

---

# COALITION FOR ACCESSIBLE TREATMENTS

---

March 25, 2015

The Honorable David McKinley  
412 Cannon House Office Building  
Washington, DC 20515

The Honorable Lois Capps  
2231 Rayburn House Office Building  
Washington, DC 20515

Dear Representatives McKinley and Capps:

The Coalition for Accessible Treatments (CAT), representing 32 patient and provider groups dedicated to ensuring all Americans have access to critical life-changing and life-saving medications, is pleased to offer this statement of support for the Patients' Access to Treatments Act (PATA). We applaud your commitment to making critical, often life-saving medications affordable for patients by addressing the issues of specialty tiers and co-insurance in the commercial health insurance market.

An alarming trend in today's health insurance market is the practice of moving more expensive drugs onto specialty tiers that utilize high patient cost-sharing methods. The patient costs for drugs in specialty tiers can reach into the thousands of dollars a month, placing medically-necessary treatments out of reach of average insured Americans. For many patients, this leads to failure to adhere to a treatment plan, which can lead to worsening disease, increased rates of disability, and rising health care costs.

Your legislation would limit cost-sharing in specialty tiers to that of the non-preferred brand drug tier, which would greatly increase accessibility and affordability of specialty drugs for patients who rely on them. The member organizations of the Coalition for Accessible Treatments recognize the importance of PATA and of making specialty drugs affordable:

"A patient's financial responsibility or cost-sharing for a prescription medication should not be so large that it inappropriately restricts or interferes with medically-necessary use of medications," says Ann Palmer, president and CEO of the Arthritis Foundation. "PATA would rein in high cost-sharing for specialty medications, enabling more patients with chronic, disabling, and life threatening conditions, such as arthritis, to access and afford the treatments they need."

*Ann M. Palmer, President & CEO, the Arthritis Foundation*

"People living with HIV have been one of the groups who have been singled out for having been subject to high cost-sharing for their medications. This has made it extremely difficult for them to afford their life-saving treatments. We applaud Reps McKinley and Capps for their leadership to address an alarming trend in the health insurance market. The bi-partisan Patients' Access to Treatment Act will go a long way toward keeping cost-sharing at an affordable level so that people with chronic illnesses can obtain the medications that their providers prescribe."

*Michael Ruppal, Executive Director, The AIDS Institute*

---

# COALITION FOR ACCESSIBLE TREATMENTS

---

“Psoriasis is a painful, chronic, noncontagious autoimmune disease without a cure, costing our society \$135 billion annually. Access to safe and effective treatments is the number one challenge for our community. Patients’ Access to Treatment Act (PATA) will lower out-of-pocket costs on vital medications, allowing millions with psoriatic disease to better manage their condition.”

*Randy Beranek , President & CEO, National Psoriasis Foundation*

“People with lupus need and deserve a full arsenal of treatments. With many new and innovative drugs for lupus in the development pipeline, these highly anticipated treatments will mean nothing if people with lupus cannot afford them. The Lupus Foundation of America is committed to ensuring people with lupus have access to life-saving treatments and fully support Congressman McKinley and Congresswoman Capps in their efforts to pass the Patients’ Access to Treatments Act.”

*Sandra C. Raymond, President and CEO, Lupus Foundation of America*

“Rheumatologists treat many patients with chronic diseases like rheumatoid arthritis that are potentially disabling and debilitating. Patients with these chronic diseases need access to the most effective therapies that can enable daily functioning and pursuit of their livelihoods. Among these therapies are innovative medications that are often very expensive. When insurers demand excessive cost sharing for these medications, the average American with a chronic disease no longer has access to affordable treatment. We are grateful to Congressman McKinley and Congresswoman Capps for their leadership in reintroducing the bipartisan Patients’ Access to Treatments Act and pledge our full support toward passage of this important bill.”

*E. William St.Clair, President, American College of Rheumatology*

“Patient Services, Inc. (PSI) has helped patients with rare and expensive chronic conditions afford their health insurance premiums and co-payments for over 25 years. Unfortunately, today we are extremely concerned that access to needed, and often life-saving, treatments is becoming more challenging for our patients because of rapidly increasing out-of-pocket costs. By providing our patients with manageable cost-sharing, the Patients’ Access to Treatment Act (PATA) will ensure access for our patients.”

*Dana Kuhn, President and Founder, Patient Services, Inc.*

“Hemophilia is a rare genetic disorder where the cost for medication can range anywhere from \$250,000 to over \$1 million annually. Bleeding disorders are treated by infusing biologics for which there are no generic alternatives and patients are dependent upon the medicine to avoid costly hospitalizations, permanent joint and muscle damage, and even death. Our patients need PATA to keep life-saving treatments affordable.”

*Kimberly Haugstad, Executive Director, Hemophilia Federation of America*

---

## COALITION FOR ACCESSIBLE TREATMENTS

---

“On behalf of individuals struggling to manage complicated, debilitating, volatile, and potentially fatal diseases of unmet need like Lupus and those who love, advocate for, and treat them, we are thrilled that the Patients’ Access to Treatments Act has been reintroduced. We commend Representatives McKinley and Capps for sponsoring this important legislation establishing essential cost-sharing safeguards that will improve access to vital therapies; in turn reducing the physical and economic impact of disease and allowing individuals to lead more productive lives.”

