



IMMUNE DEFICIENCY FOUNDATION

The National Organization Dedicated To Research And Education For The Primary Immune Deficiency Diseases.

ADVOCATES FOR PRIMARY IMMUNE DISEASE COMMUNITY TAKE TO CAPITOL HILL TO WARN OF NEW CHALLENGES, APPLAUD PROGRESS

Senator Landrieu to be Honored for Long Commitment to Research on Primary Immune Deficiency Diseases that Affect Thousands of Americans

(Washington, DC) June 19, 2003 – Patients living with primary immune deficiency diseases and their caregivers are gathering on Capitol Hill today to recognize progress made in the past two decades, and to urge Congress to maintain and increase crucial research funding for the treatment of diseases that threaten the lives of thousands of Americans.

Primary immune deficiency diseases, disorders in which part of the body's immune system is missing or does not function properly, are caused by intrinsic or genetic defects in the immune system. The World Health Organization recognizes more than 100 primary immune diseases. As many as 50,000 people in the U.S. have a clinically significant primary immune deficiency disease.

“Today’s message to Congress is two-fold: yes, we’ve made great progress in treating primary immune diseases over the past 20 years – and we *must* build on that momentum by expanding research funding to find new cures and prevention strategies,” said Gail Nelson, spokesperson for Immune Deficiency Foundation, and constituent of Senator Mary Landrieu.

The organization is also honoring U.S. Senator Mary Landrieu (D-LA), a member of the Appropriations committee and member of the subcommittee funding health research, at an awards presentation. Senator Landrieu has been an aggressive advocate for doubling funding at the National Institutes of Health and for increasing public awareness and monitoring of primary immune disease threats through the NIH and U.S. Centers for Disease Control and Prevention.

The group also highlighted new findings about primary immune diseases never before available. Results from the first nationwide report of patients treated for primary immune deficiency diseases, released recently by IDF, show a dramatically changing face of primary immune diseases, as well as new threats. Once thought to be a pediatric problem, the diseases now affect more adults than children. This change is due in large part to more successful treatment methods, particularly intravenous immunoglobulin (IGIV), which replaces missing antibodies and allows patients to live longer, near-normal lives.

However, with longer lives come new challenges for those struggling with compromised immune systems. It appears that the emerging West Nile Virus can be transmitted by blood transfusion and organ transplantation. Moreover, patients could be at greater risk from potential threats such as smallpox because the vaccine to prevent smallpox is a live virus and could be

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deadly for those with compromised immune systems. At this time, however, concerns about transmission by IGIV remain theoretical as current viral inactivation techniques used on IGIV should inactivate or remove the virus.

To address the first concern, those with immune deficiency conditions should take extra precautions to avoid mosquito bites by following CDC recommendations which include remaining indoors during mosquito feeding times (early evening), using protective netting, and using DEET-containing repellants.

The IDF is also asking Congress to support the inclusion of home infusions of IVIG as part of Medicare's benefits package. Most primary immune deficient patients receive regular infusions of a medicine known as Intravenous Immune Globulin (IVIG) to bolster their immune systems. Medicare does pay for this life-saving drug, but only when it is delivered in a hospital or doctor's office. Therefore, Medicare's benefits package should be updated to include home infusion of IVIG. Adding this option would be safe and affordable and would not compromise patients' access to this life-saving drug.

“Based on advances over the last 20 years, the primary immune disease community has great reason for hope of future medical advances. But hope will only become reality if research continues into new treatments and cures for primary immune diseases,” said Gail Nelson. “Congress can and must ensure the national commitment to medical research remains strong.”

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The Immune Deficiency Foundation (IDF) is the national non-profit health organization dedicated to improving the diagnosis and treatment of primary immune deficiency diseases through research, education and advocacy. More information about primary immune deficiency diseases and IDF can be found at www.primaryimmune.org.

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