

IMMUNE DEFICIENCY FOUNDATION COMMENTS

TO PROPOSED RULE TO REVISE MEDICAL CRITERIA FOR EVALUATING IMMUNE SYSTEM DISORDERS OF ADULTS AND CHILDREN FOR DISABILITY BENEFITS UNDER TITLE II AND SUPPLEMENTAL SECURITY INCOME (SSI) PAYMENTS BASED ON DISABILITY UNDER TITLE XVI OF THE SOCIAL SECURITY ACT

Primary Immune Deficiency diseases (PIDD) are a diverse group of more than 100 diseases caused by intrinsic defects in the cells of the immune system, many of which result from a single gene defect. Primary Immune Deficiency diseases are characterized by an increased susceptibility to recurrent severe and unusual infections.

Primary Immune Deficiency diseases can be classified according to the affected components of the immune system. Please update and revise sections 14 and 114 by adding the following classifications of Primary Immune Deficiency diseases: antibody deficiencies (including X-linked Agammaglobulinemia, Common Variable Immune Deficiency, and Selective IgA Deficiency); combined immune deficiencies (including Severe Combined Immune Deficiency, Wiskott-Aldrich Syndrome and Ataxia-Telangiectasia); phagocytic deficiencies (including Chronic Granulomatous Disease and Leukocyte Adhesion Defect); Cellular Immune Deficiencies (including DiGeorge Syndrome); and complement deficiencies (including C2 deficiency).

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. Over the past ten years, IDF has conducted various surveys of its members that we would like to bring to your attention as you are updating and revising eligibility for SSI benefits for those suffering with immune system disorders. Some of the issues included in our surveys are as follows: source of health insurance coverage, employment status, types of permanent functional impairments, activity limitations, other chronic diseases in addition to primary immune deficiency, acute conditions, past year hospitalization, and the ability to work and/or attend school.

According to our 2002 data (which included 1,526 participants):

- Source of Health Insurance:
15% Medicare, 11% Medicaid
- Employment Status:
16% Disabled, 44% Full-time, 9% Part-time
- Types of Permanent Functional Impairment:
23% Lung Function, 11% Hearing, 9% Digestive Function, 7% Mobility, 2% Neurological, 2% Vision
- Activity Limitation:
14% Severe Limitation, 25% Moderate Limitation, 29% Slight Limitation
- Other chronic diseases in addition to Primary Immune Deficiency:
53% Yes (diseases include: Asthma, Sinusitis, Chronic Lung Disease, Arthritis, Allergies, Diabetes, Fibromyalgia, GERD, Hypertension, Hypothyroidism, IBS, Lupus, Depression)
- Acute Conditions (in the past year):
45% Bronchitis, 34% Repeated Diarrhea, 25% Repeated Ear Infections, 17% Pneumonia, 17% Urinary Infection, 17% Candida, 16% Eye Infections, 8% Malabsorbtion, 3% Neutropenia, 3% Lymphopenia, 2% Sepsis
- Past Year Hospitalization
30% Yes

According to our 1995 data (which included 898 participants):

- Ability to Work and/or Attend School (due to a patient's health in the past year)
29% Patients Unable to Work, 17% Parents Unable to Work, 18% Unable to Attend School, 6% Needed Special School/Classes

As you can see from the sampling of data that we have provided, people who are diagnosed with a Primary Immune Deficiency disease and apply for SSI benefits should be eligible. PIDD patients have to contend with the disease, its symptoms, time-consuming treatments (including IGIV infusions) and side-effects, as well as acute complications. PIDD patients may also develop chronic diseases.

If there is any additional information you need, please do not hesitate to contact Michelle Vogel, Director of Government Affairs, at (800) 296-4433 or (410) 321-6647.

Thank you for your kind consideration.