

## April 2015 Board Update

### WHAT'S AHEAD?

This is the fourth issue of our monthly Board Update. Here you'll get the latest information about what's going on at the Arthritis Foundation – including highlights from our core pillars, fundraising and a short profile spotlighting a volunteer, employee, partner or someone else who is making a difference in the lives of people with arthritis. You can access these updates monthly on the Board Portal.

In this issue:

- We introduce our new brand to the world and let everyone rediscover who we are and how we will fight to conquer arthritis.
- Learn about the sale of our National Office headquarters.
- Read about the importance of regional and national fundraising partnerships.
- Get amazing news and milestones happening in each pillar.

### CONQUERING ARTHRITIS TOGETHER

We hope these Board Updates offer a transparent look into the large and small victories that help inspire us to deliver on our brand promise of being a Champion of Yes for everyone impacted by arthritis. We're happy to share our good news and hope you'll do the same!

To provide updates you would like us to share in this summary, please email Melanie Preis at [mpreis@arthritis.org](mailto:mpreis@arthritis.org).

Thank you!

## APRIL 2015 BOARD UPDATE

### CHAMPIONS CORNER

#### ***Our New Brand Launched***

It's a brand new day at the Arthritis Foundation! We've officially unveiled our Champion of Yes brand, announcing to the world that this transformation will help foster greater change, stronger impact and further reach for the people we serve every day. We will work to conquer arthritis together, with a fresh look and feel that will allow us to truly distinguish ourselves and make our presence known. **Check out the new face of [arthritis.org](http://arthritis.org)!**

We sent customized brand toolkits and a variety of helpful resources to guide staff, volunteers, partner organizations, sponsors, Advocates/Ambassadors and health care providers on launch day. Important collateral like our Mission Deck, Brand Messaging Guide and many other tools will help you, our committed Arthritis Foundation leaders, talk about who we are and what we stand for using our new voice.

Please click and bookmark the Volunteer Brand Launch Toolkit at [www2.arthritis.org/volunteerlaunchtoolkit](http://www2.arthritis.org/volunteerlaunchtoolkit) to access documents, videos, templates, imagery and other resources you may need as the Foundation embarks on this new and exciting journey. Please take a look at the [photo gallery](#) created on launch day, consisting of staff-contributed photos from around the country.

#### ***We're Moving!***

After a year-long process of pursuing options to sell the National Office headquarters at 1330 West Peachtree Street, we found a buyer. We have now signed a lease for office space at 1355 Peachtree Street, occupying the sixth floor of The Peachtree Building in midtown Atlanta. We expect the move to take place in November. We believe it will allow us to focus fully on our mission while favorably impacting the Foundation's financial position. Enhanced amenities in the new location include deck parking, on-site security and management, café, exercise facility, newsstand and sundries shop and convenient accessibility to nearby highways and public transportation stops.

#### ***Arthritis Foundation Gets Coverage on Marketplace***

National Public Radio's (NPR) "Marketplace" ran a story late last month about the recent popularity of hip surgeries. The story covered the surge of patients undergoing hip replacement surgeries in the United States, and our own **Randeep Kahlon, national board member and orthopedic surgeon, was quoted in the piece.** He spoke about how younger,

healthier people are now getting the procedure since these active individuals aren't ready to live a life with pain. To hear the "Marketplace" story in its entirety, [click here](#).

### ***Fundraising News***

**It's Walk to Cure Arthritis season!** Volunteers and staff from around the country are raising funds fast and furiously. One of our shining stars this month is Renee Cafaro, the 2015 Walk to Cure Arthritis Adult Honoree. Renee has activated teams in three states – New York, Ohio and California – and is constantly recruiting friends and family to join the effort. At the end of April, she traveled to Ohio for a fundraiser coordinated by her sister that raised more than \$50,000! Renee's success is a testament to a fantastic partnership between multiple regions and the National Office – as one big team we are more powerful!

**Jingle Bell Run/Walk website templates are live**, which means field staff are working to get the websites built. As of press time, 35 sites were already in progress, and we anticipate that number to rise dramatically throughout the first several weeks in May. We expect more than 100 Jingle Bell Run/Walk events to take place across the country in 2015.

**Alpha Omicron Pi (AOII) has doubled their financial support** of the Arthritis Foundation in 2015. Through the AOII Foundation, the sisters of AOII allocated almost \$400,000 to support the Foundation's Juvenile Arthritis Conference Scholarships and the JA Power Packs. For more than 40 years, AOII has raised millions of dollars to help individuals and families say Yes in their fight against arthritis.

