

# The Eagle-Tribune

## **Congress must act to expand immune disorder treatment**

By Henriette Bauer

December 7, 2007

People are always telling me they can't believe I'm 94-years-old! My doctors compare my energy level to someone in their 70s. They should have seen me 7-8 years ago. The truth is, I have a genetic disorder that affects my immune system and it is unable to fight infection.

Let me explain. I always had infections 2-3 times a year and would get antibiotics and then I was OK. I started to have more and more infections and it got to the point that I hardly got over one and then a new one started. This went on for many years and some of the antibiotics either had dangerous side effects or did not work.

One day my doctor said to me – I am sorry, try to find another doctor. I can't help you anymore.

It was my good fortune to find a doctor who was willing to help me. He has been my primary care doctor for the last 8 years. He tried different things and then he tested me for gamma globulin.

He found the cause - this was the answer.

I need the Gamma infusion to be able to fight the infections. I started to feel better; my energy level was going up. I still get a few infections, but thanks to the ICIG, I am able to fight them. Then after years of IVIG, my doctor said he can no longer afford to treat me because Medicare's reimbursement rates for IVIG became inadequate

I was terrified since this treatment is a matter of life or death.

My son desperately called at least a dozen hospital clinics. All we got was denials. I was losing hope when I became seriously ill. My primary care doctor got me in a local hospital outpatient clinic where I got temporary infusions. He tried to get me again into a place with no luck. He set up an appointment for me at a leading local outpatient clinic. After a long discussion with the head of the Immunology division, he agreed to treat me. Now I meet with the physician at the medical center every six months. Each time I go, I'm terrified he will no longer agree to treat me. Without IVIG, it is certain I will get seriously sick again.

I owe a world of gratitude to the 2 doctors for caring and helping me.

My disorder is called common variable immune deficiency disease (CVID) and the medical treatment that keeps me alive is a plasma therapy called IVIG, shorthand for intravenous immune globulin. Unfortunately, thousands of CVID patients across the country are finding it difficult to get the IVIG treatments that help them lead healthy and normal lives.

The problem – and the solution – can both be found in Washington, D.C.

I am not the only patient struggling to survive during this IVIG access crisis. For the majority of CVID patients, IVIG is the only viable treatment option. Sadly, private insurers are beginning to follow Medicare's lead by changing their reimbursement rates for IVIG. Without action, many of us will face debilitating illnesses and death.

But there is hope. Working with the Immune Deficiency Foundation, I learned about legislation recently introduced in House of Representatives. A bill called the "Medicare IVIG Access Act" (H.R. 2914) provides a solution to this crisis by setting up a process for reviewing IVIG reimbursement and adjusting rates appropriately. The bill also authorizes Medicare to pay for the costs of administering IVIG in the home, giving me an alternative option for treatment location.

Similar legislation has not yet been introduced into the Senate, but its important Senators are made aware of the issue before they act on Medicare issues this year. CVID patients can live productive and healthy lives. We can even fool others about our age.

Please, contact senators John Kerry and Ted Kennedy and representatives John Tierney and Niki Tsongas; ask them to fix the IVIG access issue. We can't afford to wait. We need your help now.

-----

*Henriette Bauer is a resident of North Andover. She wrote the column with the assistance of her son, Alan Bauer, also of North Andover, and the Immune Deficiency Foundation of Towson, Md.*