Americans compared with Caucasians
  - higher in the U.K. among Asian Indians compared with Caucasians. (Rus 2002)

- 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 being most susceptible. (Crosslin 2009)

- In Georgia, striking gender, age, and racial disparities in systemic lupus erythematosus (SLE) have been confirmed.
  - Compared to men, women
    - have more than 5 times higher risk of having SLE.
    - are diagnosed with SLE more than 8 times more often.
  - The prevalence of SLE is 3 to 4 times higher in African Americans than Caucasians.
  - Disease onset occurs at a younger age among African Americans. (Lim 2014)

- In Michigan, systemic lupus erythematosus prevalence is
  - 2.3 times higher in African Americans than in Caucasians.
  - 10 times higher in females than in males. (Somers 2014)
- International comparison of all race prevalence shows:
  - In the U.S., 52.2 cases per 100,000 people.
  - In the U.K., 26.2 cases per 100,000 people.
  - In Japan, 28.4 cases per 100,000 people. (D’Cruz 2007)

- International comparison of all race incidence shows:
  - In the U.S., 5.1 per 100,000 people.
  - In the U.K., 3.8 per 100,000 people.
  - In Japan, 2.9 per 100,000 people. (D’Cruz 2007)

Human and Economic Burdens
- Poverty, either current or at some time, plus severity of poverty has an adverse effect on accumulation of disease damage throughout the body in patients with systemic lupus erythematosus. (Yelin 2017)

- Care fragmentation is associated with increased risk of severe infection and comorbidities. These results suggest that improved health information exchange could positively impact outcomes for systemic lupus erythematosus patients. (Wolunas 2016)

- Distinct patterns of disease presentation, severity and course can often be related to differences in ethnicity, income level, education, health insurance status, level of social support and medication adherence, as well as environmental and occupational factors. (Carter 2016)

Comorbidities and Health Burdens
- As an intangible cost, systemic lupus erythematosus patients are likely to endure considerably reduced health-related quality of life. (Carter 2016)

- Fatigue in systemic lupus erythematosus is known to be related to
  - physical inactivity
  - poor sleep quality
  - depression
  - anxiety
  - negative mood
  - cognitive dysfunction
  - obesity
  - vitamin D deficiency/insufficiency
  - and comorbidities such as fibromyalgia. (Ahn 2012)

- Depression in lupus is multifactorial. Global disease activity is not a risk factor, but skin involvement and certain types of neurologic activity (myelitis – inflammation of the spinal cord) are predictive of depression. (Huang 2014)

- Higher-dose prednisone (20 mg or more daily) is one important risk factor for depression in lupus patients.
  - The independent effect of prednisone provides clinicians with an additional incentive to avoid and reduce high-dose prednisone exposure in lupus. (Huang 2014)

- Neuropsychiatric manifestations (mental or emotional disturbance related to disordered brain function) usually occur early in systemic lupus erythematosus (SLE). (Hanley 2007)
  - In SLE, the occurrence of neuropsychiatric events is associated with a lower quality of life and poor prognosis. (Hanley 2010)

- Cognitive dysfunction is present in up to 80 percent of patients with systemic lupus erythematosus. (Meszaros 2012)

- Cross-sectional studies report the prevalence of obesity among adults with systemic lupus erythematosus (SLE) at around 28 percent. (Chaiamnuay 2007)

- Glomerulonephritis (acute inflammation of the kidney) is seen in 30 to 50 percent of unselected patients with systemic lupus erythematosus at the onset of the disease, and kidney involvement is observed in at least 60 percent in this disease. (Rajashekar 2008)

- Kidney damage is one of the principal causes of morbidity and mortality in patients with systemic lupus erythematosus. (Rahman 2008)

- Lupus nephritis is a severe manifestation of the disease, affecting up to 60 percent of patients at some point. (Singh 2009)

- The overall reported prevalence of end-stage kidney disease caused by lupus nephritis has increased 56 percent over the 10-year period of 2000 to 2010. (NIH 2010)
The prevalence of kidney and cardiovascular damage in systemic lupus erythematosus (SLE) is higher among African Americans than Whites. African Americans with SLE also suffer these complications at earlier ages. (Ward 2007)

Acute joint involvement is an important feature of systemic lupus erythematosus and has been described in 70 percent of children and 90 percent of adults with the disease. (Tarr 2015)

About 44 percent of the hip and knee joints of systemic lupus erythematosus patients undergoing 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). (Nakamura 2010)

Serious infections are recognized as major causes of morbidity and mortality in patients with lupus, accounting for:
- 13 to 37 percent of hospitalizations
- 65 percent of avoidable hospitalizations
- and one-third of deaths. (Tektonidou 2015)

Systemic lupus erythematosus patients have two to five times the risk of death compared with the general population. (Fors Nieves 2016)

**Pregnancy Impact**
- Pregnancies in women with lupus were associated with a higher risk of complications, higher healthcare costs, and fewer pre-scribed medications, including immunosuppressants, than healthy women. (Petri 2015)
- Maternal outcomes (such as pre-eclampsia, hypothyroidism, stroke and infection) were more common among women with systemic lupus erythematosus (SLE).
  - 16 percent of prevalent-SLE pregnancies were diagnosed with pre-eclampsia, compared with 5 percent of those from the general population.
  - Among the pre-SLE women, pre-eclampsia was found in 26 percent of those with SLE within two years postpartum and 13 percent in those with SLE within two to five years postpartum. (Arkema 2016)
- Infant outcomes, such as preterm birth, infection and mortality, were worse among those born to mothers with prevalent SLE and pre-SLE during pregnancy. (Arkema 2016)
- Adverse pregnancy outcomes (APO) occurred in 19 percent (almost one in five) of pregnancies in women with lupus:
  - fetal death occurred in 4 percent
  - neonatal death occurred in 1 percent
  - preterm delivery occurred in 9 percent
  - 10 percent of neonates were small for their gestational age (birthweight was below the fifth percentile).
  - maternal flares and higher disease activity also predicted the APOs. (Buyon 2015)

**Work/Employment Impact**
- Systemic lupus erythematosus is one of the leading causes of work disability in the U.S., accounting for about 20 percent of the more than estimated 1.5 million Americans with a work disability. (Agarwal 2016)
Due to the chronic, unpredictable, and systemic nature of complete systemic lupus erythematosus, patients often have reduced ability to perform work, care for their dependents and engage in other unpaid work.

