



Advocacy in ACTION

Fighting for People with Arthritis



Advocacy in Action

January 30, 2015

Volume 2, Issue 2

Arthritis Foundation Fights for Patient Protections in Research

Earlier this month, the Arthritis Foundation signed onto a letter urging the Obama administration to strengthen the rules on patient protections, particularly for those who participate in research that evaluates treatments recognized to be standards of care for treating diseases. 108 advocacy groups who signed the letter share our belief that the current draft rule would harm, not help, patients, and would create barriers to current and future care delivered from research studies. The Arthritis Foundation firmly believes individuals participating in clinical research projects should be made aware of the goals and purpose of the research study so they can make a more informed decision about their participation.

Congress Prepares to Introduce Landmark 21st Century Cures Legislation

Representatives Fred Upton (R-MI) and Diana DeGette (D-CO) will soon introduce landmark legislation that changes the way medical research is conducted. Currently, there are over 7,000 known diseases, and only 500 have cures and treatments. Arthritis is one of the many diseases with no cure, and even the best treatments can have severe side effects.

Researchers, clinicians and patients alike agree that the current system of conducting research is overly complicated and delays vital progress on treatments and cures. This legislation will work to close the gap between the needs of science, regulatory burdens and patient safety requirements.

Reps. Upton and DeGette outlined several areas the legislation will address, including:

- updating the clinical trials system
- doing a better job of integrating patient perspectives
- promoting better clinical information sharing and access

- investing in the future generation of scientists
- driving the development of new drugs and devices for unmet needs

The Arthritis Foundation has provided written comments and engaged in personal meetings with the members of Congress and their staff members writing this groundbreaking legislation. Once the bill is introduced, we will share more detailed information and ask you to contact your member of Congress to advocate for the key provisions affecting people with arthritis.

Arthritis Foundation Testifies in Idaho: “Put Patient Safety First”

Mark Guimond, the Arthritis Foundation’s Director of State Legislative Affairs, testified before the Idaho House of Representatives’ Health and Welfare Committee on the important issue of biosimilar substitution. (Note: the Arthritis Foundation believes that any substitution with a biosimilar should be communicated to the prescribing physician and entered into the patient’s pharmacy and health records.) [A copy of the Foundation’s policy paper can be viewed here](#). Listen to Guimond’s testimony from the January 19 meeting [here](#), starting at 32:05. Please select House Standing Committees > Health & Welfare > January 19.

Join Us for the 2015 Advocacy Summit

Register now for the Arthritis Foundation’s [2015 Advocacy Summit](#) – the ultimate advocacy experience! The Summit will be held on Monday, March 23, and Tuesday, March 24, at the Double Tree Crystal City in Arlington, VA. Attendees will have the unique opportunity to hear from policy experts, advance their advocacy skills, connect with other advocates and meet with their legislators. Also, for the first time ever, **registration is free!**

A special room block is available at the Double Tree by mentioning the Arthritis Foundation Advocacy Summit when you call for a reservation. Single and double rooms are \$219 a night, and triple and quad rooms are \$229 a night. The room block ends February 13, 2015!

Want to learn more? [Visit the Advocacy Summit website!](#)

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

