

## First-ever Congressional Briefing on Lupus Research Highlights Issues and New Research Initiatives



**LUPUS** was a familiar word on Capitol Hill in September, when more than 100 people attended the LRI National Coalition's educational briefing for Congressional Members and staff. The research briefing, moderated by Margaret Dowd, LRI President, was hosted by Congressman Sherwood Boehlert (R-NY).

At the briefing, congressional staffers not only learned about some of the research directions at NIH but had a chance to hear directly from patients and family members. Robert Ravitz, LRI Co-Chairman, discussed the plight of his daughter Annie, who has endured 40 hospitalizations in 29 years.

Josiah Wedgewood, MD, PhD, of the National Institute of Allergy and Infectious Diseases, said: "The government needs to be more efficient and that is one of the primary tasks of the Autoimmune Disease Coordinating Committee (AADC)—to try to bridge the work that is being done at the various institutes." Dr. Wedgewood is the incoming Chair of the AADC.



*"We have to make sure that NIH and the people deciding on allocation of resources recognize that it's not just Alzheimer's or cancer—the high profile issues—that need attention. It's diseases like lupus," said Congressman Sherwood Boehlert at the briefing.*

Joel Schiffenbauer, MD, a Medical Officer/Team Leader at the Food and Drug Administration, briefed the audience on the agency's programs that advance drug development in lupus, such as the accelerated approval program, an orphan drug program, and the development of guidance documents (a report on drug development in lupus is expected to be finalized soon). Also presenting at the briefing was Barbara Boyts, president of the Alliance for Lupus Research.



*Stuart Kassin, MD, Chairman of the Lupus Foundation of Colorado Board of Directors (left) provided a medical overview of lupus; and Elizabeth Gretz, PhD of NIAMS/NIH provided an overview of lupus research at the NIH.*



Coalition member Kathleen Arntsen, President/CEO of the Lupus Foundation of Mid and Northern New York (pictured at top, center), gave a personal perspective on lupus. Pointing to the audience, Arntsen said, "One does not have to look very far to witness the devastation of lupus. Within this very audience today are lupus patients who have suffered heart attacks, survived strokes, endured multiple joint replacements, agonized over numerous miscarriages, and tolerated organ transplants. We are a tenacious bunch traveling here today to share our heartbreaking tales with you. The LRI is truly the patient voice for lupus research."

After the briefing, coalition members who represented major areas centers in the country, visited their congressional offices.

## LRI NATIONAL COALITION MEMBERS & PARTNERS

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# LRI National Coalition Partners with the Association of Black Cardiologists in Congressional Black Caucus Educational Forum



A multidisciplinary team of specialists joined together in September to alert participants at the 34th Annual Congressional Black Caucus Legislative Conference about a serious health threat to women of color: heart disease in those with lupus. "It's high time that the national spotlight turn on this twin threat that cripples the lives of so many African American women," said LRI President Margaret G. Dowd. According to Rosalyn Scott, MD, consulting medical director of the ABC, "the support of congressional leaders and collaboration of organizations such as the ABC and the LRI is imperative. This support enables us to better understand and articulate the correlation of these two diseases and how education, early detection and treatment are vital in improving the quality of life for women of color." The CBC Forum, which was attended by more than 100 people, was co-sponsored by Congressman Edolphus "Ed" Towns (D-NY) and Congresswoman Gwen Moore (D-WI).



*Pictured (clockwise): Forum audience members; Frances Ashe-Goins, MPH, RN of the Dept. of HHS; Patricia Davidson, MD, cardiologist; Rosalyn Scott, MD of the ABC with LRI President Margaret Dowd; Panelists included (l-r) Rep. Gwen Moore (D-WI), Tarsha Franklin, MPH Health Advisor to Rep. Ed Towns (D-NY), and Gregory Dennis, MD of NIAMS/NIH. Panelists not pictured are Lisa Begg, PhD, RN of the NIH, Doris Jackson, RN of Lupus Mid-Atlantic and moderator Lucille Norville-Perez, MD of the NAACP.*

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