- Hence, the resulting indirect costs can exceed direct costs by two-to-four-fold. ([Choi 2016](#))

- Annual hours of employment decreased since the year of diagnosis, from 1,378.2 hours per year to 899.5 hours per year for people with systemic lupus erythematosus.
  - 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 productivity cost of $8,659. ([Panopalis 2008](#))

- The symptoms of lupus can have a profound impact on the person’s employment.
  - Impacts of lupus are more pronounced among young and middle-adulthood.
  - Studies have shown that loss in work hours cost the nation nearly $13 billion annually.
  - The loss also impacts the individual’s work, quality of life, self-management, and self-efficacy. ([Agarwal 2016](#))

- Studies from the U.S. reveal that 15 percent to 40 percent of systemic lupus erythematosus patients are unemployed within 5 years of diagnosis. ([Drenkard 2014](#))

- According to a longitudinal survey of persons with systemic lupus erythematosus (SLE),
  - in the year of diagnosis, 76.8 percent of participants had been employed
  - only 48.7 percent were employed at the end of the study. ([Panopalis 2008](#))

- A longitudinal study among predominantly middle-class white women with systemic lupus erythematosus indicated that more than 60 percent were out of the workforce 20 years after the diagnosis. ([Yelin 2007](#))

### Medical/Cost Burdens

- Given the potential for the disease to cause such severe and widespread organ damage, not only are the attendant direct costs high, but these costs are sometimes exceeded by indirect costs owing to loss of economic productivity. ([Carter 2016](#))

- The medical costs of systemic lupus erythematosus are substantial, with a mean total medical care cost of $51,295 over 4 years. ([Kan 2016](#))

- Systemic lupus erythematosus (SLE) flares were experienced by 97 percent of SLE patients, with an average of 2.6 flares per patient per year.
  - 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 as their highest flare severity. ([Kan 2013](#))

- From 2000 to 2009, most systemic lupus erythematosus direct costs were related to
  - inpatient (16 to 20 percent) care
  - outpatient (24 to 56 percent) services
  - medications (19 to 30 percent). ([Slawsky 2011](#))

### The medical costs of LUPUS total

$51,295

(mean total over a 4 year period)

([Kan 2016](#))
- In a study of U.S. Medicaid enrollees between 2000 and 2009, systemic lupus erythematosus (SLE) patients had significantly higher healthcare utilization and higher overall expenditures than patients with no SLE.
  - SLE patients incurred $10,984 more total cost per year
  - 55 percent of that being attributed to inpatient care. (Kan 2016)

- Hospitalization rates for serious infections in systemic lupus erythematosus (SLE) increased substantially between 1996 and 2011.
  - They were over 12 times higher than in patients without SLE in 2011. (Tektonidou 2015)

- Between 2000 and 2010 in the U.S.
  - The mean annual direct costs of systemic lupus erythematosus (SLE) patients ranged from $13,735 to $20,926
    - with nephritis, costs ranged from $29,034 to $62,651
    - without nephritis, costs ranged from $12,273 to $16,575. (Slawsky 2011)

- Across studies of a general systemic lupus erythematosus (SLE) population:
  - Pharmaceutical costs composed 19 to 30 percent of total expenditures.
  - Inpatient costs accounting for 16 to 50 percent of overall costs
  - Outpatient costs accounting for 24 to 56 percent of overall costs. (Slawsky 2011)

STUDIES FROM THE U.S. REVEAL THAT 15 PERCENT TO 40 PERCENT OF SYSTEMIC LUPUS ERYTHEMATOSUS PATIENTS ARE UNEMPLOYED WITHIN 5 YEARS OF DIAGNOSIS.

(Drenkard 2014)
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 the body. In Sjögren’s syndrome, the infection-fighting cells of the immune system attack the normal cells of glands that produce moisture and other parts of the body. This damages glands, making them unable to produce moisture. In addition to affecting the eyes and mouth, 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.

The disease is classified either as:

- Primary Sjögren’s. 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. It overlaps with another rheumatic disease, such as rheumatoid arthritis.

Prevalence (Primary Sjögren’s Syndrome)

- Primary Sjögren’s syndrome is an autoimmune chronic inflammatory disorder affecting 0.2% to 3.0% of the population, with a 9:1 female to male ratio. (Reksten 2014)

- Although the average age of onset of primary Sjögren’s syndrome is usually in the patient’s 40’s to 50’s, onset of the disease in the patient’s 60’s or 70’s can occur. (Patel 2014)

- The prevalence of primary Sjögren’s syndrome in the elderly population is between five to eight times higher than in younger and middle-aged adults. (Patel 2014)

Comorbidities (Secondary Sjögren’s Syndrome)

- Sjögren’s is the most frequent disorder that occurs in conjunction with other autoimmune and rheumatic diseases. (Hammitt 2014)

- About half of the time Sjögren’s syndrome occurs alone, and the other half it occurs in the presence of another connective tissue disease such as rheumatoid arthritis, lupus, or scleroderma. (SSF 2017)

- If a Sjögren’s patient has another major rheumatic, autoimmune disease such as lupus, rheumatoid arthritis, scleroderma or multiple sclerosis, they would have traditionally been categorized as have “Secondary Sjögren’s”.

  - Use of this diagnosis does not apply when it is found with autoimmune thyroid diseases. (Hammitt 2014)

- The most frequent autoimmune diseases observed in Sjögren’s syndrome patients are thyroid disease, rheumatoid arthritis, and systemic lupus erythematosus. (Anaya 2016)

Human and Economic Burdens

Health Burdens

- The disease’s predominant effects are on the tear and salivary glands, as well as other moisture producing glands in the larynx (hoarseness), trachea (cough), skin (pruritus), and vagina (dyspareunia). (Baldini 2014)

- Up to 75% of patients with primary Sjögren’s syndrome suffer from diseases that affect

  - the skin (abnormally dry skin)
  - joints (inflammatory arthritis)
  - lungs
  - kidneys
  - blood vessels (purpura, Raynaud’s disease)
  - digestive system
  - and nerves (peripheral neuropathy). (Baldini 2014)

- Up to 25% of patients with primary Sjögren’s syndrome develop moderate or severe non-glandular disease. (Baldini 2014)

- Neurological issues seem to affect about 20% of patients with primary Sjögren’s syndrome (pSS).

  - It is not uncommon for them to occur before other signs and diagnosis of pSS. (Carvajal 2015)
- High blood pressure and high cholesterol are more common in primary Sjögren’s syndrome patients.
- They also have an increased risk of cerebrovascular events (such as strokes and aneurysms) and heart attack. (Bartoloni 2015)

- 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 9.8%. (Solans-Laqué 2011)

- The increased risk of developing non-Hodgkin B cell lymphoma is higher than that of patients with rheumatoid arthritis and systemic lupus who also have an increased risk of developing non-Hodgkin lymphoma. (Nocturne 2015)

- The prevalence of fatigue among patients with Sjögren’s syndrome may be as high as 65 to 70 percent. (Haldorsen 2011)

- Individuals with Sjögren’s syndrome frequently experience voice disorders and specific voice-related symptoms (ie, included frequent throat-clearing, throat soreness, difficulty projecting, and vocal discomfort) that are associated with reduced quality of life. (Tanner 2015)

- Sjögren’s syndrome (SS) is an autoimmune disease that affects exocrine glands and therefore may affect 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.
  - 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. (Ebert 2012)

- Sjögren’s syndrome patients are prone to develop a newly recognized 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. (Mavragani 2010)

- Autoimmune thyroid diseases have been observed in 45% of Sjögren’s syndrome patients. (Perez 1995)

- Fatigue related to Sjögren’s syndrome has been reported to be continuously present and patients said they never felt refreshed.
  - Some patients reported disturbed sleep caused by increasing stiffness and aching. Others slept so deeply that they did not notice the stiffness until they woke up, but even then they were still 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. (Mengshoel 2014)

- Dry eye from Sjögren’s syndrome can cause ocular complications include corneal ulceration and scarring, and bacterial corneal and eyelid infections, which require continuous medical care and treatment. (Mavragani 2010)

- Dry mouth 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. (Mavragani 2010)
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.

