Connecting Families Living with Juvenile Arthritis

When Mandie Kozlowski made the trip from Middle Grove, NY, to the national Juvenile Arthritis Conference in Keystone, Colorado, she assumed she’d pick up a few good tips. After her daughter, Payton, was diagnosed with juvenile arthritis (JA) three and a half years ago, she and her husband, Robert, became immersed in understanding arthritis and treatment options.

But she learned so much more at the conference. “Every part of it was powerful,” she says. “The workshops and information were excellent. Talking with parents who are going through the same things as us and dealing with the same challenges was so helpful and rewarding. Everyone should go at least once and see for themselves.”

For families like the Kozlowskis, Arthritis Foundation programs like Family Days, summer camps and the National JA Conference are a lifeline to information and connection to other families. Mandie says her family is already planning their trip to the 2015 JA Conference taking place next July in Orlando, Florida.

“Having a child diagnosed with JA can be very scary and isolating,” says Michele Greco, Regional Director of Programs and Advocacy. “Our programs run the continuum of family needs and kids’ life stages as they grow and cope with the disease,” she says.

JA is one of the most common childhood diseases affecting more than 300,000 children in the U.S. In the Arthritis Foundation Northeast region, serving New York, New Jersey and eastern Pennsylvania, 32,000 children live with the disease.

Camper James Kinter at Camp JRA in Millville, PA, is looking forward to being a CIT (counselor in training) next year.

The Kozlowski family arrive at the National JA Conference.

Kids enjoy recreation and talking about juvenile arthritis at one of our JA Family Days.
Stopping Osteoarthritis in its Tracks

Of the over 50 million Americans with arthritis, more than half have osteoarthritis (OA), a degenerative disease caused by the breakdown of cartilage in the joints. OA can cause chronic pain and stiffness, most commonly in the spine, hips, knees and hands.

It is a common perception that OA is a natural outcome of growing older, however, OA quite often starts in a person’s younger years. Researchers already know that one notorious trigger of OA is the tearing of a major knee ligament -- called the Anterior Cruciate Ligament (ACL) -- often from a sports injury.

Each year, more than 200,000 people in the U.S. tear an ACL and more than half are diagnosed with OA within 10-20 years.

Thanks to a lead grant by Drs. Henry and Marsha Laufer, the Arthritis Foundation is leading a groundbreaking research study to pinpoint the start of OA before its effects set in and discover new therapies and medicines to halt its progression.

The “ACL Intervention Initiative” includes a team of researchers at the Hospital for Special Surgery (HSS) in New York City, Mayo Clinic in Rochester, Minn., and the University of California, San Francisco (UCSF).

The study recruits patients who recently suffered an ACL injury and conducts ongoing testing to look for biomarkers — measurements of the presence of the disease — that detect OA as it forms at the cellular and molecular level and measure its progression over time.

If successful, the study will allow physicians to track response to treatment and drive the development of more effective therapies. It will also help to cut health care costs as OA results in 1 million joint replacements each year.

Our ACL Intervention Study has the potential to revolutionize the future treatment of osteoarthritis.

John A. Hardin, MD
Director of ACL Research Program, Arthritis Foundation
Professor of Medicine, Orthopedics, Microbiology and Immunology, Albert Einstein College of Medicine.

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Store Hours:
Monday – Saturday, 9 a.m. – 6 p.m.
Juvenile Arthritis Family Programs and Support

A diagnosis of JA can turn the lives of families upside down. Our programs through our offices in New York, New Jersey and eastern Pennsylvania offer support, information and connection to families living with JA.

JA Summer Camps
Our sleep-away camps for children diagnosed with JA and other rheumatic diseases offer a place for children with arthritis to have fun, make new friends and learn how to manage their disease. The camps, based in upstate New York, New Jersey and Pennsylvania, provide quality care for over 200 kids with arthritis each summer and allow them to participate in activities that are adapted to their abilities.

JA Family Days
JA Family Days bring families together with some of the region’s prominent pediatric rheumatologists and other medical and health experts for a day of education and discussion about JA. While kids spend time enjoying supervised recreational activity, families talk with experts and other parents about medical treatments, nutrition, medications and more.

Welcome Kit/Power Pack
There are many questions and concerns when a child is diagnosed with JA. Families of newly diagnosed children can receive our Welcome Kit and Power Pack by emailing P2P@arthritis.org or calling our toll-free number at 1-855-552-4878.

Parent2Parent Network
Through our Parent2Parent Network, we pair parent mentors with parents of children who are newly diagnosed with JA or other rheumatic diseases. Our mentors are trained volunteers who understand the challenges of raising a child with arthritis and can provide understanding, guidance and support.

