

February 3, 2015

The Honorable Fred Upton  
2183 Rayburn House Office Building  
Washington, DC 20515

Dear Chairman Upton:

As you work to introduce and pass the 21<sup>st</sup> Century Cures legislation, the undersigned organizations urge you to address medication access and affordability issues by including the Patients' Access to Treatment Act (PATA) in the final bill. We applaud your effort to improve the discovery, development and delivery of medical treatments and cures. Based on the roundtables and hearings the Committee has held over the last eight months on the 21<sup>st</sup> Century Cures Initiative, we know you are well aware that if patients cannot access these treatments and cures, the discovery and development you seek to foster and accelerate will not deliver the benefits to the very people they are intended to help.

Your draft legislation goes a long way towards including patients in the bio-medical research process and addressing issues around chronic disease, such as creating a framework at FDA to better incorporate patient experiences in the drug development process, and authorizing a longitudinal study to improve the outcomes of people with chronic diseases. We believe inclusion of PATA will help address access and affordability of medications, and satisfy this important pillar of the research continuum.

Accessing affordable medications is vital for those with such chronic, disabling and often life-threatening conditions as multiple sclerosis, rheumatoid arthritis, psoriatic arthritis, lupus, cancer, HIV, and primary immunodeficiency diseases. Studies show that the higher the out-of-pocket costs, the less likely patients are to take their medications on time, if at all. Foregoing medications often results in disability and other health complications that can lead to poor long-term health outcomes and increase health costs.

Breakthroughs in new medications such as biologic drugs are helping people with chronic diseases lead productive lives. These medicines, while revolutionary, are complex to manufacture and distribute, and are often very expensive. The cost of specialty medications like biologics has pushed health insurers to use enhanced benefit design to balance access and cost. An alarming trend in today's health insurance market is the practice of moving vital medications like biologics into specialty tiers that utilize high patient cost-sharing methods. Specialty tiers commonly require patients to pay a percentage of the cost of the drug or a co-insurance that can range from 25% to 50%, costing the patients hundreds of dollars, even thousands of dollars, per month out of pocket for a single medication.

PATA, soon to be re-introduced by Representatives David McKinley (R-WV) and Lois Capps (D-CA), proposes to limit cost-sharing requirements applicable to medications in a specialty drug tier (typically Tier IV or higher) to the dollar amount applicable to drugs in a non-preferred brand drug tier (typically Tier III). This bill would greatly increase access and affordability of specialty medications, thereby reducing disability and constraining health care costs over time.

This bi-partisan legislation had over 140 co-sponsors in the last Congress, and enjoys wide support among patient and provider advocacy groups. Including PATA would not only satisfy access and affordability, but also complement many of the provisions under Title IV of the draft legislation,

particularly Rep. Gus Bilirakis's provision allowing Medicare beneficiaries to better identify the out-of-pocket costs given their treatment.

Patients need access to the cures and treatments the 21<sup>st</sup> Century Cures Initiative is intended to advance. Legislation modernizing the bio-medical research enterprise must address access and affordability issues to benefit the very people this research is intended to help. Again, we urge you to include PATA in the final 21<sup>st</sup> Century Cures legislation and we look forward to working with you to bring better treatments – and ultimately cures – to patients. Please contact Sandie Preiss at the Arthritis Foundation at [spreiss@arthritis.org](mailto:spreiss@arthritis.org) or 202-887-2910 with any questions.

Sincerely,

American Academy of Dermatology Association  
American Academy of Neurology  
American Autoimmune Related Diseases Association  
American College of Rheumatology  
American Society of Hematology  
Arthritis Foundation  
Colon Cancer Alliance  
Crohn's and Colitis Foundation of America  
Digestive Disease National Coalition  
GBS/CIDP Foundation International  
Hepatitis Foundation International  
Hemophilia Federation of America  
Hematology/Oncology Pharmacy Association  
Immune Deficiency Foundation  
International Foundation for Functional Gastrointestinal Diseases  
Leukemia & Lymphoma Society  
Lupus Foundation of America  
National Brain Tumor Society  
National Hemophilia Foundation  
National Organization for Rare Disorders  
National Psoriasis Foundation  
Patient Services Incorporated  
Prevent Cancer Foundation  
Pulmonary Hypertension Association  
Scleroderma Foundation  
Sjogren's Syndrome Foundation  
Sleep Research Society  
Spondylitis Association of America  
The AIDS Institute  
US Hereditary Angioedema Association