(Mengshoel 2014)
- Secondary Sjogren’s syndrome with Rheumatoid Arthritis
  - Secondary Sjogren’s syndrome patients have a more severe form of arthritis.
  - Secondary Sjogren’s syndrome 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 Sjogren’s syndrome patients than in rheumatoid arthritis or in primary Sjogren’s syndrome patients.
  - The incidence of coronary heart disease and cardiovascular events is higher for secondary Sjogren’s syndrome patients than for patients with rheumatoid arthritis alone.
  - Interstitial lung disease, a common lung complication associated with rheumatoid arthritis (RA), was also more likely to be found in RA patients with secondary Sjögren’s syndrome.
  - About 4% to 31% of patients with rheumatoid arthritis (RA) meet the diagnostic criteria for secondary Sjögren’s syndrome. However, about 30% to 50% of RA patients may have dry eye or mouth, but do not meet the full criteria for secondary Sjögren’s syndrome diagnosis. (He 2013)

- Secondary Sjogren’s syndrome with Lupus:
  - Sjogren’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).
  - Sjogren’s syndrome (SS) patients with lupus 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 SS. (Baer 2010)

Work/Employment Impact
- 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 underrecognized activities that are of value to society (like housework, caring for children or parents, or voluntary activities). (Dumusc 2017)

- Work disability, including sick leave and disability pension, is significantly higher among patients with primary Sjögren’s syndrome than in the general population. (Dumusc 2017)

- A study in Sweden showed:
  - 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 2 years after diagnosis, 41% were receiving a disability pension. (Mandl 2017)

- Sjögren’s syndrome with Fibromyalgia
  - In Sweden, there was an 82% increase in patients with Sjögren’s syndrome and fibromyalgia (FM) having work disability 2 years after diagnosis compared to 30% of patients with FM alone. (Mandl 2017)

Medical/Cost Burdens
- Direct costs of primary Sjögren’s syndrome based on claims database information from 10,000 patients in the U.S. found that annual healthcare costs in the year following diagnosis increased by 40% to $20,416 per person. (Birt 2016)

- Secondary Sjögren’s syndrome patients require more therapy during treatment and incur higher hospitalization costs due to the higher incidence of anemia. (He 2013)

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Scleroderma

Scleroderma, which means “hard skin,” affects about 300,000 Americans. Scleroderma involves the buildup of scar-like tissue in the skin, but it can also damage the cells in the walls of the small arteries. It is not contagious, infectious or cancerous. Scleroderma may occur in two forms - localized scleroderma and systemic sclerosis.

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.** This kind affects the skin on the face, fingers and hands, and lower arms and legs. For many, the first symptoms are Raynaud’s phenomenon and puffy fingers, which can begin several years before other symptoms. If internal organs are involved, it tends to be mild. However, some people experience severe Raynaud’s phenomenon, gastrointestinal problems or serious effects on the lungs.

- **Diffuse scleroderma.** Skin thickening is widespread. 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. Kidney problems may lead to high blood pressure and, if untreated, kidney failure. Lung damage is the leading cause of death with this condition.

**Prevalence**

- The prevalence of scleroderma in the US seems to be stable with 240 cases per million adults. (Mayes 2003)

- Most adults with systemic scleroderma are diagnosed between the ages of 30 to 50. (Mayes 2003)

- Localized scleroderma (LS) has several subtypes. Plaque morphea, the most common adult subtype, occurs in about 60% of adults with LS. (Zulian 2006)

- Scleroderma does not occur randomly in the population, there are groups who are at greater risks.
  - Women are affected 4.6 times more often than men.
  - Scleroderma occurs more frequently in African Americans than in whites. In addition, scleroderma is diagnosed at a younger age in African Americans. (Mayes 2003)

- The highest reported prevalence of scleroderma in the U.S has been reported in a Choctaw Indian group in Oklahoma. (Arnett 1996)

**Human and Economic Burdens**

**Health Burdens**

- Mild renal (kidney) problems are not uncommon in systemic sclerosis. Scleroderma-related renal crisis occurs in about 15% of adult patients. (Torok 2012)

- The presence of pulmonary arterial hypertension (PAH) in scleroderma patients has a detrimental impact of survival. (Fischer 2012)

- 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. (Coghlan 2006)

The average annual medical costs of **SCLERODERMA** is more than **3 times** higher than costs for patients without the disease. (Furst 2012)
- Pulmonary arterial hypertension is estimated to occur in 10 to 15% of adults with scleroderma. (Martini 2006)

- 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. (Mayes 2003)

- Survival is strongly dependent on the degree of internal organ involvement. The average 10-year survival rate for adults is now 70 to 80%. (Korn 2003)

- Progressive pulmonary fibrosis, pulmonary hypertension, severe gastrointestinal involvement, and scleroderma heart disease are the main causes of death. (Mayes, et al 2003)

**Economic Burdens**

- 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. (Furst 2012)

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

- 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 rheumatoid arthritis and/or psoriatic arthritis patients. (Miner 2010)

- 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.
  - 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. (Bernatsky 2009)

**THE HIGHEST REPORTED PREVALENCE OF SCLERODERMA IN THE U.S HAS BEEN REPORTED IN A CHOCTAW INDIAN GROUP IN OKLAHOMA.**

(Arnett 1996)
Spondyloarthritis (SpA)

Spondyloarthritis is an umbrella term for inflammatory diseases that involve the joints, ligaments, and tendons. The most common of these diseases is ankylosing spondylitis. Others include reactive arthritis, psoriatic arthritis and enteropathic arthritis, which is associated with the inflammatory bowel disease.

Spondyloarthritis has two main symptom patterns. Spondyloarthritis, in most cases, primarily affects the spine. For most people, the first and predominant symptom is low back pain.

Some forms can affect the peripheral joints -- those in the hands, feet, arms and legs. Peripheral spondyloarthritis is the less common symptom pattern. The main symptom is swelling in the arms and legs.

Joint inflammation often comes and goes and is accompanied by fatigue. Other problems can occur along with spondyloarthritis, including osteoporosis, pain and redness of the eye, inflammation of the aortic heart valve, intestinal inflammation and the skin disease psoriasis.