### ***Volunteer Spotlight: Meaghan Victory***

Meaghan Victory is destined for greatness. Just take a look at her name – she's a born Champion of Yes.

After receiving a diagnosis of juvenile arthritis at the age of 9, Meaghan could have spent her time focusing on treatments and therapies. Her own disease. Her own life. No one would think any less of a child, or any patient for that matter, tending to their own pain and trying to lead a normal life.

But that's not the path Meaghan took. Instead, she turned her attention to advocacy – her cause was, and still is, to conquer arthritis. She started attending Advocacy Summits, participating in Arthritis Foundation walks and other events, and bringing in money as a powerful fundraiser; she was the nation's top individual fundraiser in 2010. Meaghan has served as the captain of TEAM VICTORY, a Jingle Bell Run/Walk team, which has been active for more than seven years. TEAM VICTORY has raised over \$75,000 and recruited more than 600 runners!

"Over the years, the Arthritis Foundation has given me the opportunity to advocate for myself and everyone else on this same journey," she says. "I knew these small opportunities were a great way of helping our common cause. They have given me the chance to have my voice heard and become a go-getter. They've also assisted me in being more confident and not to be afraid to speak up and share my story."

Meaghan is definitely all-in when it comes to fighting arthritis on every front. The now 19-year-old, from Issaquah, WA, is a camp counselor at [KAT-FISH](#), a place for kids and teens with arthritis to develop leadership skills, increase self-confidence and make friends. She gives speeches at Arthritis Foundation events and was a presenter at Rheumapalooza, a rheumatology course that helps give second year medical students at the University of Washington a sense of the personal impacts arthritis makes.

And on top of all that, plus participating in multiple research studies, plus talking with her elected representatives about joining the Bicameral Congressional Arthritis Caucus, Meaghan is a nursing student at Gozanga University. She wants to give the same genuine care to her patients like she has received over the years.

Sure, Meaghan has bad days like everyone else living with arthritis. In fact, she was ill from the side effects of her arthritis medication the night she was to accept the 2015 Emerging Leader in Advocacy Award in Washington, DC. Her father stepped in and lovingly read her acceptance speech. But this Champion of Yes doesn't let the bad days overshadow the good ones.

Meaghan's motto is: "Failure will never overtake me if my determination to succeed is strong enough."

"Actively doing things to get the word out about arthritis and promoting our cause as much as possible is so vital," she says. "We are not just helping ourselves, but giving a better life to everyone who will be diagnosed. A pain-free world sounds pretty cool to me."

## STRATEGIC PILLARS IN ACTION

### **Scientific Discovery**

- **The Arthritis Foundation Registry Workshop – *Improving Health Outcomes for People with Arthritis*** – will convene May 13-14 in Atlanta. This is an interactive workshop to kick off building an international community of data collection and analysis experts for arthritis and related diseases. Recommendations from the workshop will determine

what actions the community wants to work on together. Workgroups will be formed to implement the recommendations, and we hope to have a second workshop next year. Experts are participating in person, through WebEx and by providing contributions via email and telephone. Bristol-Myers Squibb is a sponsor of this event.

- **More than 200 proposals are in the process of being submitted** via Proposal Central in response to the 2015 Delivering on Discovery Request for Proposals (RFP). This RFP includes a proposal template and evaluation criteria that will result in accelerated submission and review processes. The proposal submission deadline is May 12.
- **The Building Human Capital Workgroup convened its first meeting** on April 1. Members of this workgroup bring expertise in translational sciences, the patent process, venture philanthropy, proposal writing for arthritis and related diseases, research and other important human capital topics. The workgroup is identifying existing curriculum and suggesting speakers to teach the curriculum.

### ***Advocacy and Access***

- **We have been very busy working with our pediatric subspecialty coalition** on the introduction of HR 1859, Ensuring Access to Pediatric Subspecialists Act. This bill would recognize pediatric subspecialists as eligible for the National Health Service Corps, which provides loan repayment and scholarships to medical students and residents in exchange for practicing in rural and underserved areas. We also led the Coalition for Accessible Treatments Hill Day on April 16, to increase support for the Patients' Access to Treatments Act (PATA). Coalition staff met with more than a dozen representative offices to build co-sponsorship for PATA.
- **We hosted a Capitol Hill briefing on access to care issues**, in cooperation with the Arthritis Caucus. The briefing featured two patient speakers, including Mid Atlantic board member Margo Diehl. More than 60 people were in attendance, including representatives from more than 20 Hill offices. Margo and board chair Michael Ortman met with the Energy and Commerce Committee press secretary to tell her story about living with juvenile arthritis in support of the 21<sup>st</sup> Century Cures legislation being drafted.

