

# update



Programs, events and news in New York,  
New Jersey and Eastern Pennsylvania

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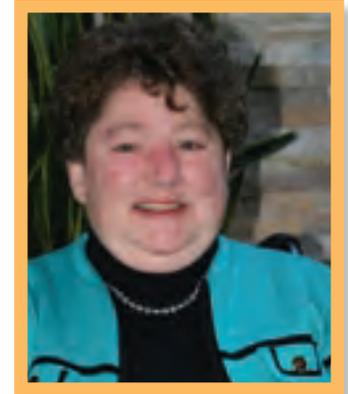
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## Champion of Yes!

**L**ynne Enman had been hearing the word “no” since she was 11 years old and diagnosed with juvenile arthritis (JA). “No” to the marching band, “no” to music school, and when she was older, “no” to working.

But her parents and grandmother thought otherwise and thanks to their belief in Lynne’s power to say “yes,” she went on to be a classically trained musician and enjoyed a career in the music industry.

Years later when her arthritis meant she needed to use a wheelchair, Lynne had to advocate for herself in a new way. “When you deal with health care and insurance, you hear ‘no’ a whole lot, but the advocate in me was born a long time ago,” Lynne said.



Lynne Enman

## Meet more of our Champions of Yes



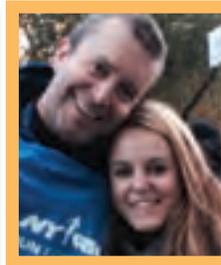
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Three years ago, Lynne came to the Arthritis Foundation to lend her voice, passion and commitment as an advocate for others living with arthritis. She has since shared her story with elected officials in their local offices, at the state capitol and in Washington, DC, to increase funding for arthritis research and improve access to care and critical medications.

Recently, Lynne was one of the few consumers in the country selected by the U.S. Department

of Defense’s Congressionally Directed Medical Research Program (CDMRP) to assist with reviewing medical research proposals to help determine which proposals receive federal funding.

“We need research to find a cure and I felt the CDMRP was the most intimate way that I could get involved in helping with research,” Lynne said. “It is just about one of the most fulfilling experiences that I’ve had so far in my life.” 



# SPOTLIGHT ON RESEARCH

## Inspired Science from Young Investigators

**T**he Arthritis Foundation funds pioneering researchers with innovative ideas that have the potential to move arthritis research in new directions.

In April, three of these funded researchers will present their findings at the Foundation's research forum in New York City. They include: Yu Grace Qiao, PhD, Hospital for Special Surgery; Wenzhao Meng, PhD, University of Pennsylvania Medical Center; and Tanisha Jackson, PhD, Feinstein Institute for Medical Research, Northshore-LIJ Health System.

Stephen I. Katz, Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIH, and Jose U. Scher, MD, Assistant Professor of Medicine, Director, NYU Psoriatic Arthritis Center, NYU School of Medicine, will also be featured. 



Yu Grace Qiao



Wenzhao Meng



Tanisha Jackson

## Arthritis Foundation Research Forum

Thursday, April 23, 2015  
6 - 8:30 p.m.

NYU Langone Medical Center  
New York, NY

To learn more, visit [arthritis.org/new-york](http://arthritis.org/new-york). To receive a special edition of our *Spotlight on Research* newsletter that highlights the findings, email us at [info.ny@arthritis.org](mailto:info.ny@arthritis.org).

## Champion of Yes: Marsha Laufer

OA fuels her commitment to scientific discovery

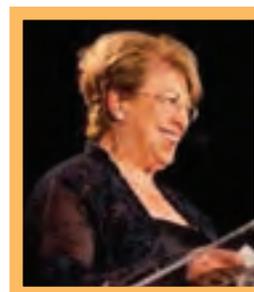
**M**arsha Laufer, PhD, has spent her life staying active—exercising daily while working in her private practice in speech-language pathology, teaching at Stony Brook University on Long Island and maintaining a busy schedule as a political activist, volunteer and philanthropist. Since developing osteoarthritis (OA) over 20 years ago, she has used a range of pain control interventions to maintain an active lifestyle for as long as possible.

Following hip replacement surgery in 2013, she and her husband, Henry Laufer, consulted with Jonathan Lee, MD, an orthopedic surgeon and family friend who told them about the Arthritis Foundation's ACL Feasibility Study. They

became very interested in the study's potential to discover biomarkers that could detect OA at its earlier stages and lead to drug discovery to prevent progression of the disease. As a result, the Laufers contributed \$1 million to launch this groundbreaking study.

