Immune Deficiency Foundation

Dedicated to Improving the Diagnosis, Treatment and Quality of Life of Persons with Primary Immunodeficiency Diseases
About the Immune Deficiency Foundation

Founded in 1980, the Immune Deficiency Foundation (IDF) is the national non-profit patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases (PI) through advocacy, education and research.

Knowing first-hand how members of the PI community face significant challenges, it is a priority of the Foundation to identify and develop resources and services to meet the needs of those who live with PI – whether a patient is newly diagnosed or has been living with PI for years.

Individuals affected by PI often find it difficult to receive proper diagnosis, treatment and specialized healthcare. They also experience difficulties financing their healthcare, finding educational materials on their disease and locating others with whom to share their experiences. Fortunately, IDF has a wealth of resources and groundbreaking information developed by a legion of dedicated professionals – healthcare, insurance, education and lifestyle advocates.

Primary Immunodeficiency Diseases

Primary immunodeficiency diseases (PI) are a group of more than 250 rare, chronic disorders in which part of the body's immune system is missing or functions improperly. Because one of the most important functions of the normal immune system is to protect us against infection, patients with PI commonly have an increased vulnerability to infections, which can be recurrent, unusually severe, or won’t clear up. People with PI can face frequent health problems and often develop serious and debilitating illnesses.

While not contagious, these diseases are caused by hereditary or genetic defects, and although some disorders present at birth or in early childhood, the disorders can affect anyone, regardless of age or gender. There are approximately 250,000 people who are diagnosed with PI in the U.S., and thousands more go undetected.

Today, with early diagnosis and appropriate therapies, many people diagnosed with PI can live healthy, productive lives.

The Voice of the PI Community

Through advocacy efforts, IDF lays the groundwork for the promise of an easier tomorrow. By mobilizing health providers, patients, families and industry throughout the country, IDF stays in the forefront of issues relevant to this community. Public policy issues that are critical to patients at national and state levels are monitored through the IDF Advocacy Center, and our Grassroots Advocacy Program organizes individuals to contact their government representatives to promote healthcare legislation that will positively affect the community. www.primaryimmune.org/idf-advocacy-center
IDF Understands the Needs of the PI Community

The Immune Deficiency Foundation (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.

Providing Valuable Education & Resources

IDF Publications – Heralded as Best Patient Resources for PI
IDF publications are developed by world renowned immunologists and healthcare professionals. www.primaryimmune.org/idf-publications

Patient Meetings – Local & National Educational Meetings for All Ages
Education Meetings, retreats and conferences offering useful information on managing PI are held throughout the country. www.primaryimmune.org/events-calendar

Advocating for Patients – Individualized Assistance
IDF offers help with the unique aspects of living with PI. Answers to questions range from offering solutions to life management issues, providing peer support, locating a specialist in a particular area, and assisting with insurance issues. www.primaryimmune.org/ask-idf

IDF Website – Information Gateway for the PI Community
Features the latest information about diagnosis, treatment, programs, services and education, as well as current events, news and connections to all of IDF’s resources. www.primaryimmune.org

IDF ePHR – Electronic Personal Health Record for the PI Community
This electronic personal health record features innovative technology, by using an advanced online system to transform how patients manage their health by helping them get organized, track symptoms, check progress, and more. www.idfephr.org

Keeping the Connection

News and Updates for the PI Community
IDF creates monthly e-newsletters, publishes a newsletter, and offers blogs, video channels and more! www.primaryimmune.org/sign-up

IDF Social Networks
IDF Friends, for adults, www.idffriends.org, and IDF Common Ground, for teens, www.idfcommonground.org, are two exclusive social networks for the PI community.

