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No child should ever have to live in a bubble again

Primary Immune Deficiency Patients deserve a normal life, says Brady

Washington, D.C. - Twenty-five years after the story of the “Boy in the Plastic Bubble” captured the world’s attention, this week congressional lawmakers from both parties joined together to ensure that Americans struggling with immune deficiencies receive affordable, effective treatment under the nation’s Medicare program.

Leaders of the effort in Washington include U.S. Congressman Kevin Brady whose district includes Shenandoah, Texas, the home of [David Vetter](#) – who from birth to his death at age 12 was confined inside a specially sterilized cocoon to combat severe combined immune deficiency syndrome – a condition absent the body’s natural ability to fight off infections. The Medicare Patient IVIG Access Act of 2009 updates the payment process for the intravenous plasma treatment and makes it more affordable and accessible through Medicare.

“For those with immune deficiency, IVIG therapy in the right setting and at the right price is critical to sustaining a normal life”, said Brady, who has championed the issue as a member of the House Ways & Means Committee. “A cookie cutter approach in Medicare can be dangerous for patients, and our bill ensures that Medicare addresses their unique needs in a timely and cost-effective manner.”

David Vetter’s mom has dedicated her life to finding better treatments and research into the disease.

“Looking back at my struggle with my son David's condition so many years ago, I am thankful that IVIG provides many with an effective treatment that allows them to live normal lives,” said Carol Ann Demaret. “It is troubling to know that so many Medicare beneficiaries have difficulty obtaining IVIG. This legislation will provide the means for Medicare to review and update its IVIG payment policy and hopefully to improve access.”

“Songs were written and movies made honoring David,” added Brady, “but the best way to honor his struggle is to make this necessary treatment available to those who need it.”

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