- **The American College of Rheumatology has agreed to support our legislative initiative to seek designated Department of Defense (DOD) arthritis research funding and increase Arthritis Caucus membership. Additionally, we supported legislation enacted in Arkansas regarding prior authorization and insurance transparency; in South Dakota on insurance transparency; and in Colorado on biosimilars.**
- **We hope you will join our upcoming biosimilars presentation on Monday, May 11, at 3 p.m. ET, with Dr. Harry Gewanter, a pediatric rheumatologist, and Mark Guimond, director of State Legislative Affairs. They will cover why this treatment is important to people with arthritis and the role legislatures and regulators play as they prepare to go to market. This presentation is by WebEx only but will be recorded. Interested board members can contact Laura Keivel, at [lkeivel@arthritis.org](mailto:lkeivel@arthritis.org) or 202-887-2913.**
- **Please mark your calendars! We are pleased to announce that the 2016 Advocacy Summit will be held March 14-15 at the Crystal Gateway Marriott, in Arlington, VA.**

### ***Juvenile Arthritis***

- **In April, the Arthritis Foundation announced our JA Conference scholarship awardees, selected through our new centralized scholarship process. This year, 461 scholarship applications were reviewed and scored by a panel of Foundation staff and volunteers from across the country. We were able to grant 246 scholarships, representing almost double the number of families awarded – and the total dollars allocated – in previous years. Also new this year was a nationwide incentive program for families who raised over \$5,000 through our signature special events in 2014 to receive either complimentary registration or complimentary registration and lodging; 41 families accepted these rewards. We're expecting a record number of attendees this year in Orlando – 700 children have already registered!**
- **The JA Conference planning committee and chairs have been hard at work the past six months. A special thank you to Andrea Jones, Rochelle Lentini and Liz Smith for their tireless dedication and efforts in planning the 2015 JA Conference. Featured guests this year include Ana Villafane, recording artist and movie star who will be performing during our opening dinner; NASCAR driver Todd Peck with his Arthritis**

Foundation-branded racing truck to entertain the kids; and Joy Ross, who will speak at our closing session.

- **Work is well underway for Know SJIA**, a new special Web section specifically for families of kids with systemic juvenile idiopathic arthritis. Know SJIA will launch on KidsGetArthritisToo.org this summer, providing important resources for families dealing with this rare and serious subtype of juvenile idiopathic arthritis (JIA), which impacts about 20 percent of children with JIA and is more challenging to diagnose and treat. The new Know SJIA section features in-depth educational information about SJIA, a print-ready symptom tracker tool for parents to complete and share with their child's doctor, and an opportunity for parents to email their questions to four experienced Arthritis Foundation parent volunteers.

### **Help & Support**

- **On April 29, the Better Living Toolkit went live**, available for order by consumers. The toolkit is packed with powerful information and resources including a welcome letter, disease-specific brochures, an arthritis.org resource guide, Track+React promotional card, *Arthritis Today* magazine, Health Tracker (based on the RAPID 3 assessment tool) and jar opener. A version featuring the Managing Your Pain brochure and 2015 Drug Guide, in place of the health tracker, is also available, targeting patients with osteoarthritis. In advance of the launch, promotional rack cards and posters were sent to regional offices. Three training webinars prepared staff with model practices for sharing the kit with health care professionals and following up with consumers who place orders. The free kit can be ordered via [www.betterlivingtoolkit.org](http://www.betterlivingtoolkit.org) or 800-283-7800.
- **Content previously on [arthritis.org](http://arthritis.org) has been updated** and moved to the new arthritis.org website, in conjunction with the launch of our new brand. The more user-friendly layout allows visitors to easily access all of the relevant information and resources to help them live better with arthritis. Now, visitors can find *Arthritis Today* digital content in "About Arthritis" and "Living with Arthritis" on the website, as well as in our new blog. Content includes articles, as well as tips and tools on topics like pain management, treatments and diet and exercise.



- The May-June issue of *Arthritis Today* is in homes and on newsstands now, featuring several powerful stories of Yes, including a cover profile on Joy Ross and her family. Learn how she beat back blindness from arthritis and is a superstar for our cause. Visit the homepage of the new [arthritis.org](http://arthritis.org).