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 to 1.4 percent. (Stolwijk 2012)

- Prevalence for two of the most common forms of spondyloarthritis is estimated at:
  - Up to 1.7 percent ankylosing spondylitis,
  - Up to 0.4 percent for psoriatic arthritis. (Stolwijk 2012)

- The axial spondyloarthritis (SpA) prevalence may affect up to 1 percent of US adults, a prevalence similar to that reported for rheumatoid arthritis.
  - The overall number of people with SpA in the U.S. ranges between an estimated 1.7 million and 2.7 million persons. (Reveille 2012)

- Current estimates of the prevalence of different forms of spondyloarthritis (SpA) in the U.S. range from:
  - between 0.2 percent and 0.5 percent ankylosing spondylitis,
  - 0.1 percent for psoriatic arthritis,
  - 0.065 percent for enteropathic peripheral arthritis,
  - between 0.05 percent and 0.25 percent for enteropathic axial arthritis. (Reveille 2011)

Human and Economic Burdens

- Prevalent patients with ankylosing spondylitis are at a 30 percent to 50 percent increased risk of incident cardiovascular events. (Eriksson 2016)

- Work disability affects 10 percent to 20 percent of patients with ankylosing spondylitis, most often in those with physically demanding jobs. Lost income and lost productivity due to work disability represent major economic difficulties to both families and society. (Reveille 2012)
Psoriatic Arthritis (PsA)

Some people might hear “psoriasis” and think of the skin disease that causes itchy, scaly rashes and crumbling nails. It’s true, psoriasis is a skin disease. But about 30 percent of people with psoriasis also develop a form of autoimmune, inflammatory arthritis called psoriatic arthritis (PsA), which can lead to joint pain, stiffness and swelling. It can affect the entire body and 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.

The following facts describe some of the features common to PsA.

Prevalence

- The presence of Pso (psoriasis), inflammatory arthritis and absence of positive serological tests for rheumatoid arthritis are the hallmarks of psoriatic arthritis (PsA).
  - In 60 to 70 percent of patients Pso precedes PsA.
  - In 15 to 20 percent arthritis precedes the onset of Pso. (Kerschbaumer 2016)

- Up to 30 percent of individuals with psoriasis may also develop psoriatic arthritis, an inflammatory form of arthritis that can lead to irreversible joint damage if left untreated. (Gladman 2005)

- In the U.S., psoriasis remains a common, immune-mediated disease, affecting 7.4 million adults. Its prevalence has remained stable since the mid-2000s. (Rachakonda 2014)

- Psoriasis frequency ranges from 1 percent to 3 percent in Caucasian populations.
  - Psoriatic arthritis occurs in 10 percent to 40 percent of psoriasis patients. (Ogdie 2015)

- Psoriatic arthritis (PsA) has a prevalence of
  - 0.05 percent to 0.25 percent of the general population
  - 6 percent to 41 percent of patients with psoriasis. (Ogdie 2015)

  - PsA has a higher prevalence in patients with more extensive skin disease and a prevalence as high as 30 percent in dermatology clinics (where patients tend to have more extensive/severe psoriasis). (Ogdie 2015)

  - Psoriatic arthritis (PsA) is underdiagnosed in psoriasis patients, which may be due to under-recognition of PsA symptoms and a lack of effective screening tools. (Liu 2014)

- In seven European and North American countries, almost a third of patients with psoriasis seen in dermatology centers had psoriatic arthritis (PsA) as determined by rheumatologists.
  - Of the patients given the diagnosis of PsA in this study, 41 percent had not received a previous PsA diagnosis, suggesting under-diagnosis of patients in dermatologic practices of this potentially debilitating disorder. (Mease 2013)

Human and Economic Burdens

Health Burdens

- Patients with psoriatic arthritis experience pain, swelling, and joint tenderness, which produce reduced functioning in daily activities and impaired quality of life. (Strand 2012)

- Severe psoriasis is more common among psoriasis patients with psoriatic arthritis (PsA) than patients without PsA. (Haroon 2013)
- Patients with psoriatic arthritis and psoriasis tend to be heavier than unaffected individuals and patients with rheumatoid arthritis. (Bhole 2012)

- Obesity has been found to predict worse outcome and poor response to treatment in patients with psoriasis and psoriatic arthritis. (Eder 2014)

- Depression and anxiety are estimated to affect more than 30 percent 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. (Dowlatshahi 2014)

- Depression or insomnia affects between 20 percent to 50 percent of patients with psoriasis or psoriatic arthritis. (Fleming 2015)

- Roughly two-thirds of people with psoriasis and/or psoriatic arthritis say their disease makes them feel angry, frustrated, and/or helpless. (Martinez-Garcia 2014)

- More than half say psoriasis interferes with their ability to enjoy life. (Martinez-Garcia 2014)

- Nearly 30 percent of people with psoriasis and/or psoriatic arthritis suffer from depression.
  - About 88 percent of family members report the same levels of depression and anxiety as those with psoriasis. (Martinez Garcia 2014)

- According to a 2014 study, 55 percent of patients with moderate-to-severe psoriasis, and 41 percent of patients with psoriatic arthritis, are not being treated to the established standards of care. (Lebwohl 2014)

- Both psoriasis and psoriatic arthritis, similar to other systemic inflammatory conditions, were linked to an increased risk of developing cardiovascular diseases. (Husted 2011)

**Economic Burdens**

- A 2013 study found that although roughly 91 percent of patients with psoriasis or psoriatic arthritis were covered by insurance, the majority spent more than $2500 per year in out-of-pocket costs for their disease. (Bhutani 2013)

- Psoriatic disease is an expensive condition: the economic burden of psoriatic disease is up to $135 billion a year. (Brezinski 2015)
IN THE U.S., PSORIASIS REMAINS A COMMON, IMMUNE-MEDIATED DISEASE, AFFECTING 7.4 MILLION ADULTS.

(Rachakonda 2014)
Section 4: Juvenile Arthritis

What is 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).** Considered the most common form of childhood arthritis, JIA includes six subtypes.

• **Juvenile-onset scleroderma.** 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.
IN MANY CHILDREN, JUVENILE IDIOPATHIC ARTHRITIS IS A LIFE-LONG ILLNESS WITH A HIGH RISK OF DISEASE- AND TREATMENT-RELATED MORBIDITY.

(Guzman 2014)
JIA Subtypes

**Systemic JIA** 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 percent 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 the other subtypes.

**Polyarticular JIA** causes inflammation in five or more joints, often the small joints of the fingers and hands, but weight-bearing joints and the jaw can also be affected. About 25 percent of children with JIA will have this form.

**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 characterized by tenderness where the bone meets a tendon, ligament or other connective tissue. This tenderness accompanies joint inflammation of arthritis and most often affects the hips, knees and feet.