Young Adult Connect
This program hosts social gatherings for young adults ages 18-32 who have arthritis and live in the Northeast region so they can meet face-to-face with others dealing with similar challenges and learn from each other.

Youth Ambassadors
Children ages 10-17 share their stories of life with arthritis with local elected officials and members of Congress, and advocate for legislation and issues important to children with arthritis.

KidsGetArthritisToo.org
Our interactive website, designed especially for the JA community, offers information, local resources and opportunities for families to connect with experts and each other.

To learn more, visit our websites:
New Jersey – www.arthritis.org/new-jersey
Eastern Pennsylvania – www.arthritis.org/eastern-penncylvania

Over 50 guests attended a special day with campers this summer at Camp CHAT in New Jersey. Among them was (l.-r.) Kathy Geller, Chair of the New Jersey Chapter Board of Directors; David and Jane Hummel, leading supporters of our camp and youth programs; and Ingrid Montecino, President & CEO of the Northeast Region.
Jingle in the Season with Us!

Starting next month, more than 10,000 runners and walkers from New York, New Jersey and eastern Pennsylvania will tie bells to their sneakers, get on their marks and ring in the holiday season with the Arthritis Foundation. They are avid racers, novice joggers, family members, corporate teams and walkers—wearing costumes and race attire—all geared up to be a part of the Jingle Bell 5K Run/Walk, our national signature race event that raises funds to find a cure for arthritis.

For competitive runners, the event features a USATF-certified 5K course with finisher awards in each age bracket. For recreation runners, the 5K route is a great distance to try for a personal best. Smaller kids can also take part in the Jingle Bell Fun Run. Companies form corporate teams to build teamwork and boost morale. And, everyone can enjoy the holiday costume contest, music and post-race refreshments.

“The Jingle Bell 5K Run/Walk is a fun event from start to finish!” says Jodi Jacoby, who leads her own team, Jodster’s Jinglers, in the Jingle Bell Run in South Jersey.

In planning each race, business leaders, physicians, local celebrities and volunteers show their support by becoming Honorees.

In New York City, Jaime Stelter, TV traffic reporter with NY 1 News, is the Celebrity Honoree. Four-year-old Tatum Stavridis, who was diagnosed with juvenile arthritis after she turned one, is the Youth Honoree.

Steve Logan, President of the Aetna, Inc., New York Market is a former Corporate Chair of the Jingle Bell 5K Run/Walk and every year organizes a corporate team. “It is more than a race,” he says. “It’s a time to celebrate our achievements, renew our sense of teamwork and embrace the spirit of giving back.”

“It is one of the most spirited events of the season,” says Joan Mistrough, Regional Director of Community Development. “You ring in the holiday season (literally!), enjoy the camaraderie of friends and other runners, and you are supporting a terrific cause.”

The Jingle Bell 5K Run/Walk is taking place in the following cities in November and December. To learn more, visit www.arthritis.org/jbr.

New York
Syracuse November 22
Clifton Park December 6
Long Island December 6
New York City December 6
Westchester December 13

New Jersey
South Jersey December 6
Metuchen December 7

Eastern Pennsylvania
Malvern December 14

Our special thanks to some of our generous Jingle Bell 5K Run/Walk sponsors:

National Sponsor:
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Janssen Pharmaceuticals

Local Sponsors:
Aetna
Bristol-Myers Squibb Company
Genentech

International Order of Odd Fellows
Keane & Beane, P.C.
New York Presbyterian/Lawrence Hospital
Lenox Hill Hospital
Upstate Orthopedics
Virtua Health
Jingle Bell Run
Meet Our Honorees

They run or walk to raise money, to spread awareness that anyone can have arthritis, and to inspire people with their stories. Meet some of our Jingle Bell 5K Run/Walk honorees.

Jamie Stelter
Celebrity Honoree, New York City

Jamie Stelter is the Emmy-nominated morning traffic anchor for NY1, Time Warner Cable’s 24/7 news channel in New York City. She has been the subject of profiles in The New York Times and the New York Post, the latter of which dubbed her the “Trans-It Girl,” also the title of her first novel. Stelter was 21 when she was diagnosed with rheumatoid arthritis (RA).

While she has treated her RA through medication, Stelter has also turned to natural approaches to managing her pain. She also focuses on teaching others about RA. She chronicles her life and the healthy meals she cooks on her food blog, “TV Dinner,” and a web series called “TV Dinner with Friends.”

Tatum Stavridis
Youth Honoree, New York City

Tatum was diagnosed with juvenile arthritis just after her first birthday.

