

February 23, 2015

The Honorable Lamar Alexander
455 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Richard Burr
217 Russell Senate Office Building
Washington, DC 20510

Dear Senators Alexander and Burr:

As you work to introduce legislation based on the Innovation for Healthier Americans report, the undersigned organizations urge you to address medication access and affordability issues by including the Patients' Access to Treatment Act (PATA) in the legislation. We applaud your effort to improve the discovery, development and approval of treatments. Based on the roundtables and hearings Congress has held over the last two years on improving the biomedical research enterprise, 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 report goes a long way towards addressing the barriers that make it difficult to bring treatments to market in a timely and cost-efficient manner. 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.

Patients need access to the cures and treatments the Innovation for Healthier Americans report seeks to advance. Legislation modernizing the bio-medical research enterprise must address access and affordability issues to benefit the people this research is intended to help. Again, we urge you to include PATA in your 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 or Kim Cantor at the Lupus Foundation of America at cantor@lupus.org 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 and Allied Diseases Association
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
Susan G. Komen
The AIDS Institute
US Hereditary Angioedema Association