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

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**Prevalence**
- More girls than boys are affected by juvenile idiopathic arthritis. ([Harrold 2013](#))
- Data from family and twin studies suggest that susceptibility to juvenile idiopathic arthritis (JIA) is inherited.
  - While siblings of JIA patients are more likely than the general population to develop JIA, the overall risk for these siblings to develop JIA is low. ([Prahalad 2004](#))
- The disorder has been identified all over the world in nearly all races and ethnicities with an average prevalence rate of one to two per 1,000 children. ([Gabriel 2009](#))

**Human and Economic Burdens**

**Health Burdens**
- Most children with JIA managed with contemporary treatments attain inactive disease within 2 years of diagnosis and many are able to discontinue treatment.
  - The probability of attaining remission within 5 years of diagnosis is about 50%, except for children with polyarthritis. ([Guzman 2014](#))
- Juvenile idiopathic arthritis-associated uveitis (JIA-U) can lead to ocular complications and permanent vision loss.
  - About 10 to 25 percent of the children in the United States with juvenile idiopathic arthritis develop uveitis within the first 4 years of their arthritis diagnosis. ([Saurenmann 2007](#))

- Methotrexate is an effective, relatively safe, and low-cost treatment for children with JIA, but its use is often limited by significant nausea. ([Falvey 2017](#))
- Patients with juvenile idiopathic arthritis have a poorer Health Related Quality of Life (HRQOL) compared to healthy peers in physical health, followed by the psychosocial domain.
  - The areas of HRQOL most affected by juvenile idiopathic arthritis are
    - global health,
    - physical functioning,
    - role social limitation (physical),
    - and bodily pain/discomfort. ([Oliveira 2007](#))
- Health-related quality of life (HRQOL) in children who are newly diagnosed with juvenile idiopathic arthritis can vary, even with excellent symptom control. Strong predictors of HRQOL include:
  - the child’s perception of social support
  - perceived difficulty with their treatment regimen
  - and missed school. ([Seid 2014](#))
- Fatigue is common in patients with juvenile idiopathic arthritis (JIA), even when they reach adulthood.
  - Fatigue is significantly more common in patients with JIA compared to the general population. ([Armbrust 2016](#))
- The consequences of JIA-induced fatigue can be major, as they hamper children’s performance at school, social life, sports, and hobbies. ([Eyckmans 2011](#))
Mental Health Impact
- It has been found that there are higher rates of depression in children with juvenile idiopathic arthritis as compared to those without, but no difference when adults. (Krause 2016)
- The increased length of illness was linked with a higher percentage of cases with psychiatric disorders. (Mullick 2005)
- The presence of psychiatric disorders was related to considerable difficulties with learning, peer relationships, and leisure activities. This suggests that early recognition of psychiatric illness and management might improve the outcome in children with juvenile idiopathic arthritis. (Mullick 2005)
- Clinical classification of disease activity and severity is not directly linked to depression and trait-anxiety in children with juvenile idiopathic arthritis.
  - Self-efficacy corresponds with less pain and somatic complaints. (Vuorimaa 2008)

School and Social Impact
- Adolescents with juvenile idiopathic arthritis spent a greater percentage of time in bed and less time on moderate to vigorous physical activity.
  - Only 23% of the JIA patients met public health guidelines on physical activity compared with 66% in healthy peers. (Leleiveld 2008)
- School functioning among adolescents with primary pain conditions (unrelated to a specific disease) and adolescents with juvenile idiopathic arthritis have
  - poorer school functioning and school quality of life
  - missed more school days
  - more visits to the nurses than healthy adolescents. (Agoston 2016)
- School function scores were not accounted for by pain intensity, pain frequency, or time since pain onset.
  - However, pain intensity did emerge as a predictor of school-related quality of life. (Agoston 2016)
- Despite health challenges, young adults with juvenile idiopathic arthritis and healthy peers are comparable in terms of family background, scholastic and occupational self-concept, and academic competence. (Gerhardt 2008)
- The percentage of high school graduates and those working, those planning for further studies or seeking employment are equivalent in young adults with juvenile idiopathic arthritis and healthy peers. (Gerhardt 2008)
- Juvenile idiopathic arthritis disease subtype, severity at presentation and time elapsed is not associated with educational and occupational accomplishment. (Gerhardt 2008)
- In spite of juvenile idiopathic arthritis and the different associated challenges, young adults are similar to their healthy peers as they transition to adulthood. (Gerhardt 2008)

Economic Burdens
- A child with juvenile idiopathic arthritis is likely to incur high medical costs due to frequent visits to physicians and therapists to manage the disease. (Bernatsky 2007)
- There is higher inpatient healthcare utilization in children with juvenile idiopathic arthritis (JIA) compared to those without JIA.
  - There is higher inpatient healthcare utilization for juvenile idiopathic arthritis (JIA) due to joint surgery, non-joint surgery, and hospitalizations. (Krause 2016)
- Fifty-three (53) percent of the parents of juvenile idiopathic arthritis (JIA) cases reported an increase in the number of missed work hours for the period covering the year before and the year after their child’s index diagnosis.
  - Parents of a child with juvenile idiopathic arthritis (JIA) were 2.78 times more likely to report work-time loss than parents having no children with JIA.
  - Parents of children without juvenile idiopathic arthritis were 64 percent less likely to experience work-time loss than parents with a child with JIA.
  - Only 32 percent of the parents of children without JIA reported a work-time loss. (Rasu 2015)
- Between 2000 and 2009, parents who had a child with juvenile idiopathic arthritis (JIA) lost an average of US $4,589.37 due to missed work.
  - Parents who had no children with JIA, who lost an estimated average of US $2,986.08 during the same period. (Rasu 2015)
IT HAS BEEN FOUND THAT THERE ARE HIGHER RATES OF DEPRESSION IN CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS AS COMPARED TO THOSE WITHOUT, BUT NO DIFFERENCE WHEN ADULTS.

(Krause 2016)
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.** It 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.** This type affects the entire body. It causes internal organ damage and may be severe.

Juvenile-onset scleroderma can occur at any age and in any race, but it is more common in girls. It is a rare disease. However, it is the third most frequent rheumatic condition in childhood after juvenile idiopathic arthritis and systemic lupus erythematosus (Zulian 2013).

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**Prevalence**

- It is estimated that 10% of all patients with scleroderma develop the disease before the age of 8. (Zulian 2013)

- Juvenile scleroderma is rare.
  - However, it is the third most frequent childhood rheumatic condition after juvenile idiopathic arthritis and systemic lupus erythematosus. (Zulian 2013)

- The clinical presentation of scleroderma differs between adults and children.
  - Children typically have either juvenile localized scleroderma or juvenile systemic sclerosis. (Adrovic 2015)

- Juvenile localized scleroderma is the most frequent form of scleroderma in childhood, but it can occasionally progress into the systemic form. (Zulian 2013)
  - About 1 to 3 new cases of localized scleroderma are diagnosed per 100,000 children per year. (Peterson 1997)
  - Localized scleroderma (LS) has several subtypes. Linear scleroderma, the most common pediatric subtype, occurs in about 50% to 60% of children with LS. (Zulian 2006)

- Less than 5% of all juvenile-onset scleroderma patients have systemic sclerosis. (Torok 2012)
  - About 1 new case of systemic sclerosis is diagnosed per 100,000 children per year. (Pelkonen 1994)
  - About 4 times as many girls are diagnosed with juvenile-onset systemic sclerosis boys. (Scalapino 2006)

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**Health Burdens**

**Juvenile Localized Scleroderma**

- 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.
- About 2.1% of children with linear scleroderma have Raynaud’s syndrome.
- Less than 2% of children with linear scleroderma have gastrointestinal, respiratory, or renal symptoms. (Zulian 2005)

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Although rare, **JUVENILE SCLERODERMA** is the third most frequent childhood rheumatic condition. (Zulian 2013)
**Juvenile Systemic Scleroderma**

- Internal organ involvement in pediatric systemic sclerosis patients (in decreasing frequency) include
  - gastrointestinal - occur in about half of pediatric systemic sclerosis patients.
  - pulmonary (lungs)
  - musculoskeletal
  - cardiac
  - renal (kidney)
  - and neurological systems. (Scalapino 2006)