At age 4, Tatum is a sweet, resilient little girl who fights arthritis every day. Tatum is excited to be this year’s Jingle Bell 5K Run/Walk Youth Honoree. She even has her own slogan: “You are running for me!”

Morgan Fisher
Youth Honoree, South Jersey

Morgan was diagnosed with JA in December 2012. Last year, Morgan celebrated her Bat Mitzvah and decided to give back by forming her own Jingle Bell Run/Walk team. She raised over $3,000 and is excited to be this year’s Youth Honoree.

“I look forward to raising money and helping others by our contributions. It would be amazing to find new medical treatments and cures for arthritis. I hope to be able to show others that you can accomplish anything you set your mind to. I believe obstacles are simply challenges to be worked around and I believe I can meet any challenge!”

Morgan Fisher
Youth Honoree, South Jersey

Morgan was diagnosed with rheumatoid arthritis (RA) at the age of 16. Now, as an adult, her RA is under control with medication, diet and exercise. However, as a result of her RA, Kathy is scheduled to have bi-lateral total elbow replacement in 2015. Kathy is a published author and is currently working on a novel that will have a character with RA. She is an active volunteer with the Arthritis Foundation and wants to educate, motivate and empower others to continue the fight to cure Arthritis.

Kathy Wooten
Adult Honoree, Capital District

Kathy was diagnosed with juvenile rheumatoid arthritis (JRA) at the age of 16. Now, as an adult, her RA is under control with medication, diet and exercise. However, as a result of her RA, Kathy is scheduled to have bi-lateral total elbow replacement in 2015. Kathy is a published author and is currently working on a novel that will have a character with RA. She is an active volunteer with the Arthritis Foundation and wants to educate, motivate and empower others to continue the fight to cure Arthritis.

Judson K. Siebert
Corporate Chair, Westchester

Judson Siebert is a partner at the law firm Keane & Beane P.C., based in White Plains, NY, which has been an avid supporter of the Arthritis Foundation over the years. Siebert is leading “Team Keane & Beane” and has organized family, colleagues and friends for this year’s Jingle Bell Run. Siebert is currently on the Host Committee of the Foundation’s Westchester Fall Fete.

Erin Edgar
Youth Honoree, Westchester

Erin likes to dance, design clothes and play with her dogs, Minnie and Cooper. Last year, Erin was diagnosed with juvenile rheumatoid arthritis (JRA). This summer, Erin attended two Arthritis Foundation summer camps and was thrilled to meet other kids who can relate to what it’s like to live with JA. She hopes that by being a Youth Honoree for the Jingle Bell Run she can let other kids like her know that they are not alone.
People living with arthritis face unique barriers to care, in particular the exorbitant costs to treat the disease. Specialized medicines like biologics that are used to treat inflammatory arthritis can cost thousands of dollars per month in out-of-pocket expenses.

“The complexity of care for arthritis patients is often misunderstood by lawmakers,” says Sandie Preiss, who took over in May as the Foundation’s national Vice President of Advocacy and Access.

Based in our office in Washington, DC, Preiss leads a team of advocacy staff across the nation and is mobilizing our network of 65,000 advocacy volunteers to pass legislation on Capitol Hill and in states that will ensure that people with arthritis have access to affordable medications.

Preiss is excited to harness her strong background in federal and state government relations to advocate for access to care for people living with arthritis.

“One driving issue behind high drug costs is specialty tiers,” she said.

Commercial health insurers traditionally charge fixed co-payments based on different tiers of medications (i.e., generic, preferred, non-preferred). Now, some insurers are moving vital medications (such as biologics) into a new specialty tier that requires patients to pay a percentage of their drug cost — typically from 25% to 50% — rather than a fixed co-payment.

“This places medications out of reach of many patients with rheumatoid arthritis, MS, lupus, hemophilia and some forms of cancer,” Preiss says.

Nationally, Preiss and her team are working as part of the Coalition for Accessible Treatments to pass the Patients’ Access to Treatments Act, which limits specialty tier practices that keep patients from accessing the medications they need. Several states, including New York, have introduced and enacted legislation that limits cost-sharing for specialty drugs.

“We are members of the Pennsylvania Coalition Against Specialty Tiers and we are working as part of a state coalition to introduce similar legislation in New Jersey,” said Preiss.

“Our overriding objective is to raise the status of arthritis on the public policy agenda,” she says. “Through our staff and volunteer advocates, we want to tell their story in a way that moves decision makers and demonstrates that we are the voice for people with arthritis.”

