

## **Congressional Briefing Draws National Attention to the Impact of Autoimmune Diseases**

PDSA attended the Congressional briefing “The Multi-Generational Impact of Autoimmune Disease: America’s Silent Health Crisis” held March 28<sup>th</sup>, 2012, at the Rayburn House Office Building on Capitol Hill, in Washington, DC. The briefing to bring national attention to the serious issue of autoimmune disease was co-sponsored by the National Coalition of Autoimmune Patient Groups (NCAPG) and the American Autoimmune Related Diseases Association (AARDA). PDSA was an Advocate sponsor.

The briefing opened with **Dr. Lindsey Criswell** of the University of California who presented “Introduction to the Autoimmune Problem: Genetics and Autoimmune Disease”. In autoimmune disease a person’s immune system attacks the body’s own tissues. The process can slowly destroy specific types of cells, tissues, organs, or joints, and disrupt normal function. Certain triggers appear to play a role in a person developing an autoimmune disease, including viruses, bacteria, toxins, hormones, heavy stress, and some drugs. These may cause an autoimmune response in a person who already has a genetic (inherited) tendency to develop an autoimmune disease.

There are over 100 known autoimmune diseases and many more that are suspected to have an autoimmune origin. According to AARDA, one in five Americans or 20 percent of the population has an autoimmune disease. With 20 million Americans affected, autoimmune disease is one of the top 10 leading causes of death in female children and women in all age groups up to age 64. It is the fourth largest cause of disability in the U.S.

Researchers have found “family clusters” of autoimmunity and persons with autoimmune diseases often find that other family members have autoimmune diseases. Autoimmune diseases are not contagious or infectious but are usually chronic and can cause major organ damage. In some cases they can be life-threatening.

Next, **Dr. Nicole McDonald** and her family shared their family’s range of members affected with some type of autoimmune disease. Dr. McDonald’s teen daughter has Graves’ disease (thyroid), her mother has ulcerative colitis (an autoimmune disease of the colon), her father has Hashimoto’s (thyroid disease), her sister has vitiligo and psoriasis (skin conditions), and her first cousin has Ankylosing Spondylitis (autoimmune degeneration in the backbone). Dr. McDonald encourages those with autoimmune disease to talk with other family members to see if they have other types of autoimmune disease.

**Dr. Lisa Rider**, from the Environmental Autoimmunity Group at NIH discussed the role of environmental exposures in development of autoimmune diseases. Dr. Rider said autoimmune disease cases are increasing. She said that understanding the role of environmental exposures can lead to prevention strategies and better decisions by the public and policymakers. A number of therapies are used to treat autoimmune disease, such as replacement hormones, as in hypothyroidism (low thyroid hormone) and replacing blood components by transfusion in patients with autoimmune blood disorders (such as ITP).

**Dr. Robert Phillips**, Director of the Center for Coping, in Long Island, NY (familiar to those who have attended past ITP conferences), discussed the emotional and family cost implications of autoimmune diseases. He specializes in helping people deal with chronic illnesses, especially those with autoimmune diseases. Dr. Phillips has more than 30 years' experience as a clinical psychologist and has worked with thousands of people with autoimmune disease. He said many people still don't understand what it is. Sometimes they may not be able to pronounce the names of many common autoimmune diseases. He said people with autoimmune disease want to feel as though they are part of society, not on the outside looking in.

He said Congressional awareness of the crisis of autoimmune disease gives patients and families hope. Hoping enhances coping. Being able to look forward to treatments coming down the pike is what helps people remain positive and optimistic that they can live a quality life despite their disease. Dr. Phillips said we need to increase sensitivity, support, and services.

**Virginia Ladd**, Director of AARDA, discussed areas of autoimmune diagnosis and treatment that need major improvement. Diagnosis takes, on average, 4 years, during which time a patient may develop major organ damage. Many autoimmune diseases are incorrectly perceived as rare and may be misdiagnosed as psychosomatic illness. Symptoms can cross specialties and are often intermittent and unspecific until the disease becomes more serious. Most treatments for autoimmune diseases primarily repress the body's immune system (which increases risk for developing other diseases) and can have serious long-term side effects. Mrs. Ladd said there have been no new treatments for the majority of autoimmune diseases in over 40 years. Autoimmune disease is underfunded, little-known or understood, and needs more research and funding to yield new treatments and prevention when possible.

The mission of NCAPG is to consolidate the voice of autoimmune disease patients and promote increased education, awareness, and research into all aspects of autoimmune disease through a collaborative approach. For further information on NCAPG and AARDA, visit <http://www.aarda.org/>

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