

**COMMITTEE ON  
GOVERNMENT REFORM AND OVERSIGHT**

**TESTIMONY PROVIDED BY**

**DONNA HOBSON**

**ON BEHALF OF  
IMMUNE DEFICIENCY FOUNDATION**

**MAY 7, 1998  
10:00 A.M.**

I would like to thank this Subcommittee for inviting me to participate in this hearing on the nationwide shortage of intravenous immune globulin. My name is Donna Hobson and I am President of the Nebraska Chapter of the Immune Deficiency Foundation. I am also a primary immune deficient patient. I would like to share with you today my personal story to allow you to understand how the current nationwide shortage of IVIG has affected my life and that of many thousands of other immune deficient patients.

For most of my adult life I could not easily recover from common infections. It would seem odd to those who knew me well that a cold, flu or sinus infection would often linger for weeks and months. However, in 1987 my health took a dramatic turn for the worse, a series of overwhelming infections including bronchitis, otitis and sinusitis lead to pneumonia and staph infections. I was hospitalized, often placed in isolation, and given intravenous antibiotics. I continued to self administer intravenous antibiotics for 1 and ½ years. And still the high fevers and infections persisted. I was sent to several doctors and hospitalized repeatedly. One year my hospital bill was \$50,000 and 38 out of 44 days I had visited my doctor in his office. Every day I was losing ground, until in 1989 I was referred to an immunologist, Dr. Kobayashi, who diagnosed me with Common Variable Immunodeficiency. This is a primary immunodeficiency, which often has an adult onset. Immediately after my diagnosis I was placed on intravenous immune globulin replacement therapy. IVIG replaces my incomplete immune system and allows me to fight off the infections to which I would have previously succumbed, and which have the potential to be life threatening.

For the past nine years I have received IVIG on a regular basis, varying from two to three week intervals, and I am very happy to report **I have not had one hospitalization since beginning this therapy.** One of my physicians stated that he believed that I was going to die and believes that without IVIG I would have died. Mine is a typical story for patients with primary immunodeficiency disease. Over 50% of all patients with primary immune deficiency disease are infants and children. Early detection and IVIG treatment in these children prevent the occurrence of debilitating infections such as pneumonia - causing lifelong chronic illness and disability.

The Nebraska Chapter was founded by me and my husband in the hope that anyone who receives a diagnosis of primary immunodeficiency will know that they are not alone. We have also worked hard to educate primary care physicians, nurses and other medical personnel to properly diagnosis and treat these patients.

This is why I am here before you today. I want to share the miracle this therapy has brought into my life and tell you the anxiety and health consequences that patients like myself are suffering as the result of the shortage.

The Immune Deficiency Foundation recently conducted a survey of physicians and patients to learn about their experience with the shortage. The results of the survey are astounding, 87% of the physicians responding report that they have had difficulty obtaining product.

45% of patients report adverse health effects, which include more infections, pneumonias, bronchitis, lung infections as well as stress and anxiety. I would like to share some of the comments made by patients on the survey forms. One mother writes: “ I find this thoroughly unacceptable that my child has to go on a priority needs list to get medication so that he may live a normal ten year old’s life.” Another writes: “My 13-year-old daughter has missed a lot of school, had more frequent and severe infections and is in more joint pain. She is requiring more antibiotic and more pain medication that she has ever needed.” Back home in Nebraska I know of a young mother of three who literally spent hours every day on the phone trying to obtain product. She worries constantly about who would care for her family if she became ill and had to be hospitalized.

My husband is Vice President of a regional pharmacy chain, my insurance company covers the cost of my therapy and still I am on pins and needles as the date of my next infusion rolls around. I go day to day wondering if the gamma will come in. I have had to rely on my physician to share his supply because my usual source has not come through. But still my biggest fear is that one day there will be none available and I will have gone long enough without my infusion that I will succumb to some type of infection that will place me back in the hospital...or worse.

I would like to thank this Committee and the Health and Human Services Committee for the attention you have brought to this critical matter. I would recommend that a strategy be developed immediately that insures that the patients who depend on this life saving therapy will be assured that their IVIG will be available.

Thank you.