

Connect with IDF's vital network that's making a difference...

IDF programs are producing untold numbers of benefits for thousands of people living with a primary immunodeficiency disease. And our efforts keep growing stronger!

Ordinary people can do extraordinary things. In addition to the work being done in the medical community to advance health care and quality of life, IDF provides access to valuable programs, meetings and support, nationally and locally.

But IDF also has a vast reserve of innovative resources when you need it... at your fingertips... online or by phone. That is the power and the dependability of IDF.

Get Connected:
www.primaryimmune.org
800-296-4433



IDF never forgets what's important to you!

Since 1980, the Immune Deficiency Foundation (IDF) has led a strong, active, patient-centered movement to enhance the lives of people living with primary immunodeficiency disease. Through the enduring work of dedicated volunteers, medical professionals, supporters and professional staff, IDF focuses on what's important to the primary immunodeficiency community — advancing diagnosis and treatment, quality healthcare and sharing information — to make a difference for patients and family members daily.

Because of IDF, a community of experts, volunteers and health care providers are available to help you learn to live a fulfilling life with your primary immunodeficiency!



Primary Immunodeficiency Diseases

In the United States, approximately 250,000 people are diagnosed with a primary immunodeficiency disease, and many more go undetected. Representing a group of more than 150 different rare disorders, primary immunodeficiencies are often difficult to diagnose. While not contagious, these diseases are caused by hereditary or genetic defects, in which part of the body's immune system is missing or functions improperly.

Primary immunodeficiency disease can affect anyone, regardless of age or sex. While infection is the most significant symptom, be suspicious and ask your physician to check for the possibility of a primary immunodeficiency disease if the infection you or a family member experience is...

Severe — requires hospitalization or intravenous antibiotics

Persistent — won't completely clear up or clears very slowly

Unusual — caused by an uncommon organism

Recurrent — keeps coming back, or if it

Runs in the Family — others in your family have had a similar susceptibility to infection

Many people with primary immunodeficiencies live their entire lives more susceptible to infections — enduring recurrent health problems and often developing serious and debilitating illnesses. Fortunately, with proper medical care, many patients are able to live healthy and independent lives.

For more information, contact IDF.



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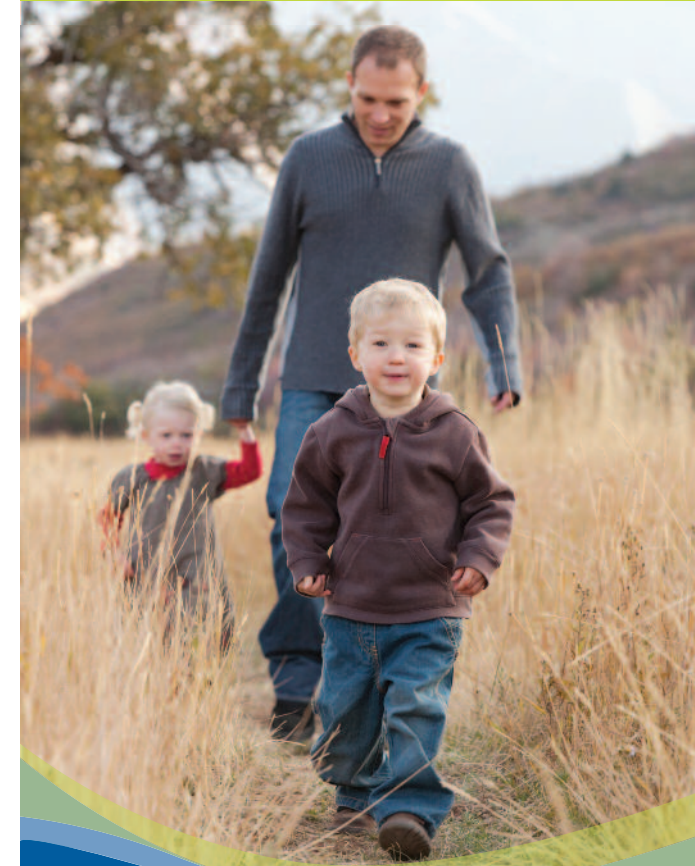
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Leading the Way



for living with
Primary Immunodeficiency Diseases



Immune Deficiency Foundation: Leading the Way for Living with Primary Immunodeficiency Diseases



IDF resources for living with primary immunodeficiency diseases

A wealth of resources and groundbreaking education and information from a legion of dedicated professionals — healthcare, insurance, education and lifestyle advocates.