- Compared to adult-onset systemic sclerosis, muscle and skeletal involvement is more common in pediatric systemic sclerosis.
  - About 30% to 50% of pediatric systemic sclerosis patients experience inflammatory arthritis. (Torok 2012)

- 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. (Torok 2012)

- Although infrequent, cardiac involvement is the major cause of scleroderma-related deaths in children with systemic sclerosis. (Torok 2012)

- Annual cardio-vascular screening for patients with juvenile sclerosis is important to reduce the cardiovascular and pulmonary complications of pulmonary arterial hypertension. (Adrovic 2015)

- Pulmonary involvement in pediatric systemic sclerosis patients ranges from 30% to 70% and includes
  - interstitial lung disease,
  - pulmonary arterial hypertension,
  - abnormal lung function tests. (Panigada 2009)

- Pulmonary arterial hypertension is estimated to occur in about 7% of children with systemic scleroderma. (Martini 2006)

- Mild renal (kidney) problems are not uncommon in systemic sclerosis.
  - Scleroderma-related renal crisis is less common in children: it occurs in less than 15% of pediatric patients. (Torok 2012)

**IT IS ESTIMATED THAT 10% OF ALL PATIENTS WITH SCLERODERMA DEVELOP THE DISEASE BEFORE THE AGE OF 8.**

(Zulian 2013)
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 has 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, dematomyositis occurs far more frequently than polymyositis, whereas in adults the ratio is more equal. (Rider 2009)

- Juvenile polymyositis occurs less frequently and accounts for only 3 to 6 percent of childhood idiopathic inflammatory myopathies. (McCann 2006)

- Juvenile dematomyositis is the most common idiopathic inflammatory myopathy of childhood, accounting for approximately 85 percent of cases. (McCann 2006)

- Juvenile dematomyositis is found in patients of all ethnic and racial backgrounds – its distribution appears to be comparable population demographics in the U.S. (Robinson 2014)

- Girls are up to 5 times more likely than boys to be affected by juvenile dematomyositis. (Symmons 1995)

- Juvenile dematomyositis (JDM) occurs in 2 to 4 cases for per one million children per year in the U.S.
  - The average juvenile dematomyositis disease onset is age 7. (Mendez 2003)

Health Burdens

Juvenile Myositis

- Despite considerable advances in the management of juvenile myositis, the conditions are still associated with significant morbidity and mortality, representing a major long-term medical, social and economic burden on patients, their families and health care systems. (Ravelli 2010)

- In of juvenile myositis patients followed between 1993-2002, damage was present in 79% of the patients 82 months after diagnosis, which most commonly included joint contractures, weakness and cutaneous scarring. (Rider 2009)

- Reduced heart rate variability in juvenile myositis patients may be associated with elevated inflammatory markers, active disease and decreased heart muscle function. (Barth 2016)

- Juvenile myositis patients may be at increased risk of cardiovascular disease in adult life. (Schwartz 2011)

Juvenile Dermatomyositis

- Juvenile dermatomyositis 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. (Pachman 1990)
- Due to improvements in treatments, 99% of patients with juvenile dermatomyositis are expected to survive. (Ravelli 2010)

- Aggressive treatment of juvenile dermatomyositis aimed at achieving rapid, complete control of muscle weakness and inflammation appears to improve outcomes and reduce disease-related complications.
  - Medication-free remission was attained within an average of 38 months in more than one-half of the children (28 of 49) whose disease was treated with this approach. (Kim 2009)

- Up to 30 percent of juvenile dermatomyositis may develop - calcinosis, which is associated with worse functional outcomes.
  - skin or gastrointestinal ulceration, which is associated with a severe course of illness. (Huber 2000)

- Minority race and lower family income was found to be associated with worse morbidity and outcomes in patients with juvenile dermatomyositis in a group of North American children
  - Minority children had worse physical function, more disease activity, and lower quality of life scores.
  - Patients with lower family income have worse physical function, more disease activity, more weakness, and lower quality of life scores.
  - African American patients were more likely to have calcinosis. (Phillipi 2017)

**GIRLS ARE UP TO 5 TIMES MORE LIKELY THAN BOYS TO BE AFFECTED BY JUVENILE DERMATOMYOSITIS.**

(Symmons 1995)
Section 5:

Gout

What is Gout?

Gout is a form of metabolic inflammatory arthritis that develops in some people who have high levels of uric acid in the blood. The acid can form needle-like crystals in a joint and cause sudden, severe episodes of pain, tenderness, redness, warmth and swelling. The pain may last hours or weeks and make it difficult to perform daily activities.

Gout is not an autoimmune inflammatory disease. It is related to the types and amounts of food we eat and how our body processes (metabolizes) them. 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. If excess of uric acid builds up, it can form needle-like crystals which cause pain in a joint.

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.

The following facts describe some of the features common to 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. (Khanna 2012)
- About 3.9 percent of adults, or 8.3 million individuals have gout in the U.S. (Zhu 2011)
- There is a progressively greater prevalence of gout associated with higher weight. In the U.S., the prevalence of gout is:
  - 1-2% among people of normal weight
  - 3% among overweight people
  - 4-5% with class I obesity
  - 5-7% with class II or III obesity. (Jurasech 2013)
- In western developed countries, contemporary prevalence of gout is
  - 3 to 6 percent in men and
  - 1 to 2 percent in women.
  - Prevalence steadily increases with age, but plateaus after age 70. (Kuo 2015)
- Men are nearly three times more likely to develop gout, compared with women, and black males are most commonly affected. (Wilson 2016)
- Gout is rarely seen in premenopausal women but can be found in postmenopausal women. (Sunkureddi 2006)
- Gout incidence increases with age in both men and women, with the most significant age-related increase noticed in postmenopausal women. (Wilson 2016)

Human and Economic Burdens
Health Burdens and Comorbidities
- About 60 percent of patients experience a recurrent gout flare within one year of an initial event.
  - About 78 percent experience a recurrent flare within two years. (Brixner 2005)
- Advanced gout is associated with impaired mobility and reduced health-related quality of life, as well as an increased risk of all-cause mortality. (Dalbeth 2016)
- Gout is associated with increased risk of death, primarily due to cardiovascular disease. (Choi 2007)
- 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. (Lindsay 2011)
- Gout has a substantial comorbidity burden, and is particularly interconnected with other diseases associated with hyperuricemia, such as diabetes, hypertension and obesity. (Karis 2014)
- Obesity is not only a risk factor for incident gout but is also associated with an earlier age of gout onset. (McAdams 2011)
- The National Health and Nutrition Examination Survey data from 2007-2008 reported that among gout patients:
  - 74 percent had hypertension,
  - 71 percent had stage two or greater chronic kidney disease,
  - 53 percent were obese,
  - 26 percent had diabetes,
  - 14 percent have had myocardial infarction and
  - 10 percent have had a stroke. (Dalbeth 2016)
- Gout flares frequently result in patients being unable to bear weight and being bedbound for the duration of the acute attack. Severe foot pain, impairment and disability were observed in a study among patients with acute gout. (Rome 2012)