Although retired in 2009, staying active and involved has remained a priority for Marsha. This past September, she underwent a successful double knee replacement at JFK Medical Center in Boynton Beach, Florida.

"When to have the operation is a highly personal decision which



Marsha Laufer

I determined once the quality of my life was sufficiently compromised," she said. "My four months of pre-preparation and 13 weeks of rigorous post-operative rehabilitation were tough but invaluable to my recuperation. I am grateful to my orthopedic

surgeon, Dr. Gregory Martin, and the innovative surgical methods now available for knee and hip replacements. When I look at where science has already taken us, I firmly believe that we will continue to find more effective therapies for arthritis along with strategies to halt the disease and one day find a cure." 

# JA Camps Help Kids Be Kids

Last spring, Dawn Edgar did not think it was possible to send her 12-year-old daughter, Erin, to summer sleepaway camp. In the past year, Erin had been diagnosed with juvenile arthritis (JA) and went from being a girl who danced, played basketball, and had earned her green belt in karate to a girl who could barely walk down the stairs.

“Erin was finally getting better, but she was still afflicted by the disease and had pain,” said Dawn. “Considering her medication schedule and daily needs, a sleepaway camp definitely wasn’t in the picture.”

But while attending an Arthritis Foundation event, the Edgars met a young woman who told them about her rewarding time at a JA camp, so the family decided to give it a try.

“It turned out to be a wonderful experience for Erin,” said Dawn. “She had fun and met other kids her age who understood what it is like to live with arthritis. The medical team is on site so I knew she was taking her medicine and that she wouldn’t feel like she was the only one going to the nurse.”

JA camp is a five- or six-day residential camping experience for kids ages 6-18 who are living with arthritis or other rheumatic diseases that require the care of a rheumatologist.

Our JA camps, based in New York, New Jersey, and central Pennsylvania, offer kids with arthritis a place to have fun, make new friends and learn how to take control of their disease.

Financial assistance is also available. Camp slots fill quickly so be sure to register early. 🏕️

“The counselors understood my disease, like if I needed to rest...and I met other kids my age who know what it is like to live with the pain, the treatments, bloodwork, and ongoing doctor visits that go with arthritis.”

**Erin Edgar**  
Camper

## JA Summer Camps

**Camp JRA, Millville PA — July 19-24, 2015** (for campers ages 8-18)  
**Contact:** Sheila Brown at (267) 238-9729 or [SBrown@arthritis.org](mailto:SBrown@arthritis.org)

**Camp CHAT, Hackettstown, NJ — July 19-24, 2015** (for campers ages 8-17)  
**Contact:** Peggy Lotkowitz at (856) 673-1365, or [PLotkowi@arthritis.org](mailto:PLotkowi@arthritis.org)

**Double H Ranch, Lake Luzerne, NY — August 4-9, 2015** (for campers ages 6-16)  
**Contact:** Aicha Diallo-Bennett at (212) 984-8713 or [ADiallobennett@arthritis.org](mailto:ADiallobennett@arthritis.org)

Our 2015 JA summer camps and camp scholarships are made possible by the generosity of these major sponsors:

- The 2015 Laurence Polatsch Memorial Scholarship Fund for JA Camps
- The Hummingbird Foundation
- Independent Order of Odd Fellows
- Charles and Mildred Schnurmacher Foundation



# Every Step Counts in Finding a Cure

**R**enee Cafaro began experiencing serious pain when she was 11 years old. It took her almost 10 years to receive a confirmed diagnosis: fibromyalgia, with a secondary diagnosis of seronegative arthritis of the tendons.

Having a diagnosis was a relief for Renee and allowed her to finally speak about her disease – and speak out for others too. Today, Renee, who lives in New York City, is the National Adult Honoree of the 2015 Walk to Cure Arthritis. This spring, Renee and tens of thousands of people in more than 115 communities across the country

will walk to raise funds and awareness about the toll that arthritis takes on people's lives and the economy.

With every individual and team who walk the 5K or 1 mile course, there is a story of struggle, support and hope.