*Kathleen A. Arntsen, President & CEO, Lupus and Allied Diseases Association*

“The Immune Deficiency Foundation enthusiastically supports the Patients’ Access to Treatments Act (PATA) to ensure our patients with primary immunodeficiency diseases receive necessary and appropriate treatment. IDF believes that all patients, regardless of income, should have access to life saving medications. By enacting PATA into law, people with primary immunodeficiencies and other chronic or rare diseases will have access to their full range of treatments without the worry of high out-of-pocket costs.”

*Marcia Boyle, President and Founder, Immune Deficiency Foundation*

"As dermatologists we have a responsibility to speak out on behalf of our patients - many of whom suffer from debilitating skin diseases. We can no longer turn a blind eye to the financial barriers that prevent our patients from getting the life-saving, life-improving treatments they need. The Patient Access to Treatments Act is a step in the right direction to lessen the cost burden for patients."

*Mark Lebwohl, MD, FAAD, President, American Academy of Dermatology Association*

“NORD supports legislation that would limit the cost-sharing of drugs placed on specialty tiers. Specialty tiers frequently adversely affect patients with rare diseases, as orphan products are often much more expensive than drugs that are more widely used. We have seen many cases where specialty tiers prices have limited patient access to medically necessary drugs and biologics. Untreated diseases not only affect patients directly and sometimes tragically, they also can be an expensive burden to the health care system. We look forward to working in support of this important legislative effort.”

*Peter L. Saltonstall, President and CEO of the National Organization for Rare Disorders (NORD)*

---

## COALITION FOR ACCESSIBLE TREATMENTS

---

“The Hepatitis Foundation International fully supports the reintroduction of the Patients’ Access to Treatments Act (PATA). PATA is a significant piece of legislation for our constituents since these patients often present with life threatening and chronic conditions. PATA enables patient’s access to needed treatments and constrain health care costs. This allows our patients the ability to maintain daily function and raise their families---to lead as normal lives as possible. PATA offers hope through biologic drugs that prevent our patients from progressing to greater disability, more serious illness, or even death.”

*Ivonne Fuller Cameron, CEO, Hepatitis Foundation International*

“The nearly 4 million patients who suffer from Sjogren’s disease, the second most common autoimmune rheumatic disease, are suffering greatly because of the lack of systemic therapies. Companies are deeply discouraged from developing biologics that could help patients because of lack of coverage for such high-cost therapies once they would come to market.. We MUST see the barriers that prevent new therapies from coming to market removed!”

*Steven Taylor, Chief Executive Officer, Sjogren's Syndrome Foundation*

“For people diagnosed with blood cancer, high out-of-pocket costs can be crippling – and can stop people from getting the medications they need. The Patient Access to Treatments Act will help rein in these costs and give more patients access to their cancer treatments. For patients who are struggling to beat cancer and make ends meet, this change will truly be life-saving. The Leukemia & Lymphoma Society is proud to support this important legislation, and we thank Representatives McKinley and Capps for their leadership.”

*Dr. Lou J. DeGennaro, Ph.D., President & CEO, Leukemia & Lymphoma Society*

“We commend Representatives McKinley and Capps for their leadership in reintroducing the Patients’ Access to Treatment Act. This vital legislation will facilitate access to therapies for people with bleeding disorders and many others with high-cost, chronic conditions. A person with severe hemophilia can spend as much as \$350,000 annually on their treatments. As a result, ensuring access to treatments is a top priority for NHF. We will work with our colleagues in the Coalition for Accessible Treatments to garner support for this important legislation this year.”

*Val Bias, Chief Executive Officer, National Hemophilia Foundation*

---

## COALITION FOR ACCESSIBLE TREATMENTS

---

“When patients in our community utilize their pharmacy benefit to pursue therapy, they almost always find that the treatment they need is part of a specialty insurance tier. This situation creates a significant barrier to access for affected individuals and we are pleased to see that Congress is working to address this serious issue in a meaningful way.”

*Ken Singleton, Executive Director, GBS/CIDP Foundation International*

The American Autoimmune Related Diseases Association, (AARDA), support the PATA legislation. Autoimmune patients with serious diseases like multiple sclerosis, lupus, rheumatoid arthritis and Crohn’s depend on biologics for their disease management. Because of the cost of these drugs and the associated out-of-pocket cost, many patients cannot afford to access these disease altering treatments. PATA would protect patients from the burden of choosing between adhering to their treatment and being able to provide life necessities for their families.

*Virginia Ladd, President, American Autoimmune Related Diseases Association*

“While specialty drugs have revolutionized how we treat patients with blood diseases such as leukemia, multiple myeloma, and hemophilia, these drugs come with one unintended side effect: financial struggle. As our patients try to pay for these life-saving therapies, some of which can cost thousands of dollars per month, we often see them delaying or forgoing treatment, which can result in disability and other complications that lead to increased long-term health-care costs. The Patients’ Access to Treatment Act will help alleviate this financial burden on our patients by lowering out-of-pocket costs for these treatments.”

*David A. Williams, MD, President, American Society of Hematology*