

# Your IDF

## Educational Resources

IDF continues to develop the most authoritative educational materials and information on primary immune deficiency diseases (PIDD) for patients and healthcare professionals. IDF publications focus on the recognition and diagnosis of these rare disorders and important life management and patient care resources. IDF also publishes health advisories on issues that affect the PIDD community.

## Volunteers

IDF provides peer support and educational opportunities throughout the country via a network of local volunteers who are committed to the mission of the Immune Deficiency Foundation and assisting patients and families in their communities. Volunteers may provide information on local resources, plan educational or support group meetings, increase awareness of primary immune deficiencies in their communities, and serve as advocates in both local and federal public policy arenas.

## Giving

If you wish to become involved by making a financial contribution to the IDF Endowment Campaign or Annual Fund, there are a number of ways you can contribute. These include: employer giving programs, gifts through estate planning, matching gifts or campaign pledges.

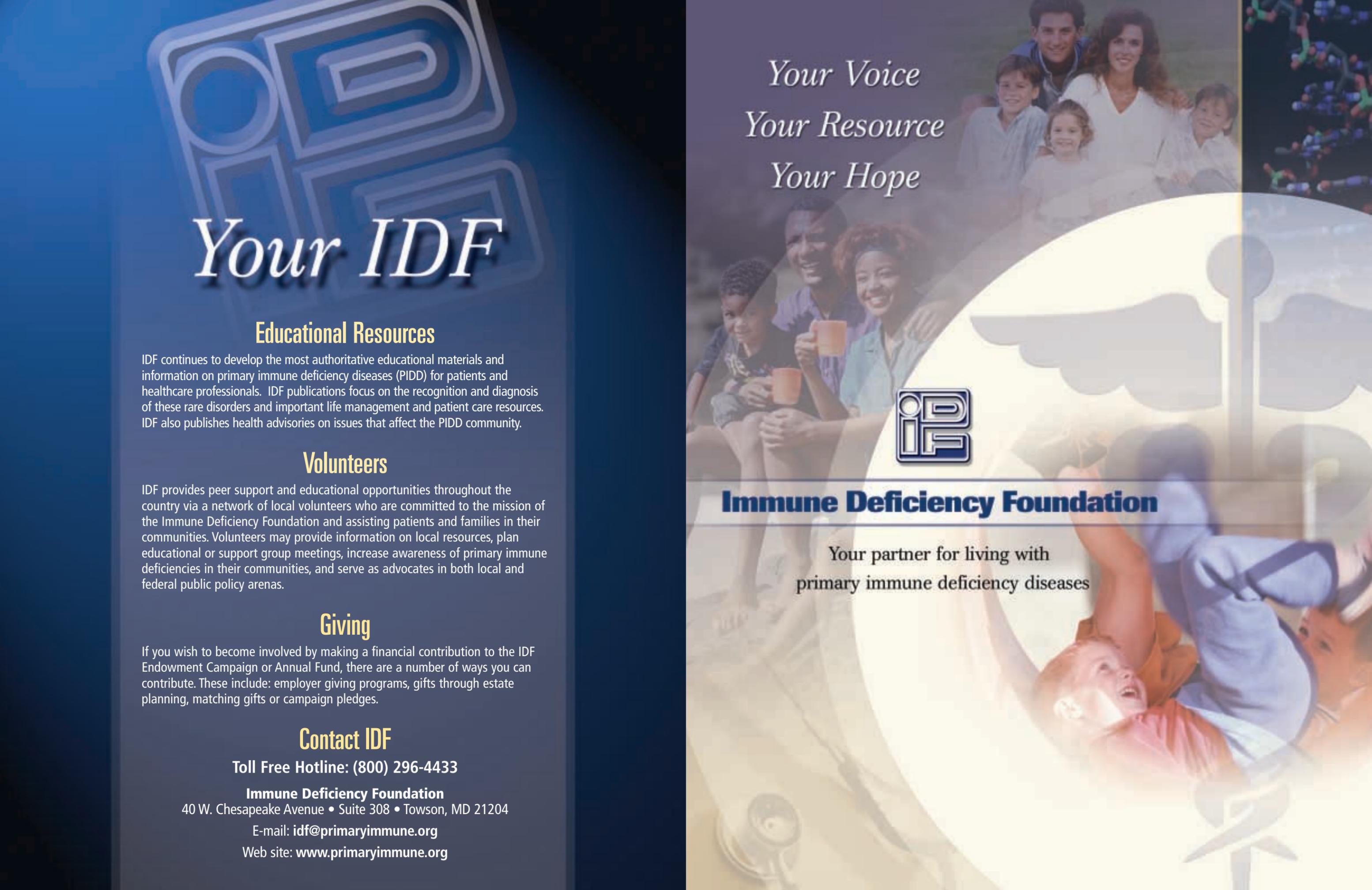
## Contact IDF

**Toll Free Hotline: (800) 296-4433**

**Immune Deficiency Foundation**  
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E-mail: [idf@primaryimmune.org](mailto:idf@primaryimmune.org)

