

2005 Congressional Briefing on Autoimmune Disease

Several Representatives from Patient Advocacy Organizations specializing in vasculitic diseases attended the **2005 Congressional Briefing on Autoimmune Disease**, held in Washington D.C. on March 16, 2005. Those present included Edward Becker, Founder and Director of the Polyarteritis Nodosa Support Network; Jane Dion, Co-Director of Churg Strauss Syndrome Association; and Joyce Kullman, Executive Director of the Wegener's Granulomatosis Association. Attendees had the opportunity to meet individually with their local congressional Representatives and Senators after listening to presentations from several activists and patients.

Speakers at the Briefing included a wide variety of interesting and significant individuals. Representative Patrick Kennedy (D-RI) discussed the importance of dealing with a rare disease. Rep. Kennedy is the sponsor of The Prevention, Awareness, and Research Autoimmune Disease Act, HR 3359, which is an amendment to the Public Health Service Act to increase public and professional awareness of autoimmune diseases. Dr. Noel Rose, the American Autoimmune Related Diseases Association (AARDA) National Scientific Advisory Board and Chair of the NIH Autoimmune Diseases Coordinating Committee, provided an update on the NIH Autoimmune Diseases Research Plan. The Research Plan has not been funded by Congress yet and the NIH is working on prioritizing certain aspects of the plan in order to expedite funding approval. Keynote speaker Bhagirath Singh, Ph.D., Scientific Director, Institute of Infection and Immunity Canadian Institutes of Health Research (CIHR), compared the amount of money that Canada spends on autoimmune research compared to that of the U.S. (Canada's spending is much higher, proportionally!).

Several patients then shared their personal stories and the challenges of living with a rare disease and its many side effects, as well as the difficulty involved in finding the right doctors to treat the disease. In addition to the physical, emotional, and financial strain in dealing with the disease, there is also an added emotional strain and frustration from locating resources, dealing with different specialists, and finding one doctor to assume overall responsibility for the patient's health care.

The Patient Advocate Representatives, pictured below, found the Briefing very positive and informative, and a key step in creating awareness of the necessity of raising funds and passing legislation for research in autoimmune diseases.



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Jane Dion, Co-Director of Churg Strauss Syndrome Association, Joyce Kullman, Executive Director of the Wegener's Granulomatosis Association, and Edward Becker, Founder and Director of the Polyarteritis Nodosa Support Network, recently attended the 2005 Congressional Briefing on Autoimmune Disease in Washington, D.C.



Members from the Wegener's Granulomatosis Association that attended the Congressional Briefing include: back row (L-R) Susan Kellogg and Janet Bruchey; front row (L-R) Christina Cornell, Joyce Kullman, Dianne Shaw, Ursula Gill, and Lynn Ann Casey.



Dr. Karen Himmel, Internist, and Edward Becker, Founder and Director of the Polyarteritis Nodosa Support Network, at the Congressional Briefing.