**Gout in Women**
- The onset of gout occurs at a later age in women. They are more likely to have comorbidities such as hypertension or renal insufficiency, they use diuretics more often. (Dirken-Heukensfeldt 2010)
- 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.
- Healthcare providers should consider gout especially in postmenopausal female patients with hypertension, diuretic use, and 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. (Dirken-Heukensfeldt 2010)

**Work/Employment Impact**
- Poorly controlled gout leads to absences from work, health care use and reduced social participation. (Khanna 2012)
- The U.S. labor force consisted of 155 million persons in July 2012. If gout is present in 2 percent of workers (3.1 million persons), and each misses five days annually as a result of the disease, the yearly loss of wages/productivity amounts to $833 per worker (based on 2010 data), or an overall loss of $2.6 billion. (Wertheimer 2013)
- Compared to workers without gouty arthritis, employees with this condition used significantly more sick leave, short-term disability and worker’s compensation benefits. (Brook 2006)
- The number of work days missed increases as the number of yearly gout flares increases. (Lynch 2013)

**Medical/Cost Burden**
- Patients with gout have higher than average medical costs and health care utilization than patients without gout. (Jackson 2015)
- 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. (Singh 2011)
- Nearly 8 percent of all emergency department visits for gout result in hospitalization, with a median inpatient stay approaching three days. (Singh 2016)
- From 1993 to 2009, the frequency of outpatient visits for gout increased three-fold, with the most significant increase after 2003. (Krishnan 2013)
- From 2002 to 2008:
  - there were a total of 50.1 million gout-related ambulatory visits in the U.S.
    - an average of 7.2 million visits per year
  - costing about $1 billion annually. (U 2013)
- From 2006 to 2012:
  - The rate of emergency department visits for gout in adults:
    - increased 14 percent, from 75.0 to 85.4 per 100,000 overall
    - increased 29 percent for those aged 45 to 54.
  - Emergency department charges increased from $156 million to $281 million (an 80 percent increase). (Jinno 2012)
- From 2009 to 2012, the number and cost of emergency department (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.
  - These accounted for 0.14 to 0.16 percent of all ED visits. (Singh 2016)
- In 2012, the combined estimate of annual direct and indirect costs of gout patient care totals more than $6 billion. This included:
  - $4 billion in direct costs
  - $2.6 billion in indirect costs. (Wertheimer 2013)
GOUT IS ONE OF THE MOST COMMON RHEUMATOLOGY DISEASES AND IS THE MOST COMMON CAUSE OF INFLAMMATORY ARTHRITIS AMONG ADULTS IN THE UNITED STATES.

(Khanna 2012)
Section 6: Fibromyalgia

What is Fibromyalgia?
Fibromyalgia is a condition associated with widespread amplified chronic pain, which is experienced in different parts of the body at different times. This, along with other symptoms such as fatigue, non-refreshed sleep, memory problems and mood changes, all strongly impact the quality of life for these patients. It is not a single disease, but a constellation of symptoms that can be managed.

Although fibromyalgia is not a form of arthritis because it does not inflame or damage joints, 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 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 a predisposing gene may exist.

The following facts describe some of the features common to fibromyalgia.
PATIENTS HAVE CHARACTERIZED LIVING WITH FIBROMYALGIA AS FEELING INVISIBLE, BEING DOUBTED BY OTHERS BECAUSE THE SYMPTOMS OF FIBROMYALGIA ARE SUBJECTIVE AND NOT SEEN BY OTHERS.

(Jussa 2011)
**Prevalence**
- Fibromyalgia is present in as much as 2% to 8% of the population, is characterized by widespread pain, and is often accompanied by fatigue, memory problems, and sleep disturbances. (Clauw 2014)
- Fibromyalgia remains undiagnosed in 3 of 4 of people with the disorder. (Clauw 2011)
- Based on newer diagnostic criteria, twice as many women are diagnosed with fibromyalgia than men. (Vincent 2013)
- The prevalence is similar in different countries, cultures, and ethnic groups; there is no evidence that fibromyalgia has a higher prevalence in industrialized countries and cultures.
  - Fibromyalgia can develop at any age, including in childhood. (McBeth 2007)

**Human and Economic Burdens**

**Disease Triggers**
- Twin studies suggest that about 50% of the risk of developing fibromyalgia and related conditions such as irritable bowel syndrome and headache is genetic.
  - about 50% is environmental. (Kato 2009)
- Environmental factors most likely to trigger fibromyalgia include stressors involving acute pain that would last for a few weeks. (Buskila 2008)
- Fibromyalgia can be triggered by infections like Epstein-Barr virus, Lyme disease, Q fever, and viral hepatitis. (Buskila 2008)
- Fibromyalgia can be triggered by trauma like motor vehicle collisions. (McLean 2011)
- Psychological stress has been shown to trigger fibromyalgia.
  - Fibromyalgia can be triggered by deployment to war. (Lewis 2012)

**Health Burdens**
- Fibromyalgia is a centralized pain state in which pain is experienced in different body regions at different times. (Williams 2009)
- Fibromyalgia may occur with other chronic pain conditions like osteoarthritis, rheumatoid arthritis, and lupus – about 10 to 30 percent of patients with these diseases also meet the criteria for fibromyalgia. (Phillips 2013)
- Magnetic resonance imaging of brain response has shown that brain activation in fibromyalgia patients is increased and they experience amplified pain (allodynia) for stimulus that people without fibromyalgia perceive as touch. (Gracely 2002)
- Patients with fibromyalgia may have imbalances or altered activity of various neurotransmitters mediating pain transmission, which may affect mood, memory, fatigue, and sleep. (Clauw 2014)
- Patients developing fibromyalgia commonly have lifelong histories of chronic pain throughout their body – regional or widespread musculoskeletal pain occurs in about 30% of patients. (McBeth 2007)
- Fibromyalgia patients are likely to have a history of headaches, temporomandibular joint disorder, chronic fatigue, irritable bowel syndrome and other functional gastrointestinal disorders, interstitial cystitis/painful bladder syndrome, dysmenorrhea and/or endometriosis, other regional pain syndromes (especially back and neck pain). (Hudson 1994)
- Living with fibromyalgia also has a significant emotional impact, with depression and anxiety being common comorbidities. (Vincent 2015)

Twice as many women are diagnosed with FIBROMYALGIA than men. (Agarwal 2016)
- Fibromyalgia symptoms 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 their personal expectations of what activities 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. (Arnold 2008)

- Patients often have difficulty adjusting to living with fibromyalgia and sometimes feel a sense of loss of identity. (Rodham 2010)

- Patients also felt isolated from health care providers whom they felt they had to convince they had a “real” condition to be taken seriously. (Rodham 2010)

- Patients have characterized living with fibromyalgia as having to manage two major burdens:
  - pain, which can be ever-present and overwhelming,
  - invisibility, being doubted by others because the symptoms of fibromyalgia are subjective and not seen by others. (Juuso 2011)

- Many patients seen in routine clinical practice who have fibromyalgia (or like syndromes) may respond well to simple interventions like
  - stress reduction
  - improved sleep patterns
  - increased activity and exercise. (Clauw 2014)