IDF Get Connected Groups
Individuals and families can meet others living with PI in their local area through local groups. www.primaryimmune.org/get-connected-groups

Nationwide Volunteer Network
Dedicated volunteers serve as peer support, offer encouragement and understanding to others. Others provide information on local resources, help facilitate educational meetings, advocate for public policy, create awareness and organize fundraising events throughout the country. www.primaryimmune.org/volunteer
Promoting Improved Care with the Medical Community

IDF actively promotes and develops medical education and resources to improve the diagnosis, treatment and care of primary immunodeficiency diseases. IDF is fortunate to have a Medical Advisory Committee and Nurse Advisory Committee comprised of prominent immunologists and clinicians dedicated to support the mission of IDF through the development of science-based standards and resources. www.primaryimmune.org/healthcare-professionals

IDF Healthcare Professional Publications
IDF publications are developed by world renowned immunologists and healthcare professionals. Resources are available for clinicians to learn more about PI.

IDF Consulting Immunologist Program
This free service provides physicians the opportunity to consult with expert clinical immunologists about patient specific questions and obtain valuable diagnostic, treatment and disease management information.

IDF Online Continuing Education Course for Nurses
This free, accredited course enhances the knowledge of the nurse clinician by providing an update on PI, immunoglobulin therapies and the nurse’s role with these therapies.

IDF & USIDNET LeBien Visiting Professor Program
This program promotes improved knowledge by providing faculty at teaching hospitals with a Visiting Professor with expertise in PI. Teaching hospitals throughout the U.S. may request a leading clinical immunologist to lead Grand Rounds or present at other educational activities.

Looking Forward - Research for a Healthier Future

IDF supports and helps advance research to enhance the lives of individuals living with primary immunodeficiency diseases.

IDF’s major focus is to better understand patient experiences and improve outcomes. In that regard, IDF conducts surveys of patients and physicians to gain a more complete representation of patient attitudes and experiences.

United States Immunodeficiency Network (USIDNET)
USIDNET is a research consortium to advance scientific research of PI. It is a program of IDF funded in part by the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institutes of Health (NIH). USIDNET consists of a patient-consented registry that acts as a resource for clinical and laboratory data. www.usidnet.org

IDF PI CONNECT – Patient-Powered Research Network
Building upon USIDNET, IDF developed an expanded health data network, PI CONNECT. This Patient-Powered Research Network transforms research by bringing together patient data from consented users in IDF ePHR with clinical data from USIDNET. PI CONNECT is an exciting, new, framework that gives patients a “seat at the research table.” Bringing patients and researchers together is one of the ways we are advancing clinical research and comparative effectiveness studies to help improve the diagnosis and treatment of PI. www.idfpiconnect.org

IDF Walk for Primary Immunodeficiency
IDF Walk for Primary Immunodeficiency is our signature fundraising and awareness event held in cities across the country, where they serve as the largest gatherings of patients and families living with PI. The walks rally the community to come together and raise critical funds to advance research. www.walkforpi.org
In 1980, with knowledge and foresight from their personal experiences, the Immune Deficiency Foundation (IDF) was founded by families of children with primary immunodeficiency diseases (PI) along with their clinicians. It is with the spirit and energy of this keen perspective that IDF exists today, thriving as an organization dedicated to all individuals living with PI.

Through the enduring work of dedicated volunteers, medical professionals, generous supporters and professional staff, IDF focuses on what’s important — advancing diagnosis and treatment, quality healthcare and valuable education — to make a difference for the PI community.

IDF programs are producing untold numbers of benefits for thousands of individuals and their families living with PI. And IDF’s efforts keep growing stronger!

Thousands depend on IDF for information, education and empowerment.
THINK ZEBRA!

The primary immunodeficiency community often identifies with zebras. This is based on an old saying. In medical school, many doctors learn the saying, “when you hear hoof beats, think horses, not zebras” and are taught to focus on the likeliest possibilities when making a diagnosis, not the unusual ones. However, sometimes physicians need to look for a zebra. Patients with primary immunodeficiency diseases are the zebras of the medical world. So IDF says THINK ZEBRA!

Is It Just an Infection?

You should be suspicious if you have an infection that 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.  

Do any of these words describe your infection? If you answered yes, ask your physician to check for the possibility of a primary immunodeficiency disease.

IDF is here to help! Call or click to ask your questions. 
800-296-4433 | www.primaryimmune.org/ask-idf

Want to make a difference? Volunteer with IDF! 
volunteer@primaryimmune.org

Mission Statement
The Immune Deficiency Foundation is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

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THINK ZEBRA!