



# Advocacy in ACTION

Fighting for People with Arthritis



**Advocacy in Action**  
**Volume 1, Issue 8**  
**December 16, 2014**

## **Thank You for Your Support!**

Dear Advocates,

2014 has been an exciting year for the Arthritis Foundation's Advocacy and Access Department! We have continued to be the voice of people with arthritis and are expanding our legislative activities at both the state and federal levels. We're also interacting with employers, letting them know what is happening with access to care challenges for people with arthritis..

In addition to creating six legislative [policy positions and issue briefs](#) – on out-of-pocket costs, biosimilars, step therapy, formulary transparency, prior authorization and narrow networks – we have also created model legislation that will be introduced in several states to limit prescription co-pay amounts and step therapy. In 2014 we have already seen success on these issues, with Delaware, Louisiana and Maryland capping the co-pay on medications, and Connecticut eliminating step therapy requirements at the request of a physician.

The Arthritis Foundation will continue working with other national chronic disease organizations to develop consistent policy positions on access to care issues that will be debated in state legislatures in 2015. A unified patient voice is essential as we lobby for patient safeguards at the state level. And, we will be calling on you, our trusted advocates, to

---

help us make the case that these bills are necessary.

You can make a big difference in our campaign to raise awareness by telling your personal stories to elected officials in state capitals and to federal policymakers. Personal stories are the most compelling form of persuasion. We'll need your ongoing support to ensure that lawmakers take into account the needs of people with arthritis as they develop policies that affect access to care.

In addition, we need your help to grow membership in the Congressional Arthritis Caucus, and [to ask your friends, family and co-workers to become E-Advocates](#), so that we can grow our community of people who support access to care for people with arthritis.

We're grateful for your continued support and look forward to working with you in 2015. We wish you and your family a very happy holiday season!

Sending my best,

Sandie Preiss  
Vice President, Advocacy and Access  
Arthritis Foundation

### **Arthritis 101 Capitol Hill Briefing**

A special thank you to our advocates for reaching out to members of Congress in our recent Arthritis 101 Hill Briefing! Fifteen House of Representatives offices and 20 Senate offices attended the briefing. The physician/patient panel did a great job of discussing the impact that arthritis has on every aspect of a person's life, and how difficult it can be to get the right diagnosis and treatment. The patient and provider panel included Arthritis Foundation board member Jan Wyatt, juvenile arthritis patient Margo Diehl, pediatric rheumatologist Dr. Harry Gewanter and orthopedic surgeon Dr. Deep Kahlon. Ms. Diehl, a college student, spoke about having to take 45 pills a day to remain functioning, and finding the right treatment is still a work in progress.

The Arthritis Caucus staff panel did a great job of articulating what the caucus is and why members of Congress should join. The take away for everyone was: We need more research, more pediatric rheumatologists, better access to treatments for patients, and we need to focus on our military and veterans populations, who have higher rates of arthritis and worse health outcomes than civilians. [Click here to see a list of the attendees](#) and please be sure to send a

---

thank you note if your legislators' staff attended! [Please click here for a sample thank you note.](#)

### **Arthritis Foundation Acts to Protect the CDC Arthritis Program**

The 2015 funding bill Congress released on Dec. 10 restores a vital arthritis program within the Centers for Disease Control and Prevention (CDC). The Arthritis Foundation took action this summer when we learned that the draft budget had zeroed out funds for this program. This is the only federal program devoted specifically to funding a number of states to connect people with arthritis to resources and programs to help manage their disease.

### **Advocacy Awards Announced**

The Arthritis Foundation is pleased to announce the winners of the Edward M. Kennedy and Emerging Leader advocacy awards! The Kennedy winner is a tie, with Mark Haubner of Aquebogue, NY, and Hanna Gruen of Pittsburgh, PA, winning the honors. Mr. Haubner has been active in advocacy for over 10 years and enjoys building relationships with his legislators and assisting with regional advocacy trainings. Ms. Gruen has been advocating with the Arthritis Foundation for more than 50 years, has built robust relationships with her legislators, and was able to persuade her congressman to sign on to the Patients' Access to Treatments Act. Both award winners are true champions of advocacy and we congratulate them on winning this prestigious award!

The Emerging Leader in Advocacy Award winner is Meaghan Victory of Issaquah, WA. As an advocate, Ms. Victory fosters relationships with her legislators and even convinced Sen. Maria Cantwell to join the Congressional Arthritis Caucus. She is currently in nursing school at Gonzaga University and never lets arthritis stop her from achieving her goals.

All winners will be honored at the Advocacy Summit Awards Dinner on March 23 in Arlington, VA.

### **U.S. Department of Health and Human Services Partners With Arthritis Foundation**

Through a partnership with the Department of Health and Human Services (HHS), the Arthritis Foundation is helping constituents without insurance by having HHS staff answer questions and provide information at many Jingle Bell Run/Walk sites throughout the country.

If you have questions about the insurance exchanges, be sure to check out the booth at your

---

local Jingle Bell Run/Walk. If there's not an event in your area and you would like to learn more, visit [www.healthcare.gov](http://www.healthcare.gov) for additional information.

### **Storybanking Opportunity on Insurance Purchased Through the Exchanges**

Have you purchased health insurance through open enrollment in the federal exchanges? The Community for a Healthy Exchange wants to hear your stories! The Community for a Healthy Exchange is committed to providing support for people who purchased insurance through a health insurance marketplace or exchange. The project serves as a resource for anyone having issues with access to care and other services with insurance purchased through the exchanges. Sharing your personal story is important because it brings to light any issues with the exchanges, shows how many people are affected by them, and what can be done to resolve them. If you would like to share your story, [please visit the website here.](#)

*This is a publication from the Arthritis Foundation Advocacy and Access Department  
For questions, please contact us at [advocacy@arthritis.org](mailto:advocacy@arthritis.org)*