- **IDF Educational Publications**, developed by world renowned immunologists, offer essential information for both patients and healthcare professionals.
- **Patient education meetings** provide valuable experiences for newly-diagnosed as well as patients and family who have lived with primary immunodeficiencies for years.
- **Individualized assistance** with insurance questions, physician location, treatment, and other unique aspects of living with primary immunodeficiencies is available.
- **Peer support volunteers** offer encouragement and advice for all members of the family.
- **Information and vital updates** on cutting-edge treatment and practices are within reach.
- The **IDF eHealthRecord**, specifically developed for individuals and families living with primary immunodeficiencies, helps patients take charge of all their health information in one place. Get organized, track symptoms, check progress, and manage appointments with this electronic personal health record.

www.primaryimmune.org

IDF sets a high standard among patient organizations through its comprehensive website and social media designed to further connect people living with primary immunodeficiency diseases through targeted, social networks, online community resources and blogs:

- **IDF Friends** connects patients and family members with common traits, interests, and causes. Visitors can create user group communities and participate in discussion forums on specific issues as well as upload videos and photos.
- Even teens and young adults living with primary immunodeficiency disease can join the IDF network through **IDF Common Ground**, a social media website filled with resources and opportunities to share information targeted to this important group.
- **IDF Reel Stories** offers patients, parents and caregivers inspiration from videos of others' experiences. Also, people living with primary immunodeficiency disorders can create videos to share their own stories.
- Young people often learn healthy lifestyle information through game playing. **IDF online games** include *Whack-A-Germ*, *Phagocyte Force - The Power to Devour*, and *Jigsaw Puzzler*.
- See what is happening in the community: **IDF Community In Action** blog highlights ways members can advance the primary immunodeficiency community.

Advocating for our community

When it comes to patient treatment and quality of life for people living with primary immunodeficiency disease, IDF is firmly at the front line of national and state public policy activity!

- The **IDF Advocacy Center** closely follows health news and provides online Action Alerts to notify our community about pertinent issues and how to become involved across the country.
- The Center provides a **Grassroots Advocacy Toolkit** for IDF volunteers to contact local and national representatives to promote health care policy and legislation that positively affect the primary immunodeficiency community. Volunteers have even created videos to share personal stories and information on how current legislative policies are affecting patients and their families.
- **IDF national patient surveys** provide crucial insight into the personal impact of primary immunodeficiency diseases and help the Foundation develop public policy for improved diagnosis and treatment.
- Follow our interactive advocacy blogs! **IDF Policy Matters** raises political awareness of IDF issues and current campaigns, and **IDF SCID Newborn Screening** traces grassroots state campaigns for mandatory newborn screenings for Severe Combined Immunodeficiency (SCID).

Primary immunodeficiency education for health care professionals

IDF fosters opportunities for medical research and continuing education programs so physicians may improve the diagnosis and treatment of patients.

- The **IDF Consulting Immunologist Program** provides physicians the opportunity to consult with expert clinical immunologists regarding patient-specific questions and obtain valuable diagnostic, treatment and disease management information.
- IDF's **LeBien Visiting Professor Program** offers teaching hospitals the opportunity to engage prominent clinical immunologists in leading Grand Rounds and other educational activities directed at the treatment of patients with primary immunodeficiency disorders.
- The **United States Immunodeficiency Network (USIDNet)** is a research consortium of leading immunologists, to advance knowledge of primary immunodeficiency disorders as well as focus on the growth of patient registries.
- The **IDF Online Course for Nurses: Primary Immunodeficiency Diseases and Immunoglobulin Therapy**, found on the IDF website, is a free, accredited course. It enhances the knowledge of the nurse clinician by providing an update on primary immunodeficiency disease and immunoglobulin therapy.