



## TALKING POINTS FOR 2014 AUGUST RECESS VISITS

### Ensuring Access to Treatments for People with Lupus

**House: Co-sponsor the Patients' Access to Treatments Act (PATA) (H.R. 460)**

**Senate: Sponsor the Patients' Access to Treatments Act**

- High out of pocket costs and co-insurance associated with specialty tiers place a significant barrier to patients accessing medications, especially new and emerging therapies treating lupus.
- Specialty tiers are becoming common practice among health insurers and are reserved for high cost therapies that are very specialized with few generic or therapeutic equivalents.
- Insurance plans are now commonly requiring patients to pay a percentage, known as co-insurance, of the actual cost of the drug on the specialty tier. Co-insurance rates range from 25% to 50%.
- For a person with lupus, having access to appropriate treatments helps prevent an individual from becoming disabled, seriously ill, or dying.
- The first drug designed to specifically treat lupus was approved by the FDA in March 2011. People with lupus and their families have waited far too long for new therapies to come to market.
- Medication can allow patients to maintain daily function, remain in the workforce and raise their families.
- Lupus annually costs the nation an estimated \$31.4 billion in direct and indirect expenditures. The estimated average annual cost of lupus ranges from \$20,924 to \$62,651.
- PATA, sponsored by Representatives McKinley (R-VW) and Capps (D-CA), would limit cost-sharing requirements applicable to medications in a specialty drug tier to the dollar amount applicable to drugs in a non-preferred brand drug tier (typically Tier III) enabling patient access to treatments. Current cosponsors of [HR 460](#).

### Support funding for lupus research at the National Institutes of Health (NIH);

#### Provide \$32 billion for the NIH in FY 2015

- The NIH is the largest funder of lupus research, yet research funding for lupus has not kept pace with funding for other diseases of similar scope and devastation.
- Sufficient funding for the NIH can lead to better research into finding the causes of lupus and the discovery of safe, tolerable, and effective lupus treatments, helping to address this burden of illness.
- \$32 billion for the NIH will support and bolster basic, clinical, and translational research across the country.

- With the significant impact lupus has on virtually any organ system in the body, people with lupus and the researchers and clinicians working diligently to help them urgently need the NIH and Congress to provide sufficient funding to bolster research at all Institutes.
- Even in an environment where difficult choices need to be made about spending, we need to ensure that lupus is a priority.
- In FY 2013, 14 of the 27 NIH Institutes funded lupus research, demonstrating the broad reaching scope of the disease and the need for lupus research that cuts across multiple disciplines and scientific arenas.
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### **Join the Congressional Lupus Caucus (U.S. House of Representatives ONLY)**

- The Congressional Lupus Caucus was founded in the U.S. House of Representatives in February 2012.
- The Caucus is led by Representatives Tom Rooney (R-FL), William Keating (D-MA), Ileana Ros-Lehtinen (R-FL), and Jim Moran (D-VA).
- To date, 55 Representatives have joined the Caucus.
- The purpose of the Caucus is to provide a forum in which members of Congress can actively engage in a dialogue to improve the quality of life for people with lupus and their loved ones through supporting the advancement of lupus research and increasing awareness of lupus among the public and health professionals.
- Please contact Andrew Callahan ([andrew.callahan@mail.house.gov](mailto:andrew.callahan@mail.house.gov)) with Representative Rooney or Sonya Sperry ([sonya.sperry@mail.house.gov](mailto:sonya.sperry@mail.house.gov)) with Representative Keating to join.
- Caucus Member [Roster](#)