For over 25 years, the Immune Deficiency Foundation (IDF) has been committed to improving the diagnosis and treatment of primary immune deficiency diseases through research, education and advocacy. Everyday at IDF, our patient advocate receives calls from patients and their families. They may be searching for physicians, needing insurance help or seeking peer support. However, their requests for information on diagnosis and treatment of primary immune deficiency diseases consistently rank as one of their top needs.

Our Consulting Immunologists Program fosters better treatment information by providing information about specific patient diagnosis, treatment and disease management to physicians. When physicians contact IDF with questions about a particular patient, they are put in touch with expert clinical immunologists who provide free second opinions or consults. Still, these physician requests indicate a need for more information and guidance on care and treatment options throughout the United States.

Survey Results Emphasize Need for Better Outcomes

Statistics from past IDF patient surveys indicated that the average time to diagnose primary immune deficiency disease was 9.2 years. During this delay, 37 percent of patients developed permanent impairments, such as loss of hearing, pulmonary function, digestive function, mobility, vision or neurological function.

These health issues may be a result of delayed diagnosis. Additional results also reported access to specialists was limited by type of health insurance. Twenty-one percent of patients surveyed had treatment delayed, 11 percent were not able to see a specialist as often as needed and 17 percent had treatment denied by insurance carriers.

IDF Fulfills a Vital Need

“Hearing the needs of patients, their families and healthcare providers, combined with the patient survey results, we knew we had to be more aggressive in providing information for patients with primary immune deficiency diseases,” said Marcia Boyle, president and founder of IDF. As a result, we are proud to present The Immune Deficiency Foundation Diagnostic and Clinical Care Guidelines for Primary Immunodeficiency Diseases.”

In partnership with leading immunologists, IDF spearheaded the development of the guidelines to enhance earlier diagnosis, improve health outcomes and increase access to specialized healthcare and optimal treatment for patients with primary immunodeficiency diseases.

Under the able leadership of Dr. Rebecca H. Buckley, from Duke University School of Medicine and chair of the IDF Medical Advisory Committee, an expert panel of 22 immunologists was formed.

The panel identified evidence-based diagnostic and clinical care guidelines for select primary immune deficiency diseases.

“We tapped much expert knowledge and experience to produce these comprehensive, evidence-based diagnostic and clinical care guidelines for the primary immunodeficiency diseases.” Dr. Buckley explained. “The practical information, invaluable for patients and healthcare providers alike, is a major step for IDF to better inform and educate everyone touched by these diseases.”

The Guidelines include recommendations, strategies and information to assist physicians and patients in making educated decisions about appropriate healthcare for their primary immune deficiencies. The publication addresses a comprehensive list of issues, and each chapter also includes frequently asked questions.

For a free copy of the Guidelines, visit www.primaryimmune.org or call IDF at 800-296-4433.