Web site: [www.primaryimmune.org](http://www.primaryimmune.org)



*Your Voice*  
*Your Resource*  
*Your Hope*



**Immune Deficiency Foundation**

Your partner for living with  
primary immune deficiency diseases

# Immune Deficiency Foundation

*Improving the diagnosis and treatment of individuals with primary immune deficiency diseases through research, education and advocacy.*

*Your Voice  
Your Resource  
Your Hope*



*The Immune Deficiency Foundation was founded by John and Marcia Boyle to advocate for individuals living with primary immune deficiency diseases.*

**The Immune Deficiency Foundation was started 23 years ago when Marcia and John Boyle decided that their young son, John G. Boyle – and tens of thousands of others with primary immune deficiency diseases – deserved better health, a better life and a strong organization that would advocate for them.**

Today, IDF is the national nonprofit healthcare organization that represents 50,000 individuals living with a primary immune deficiency disease (PIDD). Primary immune deficiency diseases are disorders in which part of the body's immune system is missing or does not function properly. In contrast to secondary immune deficiency disease in which the immune system is compromised by factors outside the immune system, such as viruses or chemotherapy, PIDD are caused by intrinsic or genetic defects in the immune system. IDF provides innovative services to patients and their families, medical programs for healthcare professionals and funding for groundbreaking research. The PIDD community relies on IDF for support, advocacy and education.

## Where to Turn

**Dean and Kerstin Driscoll's sons, Alexander and Zachary, were nine months and three years old, respectively, when they were first diagnosed with a primary immune deficiency disease. Through a series of hospital stays during which Zachary was too sick to go off of IV antibiotics, test results proved both boys' immune systems could not protect them from infection. The Driscoll's doctor told them about the Immune Deficiency Foundation (IDF).**

*"When the boys were first diagnosed, we were shocked and didn't know where to turn. When we were referred to IDF, it was like being thrown a lifeline. It really helped us cope with their immune deficiency as a lifestyle, a reality, and helped us learn to live with it."*

*– Kerstin Driscoll*

## Your Voice

### Advocacy

IDF is the leading advocate for PIDD patients and their families through a comprehensive public policy program on a national and state level. These efforts are designed to ensure access to safe and optimal therapies and increased funding for critical research. And they work.

**Just ask Sydney Nelson who struck up a conversation with his Congressman during a cross-country airplane trip, telling him about his wife Gail's struggles to get IGIV home infusions through Medicare. Five years later, after hundreds of IDF volunteers staged a letter writing campaign, a rally on Capitol Hill and held meetings with Members of Congress, President Bush signed the 2003 Medicare Bill ensuring the reimbursement of IGIV in the home.**

IDF monitors issues that are important to the primary immune deficiency disease community and takes action, such as public testimony at congressional hearings, meetings with state and federal government officials and grassroots activities like letter writing or telephone campaigns.

*"When we were referred to IDF, it was like being thrown a lifeline..."*

## Your Resource

### Education

IDF was founded on the belief that individuals with primary immune deficiency diseases and their families are their own best resource. Whether for a newly diagnosed patient or someone who has been living with PIDD for many years, IDF provides educational materials and services that help patients and families live with these rare disorders.

Through its Volunteer Support Network, IDF develops local programs and a regional network of contacts who share their experiences and knowledge. One-day educational meetings provide families and health professionals with an introduction to IDF and feature leading clinical immunologists addressing the treatment and management of primary immune deficiency diseases. The meetings also include insurance reimbursement specialists offering advice and resources, and pharmacists and nurses speaking on therapy and other life management issues.

#### Patient and Family Services

- IDF National Conference
- Education Materials and National Newsletter
- Full-time Patient Advocate
- IDF Web Site - [www.primaryimmune.org](http://www.primaryimmune.org)
- Genetic Counselor
- IDF Volunteer Support Network
- Compassionate Care IGIV Program
- IGIV Safety Net Program
- Scholarship Program
- Local Patient Education Meetings
- Regional Family Retreat Weekends
- IDF Hotline
- Health Insurance Helpline

## Your Hope

### Research

In one generation – nearly 25 years – IDF has helped people with primary immune deficiency diseases obtain better care and quality of life. Through its collaboration with industry and government health agencies, IDF has fostered a supportive environment for groundbreaking research.

IDF administers a multi-million dollar research contract to advance scientific research in primary immune deficiency diseases. Led by an international consortium and funded by the National Institutes of Health (NIAID and NICHD), the consortium was established to encourage advancements in PIDD treatment through the awarding of research grants, the redesign of disease registries, and the introduction of new clinical investigators through a mentoring program.

For more than 20 years, IDF has funded fellowship training awards for physicians and grants for researchers pursuing studies in primary immune deficiency diseases.

#### Medical and Scientific Programs

- Consulting Immunologist Program
- Fellowship Program
- IDF Research Grants Program
- Visiting Professor Program
- Continuing Medical Education