Launched every May in conjunction with Arthritis Month, the Walk to Cure Arthritis, is a full morning of festivities that brings together families, individuals, teams, and the corporate and medical community to raise awareness of the prevalence of arthritis and the critical need to discover a cure. ♻️



**Renee Cafaro**

National Adult Honoree, 2015 Walk to Cure Arthritis



The Walk to Cure Arthritis is taking place in these communities this Spring.

**New York**

**Albany** May 17

[www.walktocurearthritis.albany.kintera.org](http://www.walktocurearthritis.albany.kintera.org)

**Hudson Valley** May 2

[www.walktocurearthritis.hv.kintera.org](http://www.walktocurearthritis.hv.kintera.org)

**Long Island** May 16

[www.walktocurearthritis.li.kintera.org](http://www.walktocurearthritis.li.kintera.org)

**New York City** May 16

[www.walktocurearthritis.nyc.kintera.org](http://www.walktocurearthritis.nyc.kintera.org)

**Rochester** May 30

[www.walktocurearthritis.rochester.kintera.org](http://www.walktocurearthritis.rochester.kintera.org)

**New Jersey**

**Bergen County** May 31

[www.walktocurearthritis.bergen.kintera.org](http://www.walktocurearthritis.bergen.kintera.org)

**Essex County** June 7

[www.walktocurearthritis.verona.kintera.org](http://www.walktocurearthritis.verona.kintera.org)

**South Jersey** May 2

[www.walktocurearthritis.sj.kintera.org](http://www.walktocurearthritis.sj.kintera.org)

**Eastern Pennsylvania**

**Philadelphia** May 31

[www.walktocurearthritis.philly.kintera.org](http://www.walktocurearthritis.philly.kintera.org)

# Our Walk Champions

## Meet Dr. Neil Cobelli, Medical Honoree, New York City Walk to Cure Arthritis

Dr. Cobelli is chairman of the Department of Orthopaedic Surgery at Montefiore Medical Center and the Einstein College of Medicine and a renowned expert in the field of joint reconstruction of the hip and knee. He recently spoke with the Arthritis Foundation about his role as this year's New York City Walk Medical Honoree.



### The Arthritis Foundation is thrilled that you are our 2015 Walk Medical Honoree. What excites you most about this honor?

I have been treating patients with arthritis for over 30 years. I am excited for the opportunity to give back on a larger scale through the Arthritis Foundation.

### What has the reaction been of the doctors and staff at Montefiore?

The reaction of my colleagues and the team at Montefiore has been heartwarming. The staff has offered their congratulations and told me that they are thrilled and proud that the Arthritis Foundation is honoring me as Medical Honoree.

### You've participated in the Walk to Cure Arthritis before. What has stood out the most for you?

I was astounded by the number of people who came out to walk the Brooklyn Bridge in support of the Arthritis Foundation. I had never walked the Brooklyn Bridge and it was very moving to be walking with so many people who want to make a difference. The day was beautiful and is one I will not forget.

### As a doctor, what kind of advances in the field of orthopaedics do you see ahead?

As an Orthopaedic Surgeon, the

treatments that I offer are surgical, meaning that every other preventative measure has failed. The advancement that I look forward to is identifying the immunological and biochemical underlining causes of arthritic degeneration. I hope that we will identify the cause of arthritis and will be able to intervene early on to prevent treatment. Ideally, I hope that research will put Orthopaedic Surgeons out of business. 🏠



## Jonah Fawer, Youth Honoree, Essex County, NJ

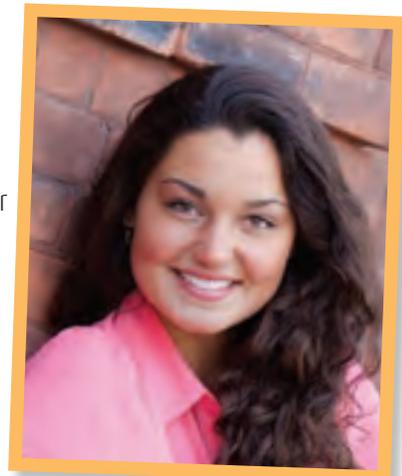
Jonah started experiencing symptoms of JRA when he was 3 years old. By age 12, he was afflicted with arthritis in his hands and feet, vertebrae, and jaw. Thanks to medication and

surgery (he has had two surgeries and has one more to come), Jonah now lives with very little pain. Currently a junior in high school, Jonah enjoys participating in sports and other extracurricular activities. He is looking forward to driving and going to college. 🏠

## Ryenn Sanger, Youth Honoree, Rochester, NY

Ryenn had to quit softball in elementary school because she couldn't run the bases due to her juvenile ankylosing spondylitis. Despite the ups and downs of medications and treatment, what Ryenn remembers the most is the care she received from her medical team.