- The importance of behavioral therapies should be emphasized, as should be normalization of sleep patterns and institution of exercise therapy.
  - Patients should understand that these treatments often will be more effective than pharmacological treatments. (Fitzcharles 2013)

- Aerobic exercise has been associated with improvements in pain and physical functioning. (Busch 2008)

- Resistance training can result in significant improvement in pain and function. (Busch 2013)

- Land and aquatic exercise appear equally effective in improvement in pain and function. (Bidonde 2014)

- 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. (Macfarlane 2016)

- Experts give a strong recommendation for the use of exercise, particularly given its effect on pain, physical function and well-being, availability, low cost and low safety concerns. (Macfarlane 2016)

**Economic Burdens**
- On average, it often takes more than 2 years and about 4 consultations with different specialists to be diagnosed with this disease. (Choy 2010)

- Fibromyalgia represents a substantial economic burden for both the patient and the health care system,
  - with increased costs for prescription medications
  - lost productivity
  - short-term disability. (Schaefer 2016)

Fibromyalgia symptoms directly affect a patient’s ability to work, frequently resulting in missed workdays, reduction in hours and having to change jobs. (Schaefer 2016)

**Juvenile-onset Fibromyalgia**
The lifetime prevalence of major depression is estimated to be 26 percent in children with juvenile-onset fibromyalgia and 61.5 percent in adults with fibromyalgia. (Schaefer 2015)

Objective physical activity monitoring has documented that adolescents with juvenile-onset fibromyalgia become very sedentary and therefore are at greater risk of deconditioning and further risk of inactivity. (Kashikar-Zuck 2010)

School absenteeism is common, with adolescents missing an average of three school days per month, and several of them are unable to attend regular school at all (that is, they are homeschooled) because of the symptoms of juvenile-onset fibromyalgia. (Kashikar-Zuck 2010)

Perhaps not surprising, adolescents with juvenile-onset fibromyalgia are seen by their classmates (and themselves) as being isolated, more emotionally sensitive than their healthy peers, and have fewer friendships. (Kashikar-Zuck 2010)
CONCLUSION

Over the past decade and longer, our health care system has been in transition, which has also brought new opportunities to advance the cause of people living with arthritis. It has never been more important than now to plan for new innovations, cut health care costs and find a cure for a chronic disease that may affect over 91 million adults (almost 37 percent) in the United States, including over 61 million aged 18-64 (Jafarzadeh 2017), plus an estimated 300,000 children.

Many issues prevent people with arthritis from accessing the treatment they need: And as the number of those affected by arthritis grows, so will the costs and other burdens.

That’s why the Arthritis Foundation was founded 70 years ago.

Since 1948, we’ve ushered in a new era of bringing arthritis to the attention of more people. Today, we’re leading four groundbreaking initiatives we believe will make the biggest impact:

**Conquering Childhood Arthritis:** We’re laying the groundwork for revolutionizing treatments for JA, including personalized therapies that take away the guesswork.

**Advancing Osteoarthritis Treatment:** We’re speeding up the process of developing cutting-edge OA treatments.

**Cultivating a New Generation of Rheumatologists:** We’re addressing the growing shortage of arthritis specialists, especially in underserved areas.

**Collaborating With Patients for Better Health:** We’re putting arthritis patients front and center of their treatment and care, so they have more control of how they feel and what they can do.

We must continue advancing our understanding of arthritis. By investing in additional scientific discoveries and supportive policies, we’re confident we’ll conquer this life-altering disease altogether. We’ll continue to fight until every person with arthritis can say “yes” to a pain-free life.

Thank you for helping us reach that goal.
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**Section 3: Autoimmune Inflammatory Arthritis**

*RA*


*SLE*


**Adult-onset Scleroderma**


**SpA + PsA**


Section 4: Juvenile Idiopathic Arthritis (JIA)


Juvenile-onset Scleroderma


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Section 6: Fibromyalgia


Appendix 2

The state arthritis facts in Appendix 2 come from the CDC web pages. The data for the map can be found here: https://www.cdc.gov/arthritis/data_statistics/state-data-current.htm
APPENDIX 1

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
- Ankylosing Spondylitis
- Back Pain
- Behçet’s Disease
- Bursitis
- Calcium Pyrophosphate Deposition Disease (CPPD)
- Carpal Tunnel Syndrome
- Chondromalacia Patella
- Chronic Fatigue Syndrome
- Complex Regional Pain Syndrome
- Cryopyrin-Associated Periodic Syndromes
- Degenerative Disc Disease
- Developmental Dysplasia of Hip
- Ehlers-Danlos
- Familial Mediterranean Fever
- Fibromyalgia
- Fifth Disease
- Giant Cell Arteritis
- Gout
- Hemochromatosis
- Infectious Arthritis
- Inflammatory Arthritis
- Inflammatory Bowel Disease
- Juvenile Dermatomyositis (JD)
- Juvenile Idiopathic Arthritis (JIA)
- Juvenile Sclerderma
- Kawasaki Disease
- Lupus
- Lupus in Children & Teens
- Lyme Disease
- Myositis
- Osteoarthritis (OA)
- Osteoporosis
- Pagets
- Palindromic Rheumatism
- Patellofemoral Pain Syndrome
- Pediatric Rheumatic Diseases
- Pediatric SLE
- Polymyalgia Rheumatica
- Pseudogout
- Psoriatic Arthritis (PsA)
- Raynaud’s Phenomenon
- Reactive Arthritis
- Reflex Sympathetic Dystrophy
- Reiter’s Syndrome
- Rheumatic Fever
- Rheumatism
- Rheumatoid Arthritis (RA)
- Scleroderma
- Sjögren’s Disease
- Spinal Stenosis
- Spondyloarthritis (SpA)
- Systemic Juvenile Idiopathic Arthritis (sJIA)
- Systemic Lupus Erythematosus (SLE)
- Systemic Lupus Erythematosus (SLE) in Children & Teens
- Systemic Sclerosis
- Temporal Arteritis
- Tendinitis
- Vasculitis
- Wegener’s Granulomatosis
APPENDIX 2

State Facts

The data presented in this appendix and on our website is from the Center for Disease Control and Prevention (CDC). The CDC presents state-specific data from the Behavioral Risk Factor Surveillance System (BRFSS), which the CDC considers the best source for state-specific arthritis prevalence estimates.

BRFSS collects information in odd-numbered years (i.e., 2003, 2005, etc.) from a randomly dialed telephone survey of non-institutionalized, US civilians aged 18 years or older. The survey is completed in all 50 states, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands. For additional information on the BRFSS and how it is used to collect specific information on arthritis, please visit their website.

Each state’s “yearly costs for days lost from work because of arthritis” has been calculated by the Arthritis Foundation’s Advocacy staff using the CDC’s Disease Cost Calculator (Version 2; Reference 4).

Visit our website for access to state specific facts for all 50 states plus Washington, D.C.
APPENDIX 2

CDC Map
Arthritis Prevalence in the U.S.

Percentage of people by state who have doctor-diagnosed arthritis. For more state-specific facts visit arthritis.org/advocate
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