

RARE DISEASE CAUCUS

Let **YOUR** representative know **RARE** diseases are important to **YOU**

Encourage Your Representative to Join Rare Disease Caucus

U.S. Representatives Joseph Crowley (D-NY) and Fred Upton (R-MI) have formally announced the newly-established Rare and Neglected Diseases Caucus. As co-chairs of the Caucus, Crowley and Upton will focus on

- Bringing Congressional attention to the 6,800 known rare diseases that currently have no approved therapies
- Ensuring sufficient funding for research and orphan product development
- Exploring ways to incentivize companies to create new drugs, biologics and humanitarian use devices and
- Providing an opportunity for Members of Congress, families and advocacy groups to exchange ideas and policy concerns

Both Crowley and Upton are looking to you to encourage your Representative to become a member of this important Caucus.

Call the U.S. Capitol Switchboard at (202) 224-3121 today and ask to be connected to your Representative's office. If you're not sure who your Representative is, go to <http://www.house.gov> and enter your zip code to find out the name. **Please encourage your Representative to become a member of this important Caucus AND let them know very briefly how Eosinophil Associated Diseases have affected your life [More information](#).**

Please email pac@apfed.org for a suggestions on how to contact your representative, a sample letter and to let us know that you have contacted your representative.

[NIH Expands Food Allergy Research Program Consortium of Food Allergy Research Renewed With a Five-Year, \\$29.9 Million Grant](#)

Today, the National Institutes of Health announce that the Consortium of Food Allergy Research (CoFAR), established in 2005, will be funded for five more years. CoFAR will continue to foster new approaches to prevent and treat food allergies and also expand in scope to include research on the genetic causes underlying food allergy **and studies of food allergy-associated eosinophilic gastrointestinal diseases (EGIDs).**

For more information about CoFAR, visit their [website](#).

NIAID conducts and supports research—at NIH, throughout the United States, and worldwide—to study the causes of infectious and immune-mediated diseases, and to develop better means of preventing, diagnosing and treating these illnesses. News releases, fact sheets and other NIAID-related materials are available on the NIAID Web site at <http://www.niaid.nih.gov>.

The National Institutes of Health (NIH)—*The Nation's Medical Research Agency*—includes 27 Institutes and Centers and is a component of the U. S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments and cures for both common and rare diseases. For more information about NIH and its programs, visit <http://www.nih.gov>.

Legislative Education in Washington DC during National Eosinophil Awareness Week!

APFED Founder **Beth Mays** and Medical Advisor **Dr. Jonathan Spergel** legislators in Washington DC about the urgent need for more research on eosinophil associated diseases



APFED Founder **Beth Mays** and Medical Advisor **Dr. Jonathan Spergel** (Philadelphia) pictured here with **Congresswoman Rosa DeLauro** (D, Connecticut)

Patients and Families are Funding Rare Disease Research

Press release from NORD

WASHINGTON DC-----An advocate for people with rare diseases today told a U.S. Senate committee that the burden of funding and driving research on rare diseases too often falls upon patients and their families.

"As a society, it is wrong for us to expect people with devastating diseases to fund the search for their treatments," said Diane Dorman, vice president for public policy of the National Organization for Rare Disorders (NORD). "There are nearly 7,000 rare diseases, and only about 200 of them in government, academia or industry.

"Through golf tournaments, raffles even bake sales and car washes, it's too often the patient community that funds and drives rare-disease research. We need a more significant commitment at the federal level."

Dorman said the word "rare" is misleading, since about one in 10 Americans have diseases classified as rare. While each disease is unique, there are many problems and challenges that all people with rare diseases share, she added.

Dorman told the committee that federal funding and guidelines are needed for natural history studies, patient registries and other basic tools to make clinical research possible. And, she said the Food and Drug Administration (FDA) should institute a statement of policy on rare diseases and orphan products to reduce regulatory uncertainty and encourage researchers to develop treatments for diseases that have none.

She also urged the nation's medical schools to enhance training on rare diseases. "NORD believes our nation is blessed with a caring and dedicated medical establishment," she said. "But we urge a greater emphasis on rare diseases in medical education centers to prepare