"Never before have I met such a compassionate, caring team who wanted to help me be pain free," she says. Today Ryenn runs, plays field hockey at college and keeps working on her health. "Even though I've had days where I feel worse than I think I should, this journey has made me grateful for the ongoing research and medications that have become available because of it." 🏠





# Advocacy in ACTION

Fighting for People with Arthritis

## Foundation Protects CDC Arthritis Program

The Arthritis Foundation led an effort among coalition partners to restore a vital arthritis program within the Centers for Disease Control and Prevention for fiscal year 2015. The Senate had released a bill that zeroed out the only federal program devoted specifically to

arthritis. It provides funding in 12 states, including New York and Pennsylvania, to connect people with arthritis to evidence-based resources and programs to help them manage their disease. It also provides technical assistance to all 50 states. "Preserving the program is

critical to ensuring there are dedicated federal resources for people with arthritis," said Michele Disken Greco, Regional Director for Advocacy and Programs. "We will continue to fight for the program to ensure it remains a vital resource," she said.

## Champion of Yes: Mark Haubner Putting a face on arthritis for policy makers

**G**rowing up, Mark Haubner, of Aquebogue, NY, knew that osteoarthritis (OA) ran in his family. His mother had OA. His grandmother struggled with severe OA, and his great grandmother was confined to a wheelchair because of OA when she was in her early 60s.

But it was still a surprise when Haubner was stricken with OA in his early 40s and needed a hip replacement at age 44.

"Arthritis is the reason I had to give up my job," Mark said. "It's the reason I can't pick up a pen. But still, there is a perception that arthritis is supposed to happen to people."

In 2002, Mark began volunteering with the Arthritis Foundation to help others living with the disease. He has worked with local media on segments about arthritis. He talks one-on-one to

people who need information and support. And he has become a local voice for arthritis with elected officials.

Over the years, Mark has been State Advocacy Coordinator and a member of the Foundation's National Public Policy Committee. He has testified before the Senate Appropriations Committee's Subcommittee on Defense on the importance of preserving funding for arthritis research in the Department of Defense budget.

"Testifying before the Senate Appropriations Committee is by far the high spot in my life as an advocate," Mark said. "Research is critically important. Imagine if we could discover biomarkers to find out if my daughter has a predisposition for OA so we can

make adjustments in her life now."

Mark was recently selected to receive the 2014 Edward M. Kennedy Advocacy Leadership Award, the Foundation's highest honor that recognizes distinguished public service and advocacy. He was honored at the Foundation's Annual Advocacy Summit in Washington, DC, this spring.

"Helping policy makers understand the toll the disease takes on people's lives and the economy is essential to securing funding for research and a cure," he said.



Mark Haubner testifies before Congress

E-Advocates are our most powerful weapon against laws and regulations that create barriers for people living with arthritis. Join our network of 65,000 advocates by visiting [www.arthritis.org/advocate/join-the-movement](http://www.arthritis.org/advocate/join-the-movement).

## Arthritis Foundation Local Offices

### Northeast Region and New York City Office

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New York, NY 10168  
(212) 984-8700  
[Info.ny@arthritis.org](mailto:Info.ny@arthritis.org)

### Offices:

#### New York State

[www.arthritis.org/new-york](http://www.arthritis.org/new-york)

#### Northeastern New York

855 Route 146, Suite 170  
Clifton Park, NY 12065  
(518) 456-1203  
[Info.neny@arthritis.org](mailto:Info.neny@arthritis.org)

#### Long Island

150 Broadhollow Road, Suite 222  
Melville, NY 11747  
(631) 427-8272  
[Info.li@arthritis.org](mailto:Info.li@arthritis.org)

#### Upstate New York

3300 Monroe Avenue, Suite 319  
Rochester, NY 14618  
(585) 264-1480  
[Info.uny@arthritis.org](mailto:Info.uny@arthritis.org)