Be a Voice for Change
The key to our success in ensuring access to care and improving funding for arthritis research is our network of more than 65,000 advocates nationwide.

Stay informed of our work by becoming an e-advocate. You will learn about all we are doing on Capitol Hill and in your state legislature and have the opportunity to take action, such as attending one of our events, making a phone call or writing a letter to your legislator, if you choose.

To join our dynamic volunteer network, visit arthritis.org/advocate/join-the-movement.
Engaging Nurses in Early Diagnosis and Treatment of RA

Imagine a patient visiting his doctor for a nagging cough. He first meets with the nurse and tells her his symptoms, but she also notices that his fingers are swollen and he has a gait when he walks to the scale.

She turns to her laptop and looks at a digital assessment, views a brief video and surmises that the patient may have the early markers for rheumatoid arthritis (RA), a disease that can go undiagnosed for years.

For the 1.5 million Americans afflicted with rheumatoid arthritis (RA), such a scenario could help ward off irreversible damage to their joints and other organs.

This early diagnosis tool for nurses and other health practitioners is becoming a reality thanks to a partnership between a working group of nurses and nurse practitioners and the Arthritis Foundation Northeast region that has resulted in the first-ever “Nurses’ Toolkit for Rheumatoid Arthritis.”

The online resource helps nurses and other interdisciplinary healthcare providers understand RA, recognize its symptoms so that it is diagnosed as early as possible, and guide patients in managing their RA.

In focus groups conducted by the Arthritis Foundation, patients said they would more readily talk with nurses about how their RA progresses and the benefits and side effects of treatment options. Nurses reported that they see their role as understanding patients’ needs, counseling them and helping them live a quality life.

The Toolkit is currently being piloted at three major medical institutions in metropolitan New York. Thanks to a generous $250,000 grant from Pfizer, it will be digitized and available online and through a web site and app in late 2015.

“While there is no cure for RA right now, studies show that early aggressive treatment can slow disease progression and limit joint damage,” says Dr. Stephen Smiles, Clinical Associate Professor for the Center for Musculoskeletal Care at NYU Langone Medical Center and chair of the Foundation’s Program Committee.

“It can make the difference between a person’s ability to perform basic daily activities, continue to work and have a quality life. That alone can be life-changing.”

Learn on Your Own

Time from Leading Arthritis Experts

Questions about arthritis? Our eLearning series allows you to learn about arthritis from doctors and health experts from leading hospitals and research institutions at your convenience 24/7.

These one-hour webinars present the latest arthritis information, including diagnosis, new therapies, managing pain, nutrition and more. Visit our websites (see page 2) to learn more.

Dr. Stephen Smiles and Eileen Lydon, nurse practitioner at NYU Langone-Hospital for Joint Diseases, and Clinical Reviewer and Editor of the Nurses Toolkit for RA.

Shop and Help the Arthritis Foundation

Visit our Thrift Shop, located on Manhattan’s upper east side, to browse designer clothing, jewelry and other accessories at bargain prices. Local residents call it a “treasure trove” of great finds. All proceeds benefit the Arthritis Foundation.

The Thrift Shop welcomes your donations of quality clothing (women’s and men’s), handbags, jewelry and antiques. Clothing may be dropped off at the Thrift Shop or at an Arthritis Foundation office near you (see page 2 for locations) Monday - Friday, between 9 a.m. - 5 p.m.
Our Annual Campaign
Every step counts in finding a cure for arthritis.

For every dollar donated to the Arthritis Foundation, more than 75 cents goes directly to fund research, advocacy and programs to help people with arthritis.

Across the country, there are more than 50 million stories of life with arthritis including that of Lena, pictured left, who was diagnosed when she was four years old, and Joe and Ann Nellis, our Annual Campaign chairs, for whom arthritis has been a part of their family life for the past 30 years.

Your annual gift will help us:

- Fund groundbreaking research by new and established scientists that could lead to new and innovative treatments and a cure.
- Raise awareness of the prevalence of arthritis and its impact on families and the nation's healthcare system.
- Connect families living with juvenile arthritis (JA) with support, information and programs that help kids manage their JA and thrive.
- Advocate for access to affordable and specialized medications.

It’s easy to make your annual gift.
Call (212) 984-8707 or email annualcampaign@arthritis.org.
You may also send a check to:
Annual Campaign • Arthritis Foundation
122 East 42nd Street, 18th Floor • New York, NY 10168

You can also create your own legacy in the form of a bequest to the Arthritis Foundation.

To receive information on how to include the Foundation in your will or trust, call Ken Kirby toll-free at 1-866-872-7319 or by email at kkirby@arthritis.org.

The Nellis Family