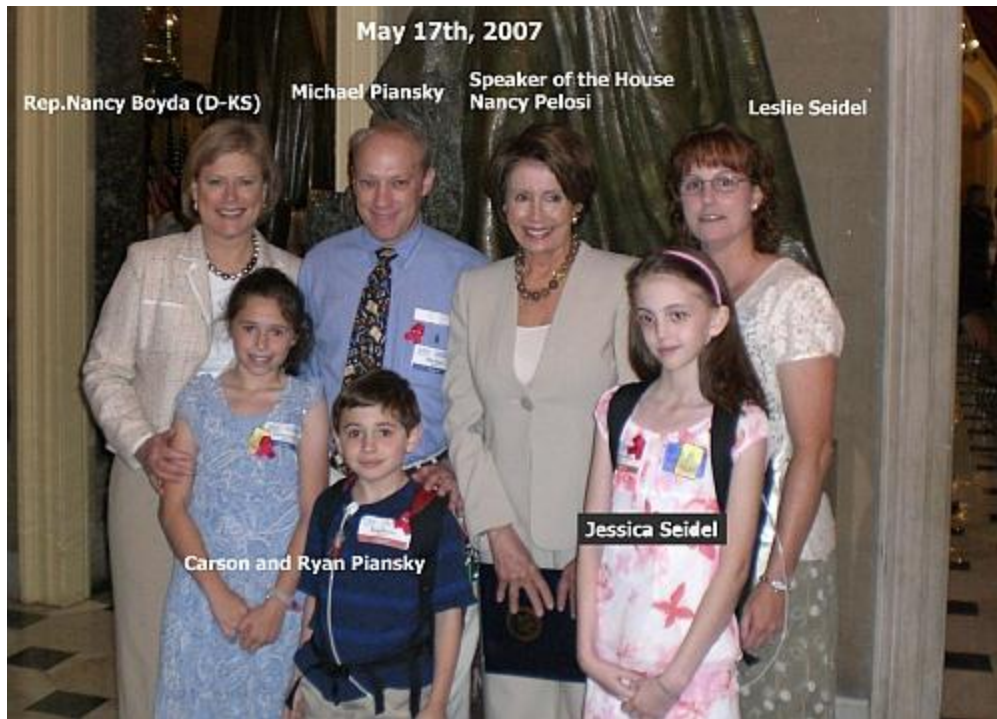
young clinicians to treat these diseases and encourage young investigators to study them."

Dorman made her comments in invited testimony before a Senate Committee on Health, Education, Labor, and Pensions hearing on the topic, "Treating Rare and Neglected Pediatric Diseases: Promoting the Development of New Treatments and Cures." The hearing was co-hosted by Committee Chair Senator Tom Harkin (D-IA) and Ranking Member Senator Michael B. Enzi (R-WY).

To address the lack of treatments, Dorman told the committee, NORD has launched several recent initiatives that offer hope for the future, working closely with FDA and the National Institutes of Health. These include:

- a new training course and a handbook to prepare researchers for the special challenges of studying rare diseases
- a task force to help NIH and FDA identify ways to work together more effectively and
- a series of focus groups through which stakeholders academic researchers, patient organizations, industry, and investors share their views with NIH and FDA officials.

NORD is a non-profit organization representing all Americans with rare diseases. It was founded in 1983 by leaders of patient organizations and provides programs of education, advocacy, patient services and research.



APFED HILL DAY (May 17th) UPDATE!

HR296 unanimously passed in the House of Representatives on May 15th 2007, forever marking the third week of May **National Eosinophil Awareness Week**. Many thanks to all of you who called and emailed your Congressman urging support for this bill! This represents a NEW BEGINNING for our community!

Our first Hill Day was an astounding success as we educated legislators about eosinophilic disorders and the needs of the community. In the near future, increased funding for research, formula coverage and ICD-9 codes are top priorities.

On Thursday May 17th, Representative Nancy Boyda (D-KS-2nd) spoke to the House about eosinophilic gastrointestinal disorders. During her speech, she mentioned one of our members, 11 year-old Jessica Seidel and her struggle with EG. Congresswoman Boyda said the hundreds of letters she received in support of HR296 and Jessica impacted her decision to speak to the House on EGID. Following the speech on the house floor, Jessica was taken to meet Speaker of the House Nancy Pelosi! If you have ever wondered if your calls and letters make a difference, they DO!

Ross Pediatrics (makers of EleCare) generously sponsored our Congressional Briefing and Luncheon at the Library of Congress. Dr. Jonathan Spergel came down from CHOP to educate staffers and Congress about eosinophilic diseases. We had two children speak about their experience with eosinophilic gastroenteritis, including 11 year-old Jessica Seidel. Both courageous young ladies were well-received! Families interacted with multiple Congressional staffers, a few of whom had personal connections to the disease.

Our Hill Day families met with multiple legislators on both the House and the Senate side to discuss the next steps: Partnerships with governmental agencies to develop programs for research and epidemiological studies on eosinophilic diseases. We were also fortunate to find a health care specialist interested in developing a plan of action for federal formula legislation. These larger projects will take time, but Congress now knows we are here!