#### Eastern Pennsylvania

[www.arthritis.org/eastern-pennsylvania](http://www.arthritis.org/eastern-pennsylvania)  
111 South Independence Mall East  
Suite 500  
Philadelphia, PA 19106  
(215) 574-3060  
[Info.epa@arthritis.org](mailto:Info.epa@arthritis.org)

#### New Jersey

[www.arthritis.org/new-jersey](http://www.arthritis.org/new-jersey)  
555 Route 1 South, Suite 220  
Iselin, NJ 08830  
(732) 283-4300  
[Info.nj@arthritis.org](mailto:Info.nj@arthritis.org)

#### Arthritis Foundation Thrift Shop

1430 Third Avenue  
(Between 81st and 82d Streets)  
New York, NY 10028  
(212) 772-8816  
Store Hours:  
Monday – Saturday, 9 a.m. – 6 p.m.

## Champion of Yes: Running for a Reason

Each year, tens of thousands of people train with purpose, heart and determination to run the 26.2 mile, five-borough course of the TCS New York City Marathon. Every runner has a story and for the 25 who run on the Arthritis Foundation's TCS New York City Marathon Team, their story is about arthritis.

In 2014, Stephane Charbonnier joined the Arthritis Foundation Marathon Team for his daughter, Margaux, who was diagnosed with arthritis when she was 18 months old.

Despite having run two marathons (Washington, DC, and Chicago), the NYC marathon tested Stephane's determination more than he planned.

"I overcame so many injuries to get to that starting line," said Stephane. After recovering from a serious car accident over the summer and dealing with a knee injury, Stephane sprained his ankle just the week before the marathon. "By the night before the marathon, I still didn't know if I would be able to run."

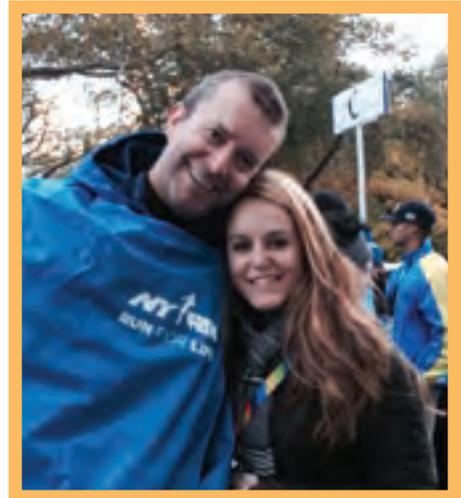
But his resolve and the support of family, friends and two million enthusiastic spectators pushed him to the finish line and led him to be the top team fundraiser, raising \$17,500.

"The connection with the crowds from the start to finish was like nothing I anticipated," he said. "You cross the bridge to Manhattan and you can hear and feel the intensity of everyone cheering for you. It literally gives you goose bumps," he said.

"I run for a reason that is close to my heart," Stephane said. "Margaux is now 17 years old, and day after day she shows great courage and resilience. I run to support research for Margaux and all children like her."

This year, the Arthritis Foundation is a New York Road Runners Charity Partner for the TCS New York City Marathon on Sunday, November 1, 2015. Running on the Arthritis Foundation Team provides guaranteed entry to the marathon. Runners need to commit to a minimum fundraising level in support of our efforts to find a cure for arthritis.

Email us at [BRoland@arthritis.org](mailto:BRoland@arthritis.org) to learn more. 



Stephane and Margaux Charbonnier



## Cake: A Painful Slice of Life

Arthritis Foundation President and CEO, Ann Palmer, joined actress Jennifer Aniston and others for a screening of the new film, "Cake," which spotlights the issue of chronic pain. Find out more at [arthritis.org/cake](http://arthritis.org/cake).



122 East 42nd Street, 18th Floor  
New York, NY 10168



# Support Our Annual Campaign

*The* Arthritis Foundation is focused on finding a cure and championing the fight against arthritis with life-changing information and resources, advocacy to ensure access to optimal care, and groundbreaking scientific research.

For every dollar donated to the Arthritis Foundation, more than 75 cents goes directly to fund research, advocacy and programs to help the 50 million people, including 300,000 children, living with arthritis.

With your support, we can help all those struggling with the disease to find their "yes."

To make your annual gift, call (212) 984-8707 or email [annualcampaign@arthritis.org](mailto:annualcampaign@arthritis.org). You may also send a check to:

Annual Campaign  
Arthritis Foundation  
122 East 42nd Street  
18th Floor  
New York, NY 10168

