Cleveland, OH
Welcome and IDF Update

July 20, 2018

John G. Boyle
President & CEO
This Evening’s Topics

- About IDF
- What to Expect This Weekend
- How We Can Help You (Education & Support)
- What We Do (Advocacy & Research)
- How You Can Get Involved
About IDF

- Dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases.
- Founded in 1980, 10 diagnoses, 1 volunteer founder and a handful of families
- Today, 350+ diagnoses, 30+ staff members, and over 250,000 diagnosed
What to Expect This Weekend

IDF Retreat
Learn from Experts in the Field

- **Presenters**
  Nicholas Hartog, MD, Spectrum Health Medical Group
  Rebecca Marsh, MD, Cincinnati Children’s Hospital Medical Center
  Nancy I. Joseph, DO, Allergy/Immunology Associates, Inc.
  Rebecca Scherzer, MD, Nationwide Children’s Hospital
  Jodi Taub, LCSW, LLC, Private Practice, NYC
  Nancy Wasserbauer, DO, University Hospitals
  M. Elizabeth Younger, CPNP, PhD, Johns Hopkins University School of Medicine

- **Interactive Q&A**

- **Learn and take this knowledge back to your physician**
Connect with Others

- Networking sessions
  - Adults with PI, ages 50+
  - Adult with PI, ages 31-49
  - Young adult with PI, ages 19-30
  - Parent of a child or teen with PI
  - Spouse/partner

- Youth programs, for children 6 months to 18 years
- Panel featuring people affected by PI sharing their stories
- Share your story with IDF Reel Stories
Visit, Learn, & Win

- Learn about the products and services available to you.
- Each day, stop by and talk with our sponsors and exhibitors.
Discover IDF

- Education
- Resources
- Support
- Research
- Public policy
- Volunteer opportunities
How We Can Help You

Education & Support
Top Reasons People Contact IDF

- Locating an immunologist in their area
- Diagnosis and treatment questions
- General education about PI
- Health insurance issues
- Peer support
- Volunteering
PI Community Services

Need to talk?

- Ask IDF
- Get Connected Groups
- IDF Peer Support
- IDF Friends

www.IDFFriends.org

IDF provides a range of programs to support people living with primary immune deficiency (PI), their families, friends, and caregivers.
Educational Programs and Resources

- IDF Website
- IDF Publications
- Education Meetings & Family Conference Days
- Teen Escapes
- National Conference

Connect & Learn: Face-to-Face and Online

IDF develops critical resources and programming that offer valuable information about treatment, management, and coping skills.
Save the Date!

2019 IDF 2019 National Conference

June 20-22, 2019
Gaylord National Resort
National Harbor, MD
Online Interaction and Education
What We Do

Advocacy & Research
IDF Public Policy

- IDF believes that healthcare professionals, in consultation with their patients, should make decisions about care and changes in treatment.

- Whether through private insurers or public payers (Medicare and Medicaid), IDF advocates for access to:
  - Affordable care
  - Appropriate medical specialists
  - All treatments and products in all sites of care
  - Newborn screening for SCID throughout the U.S.

Help individuals with PI receive lifesaving care
47 States Currently Screening for SCID
93% of all newborns in the U.S. are receiving SCID screening
Diagnosing and Treating SCID
Advancing Research

Better Information for Better Outcomes

- IDF Survey Research
  - More than 40 surveys of patients and medical professionals since 1995
    - Used to advocate with the government regarding legislative issues in the PI community
    - Cited and used by medical professionals, government and industry

- IDF Research Grants
  - Filling a critical need with seed grants for PI
  - Four grants awarded in 2018

IDF provides unique data that steers the conversation about PI
Clinical Trials for PI

www.primaryimmune.org/clinicaltrials

- What you need to know when considering clinical trials
  - Information on different types of research and studies
  - A video on what you should consider before participating
  - Once you understand what you should know, see what is available for your particular disease type, go to: www.ClinicalTrials.gov
- Allows people with PI to transform how they manage their health
- Tracks symptoms, Ig infusions, medications, log health information
- Access it via computers, tablets, phones
- ePHR app
- Ability to consent into PI CONNECT and take part in research!
USIDNET Patient Registry

- Patient consented registry of individuals with PI
- Important resource for physicians to collect clinical and laboratory data
- Experiences with PI advance vital research
- Currently, over 6,300 patients
Joins information entered in your IDF ePHR with the USIDNET patient-consented registry

Bringing this information together through PI CONNECT gives researchers valuable insight into the patient experience

Information is safe, secure & de-identified
How You Can Get Involved

Sign Up, Walk with Us, Volunteer & More!
We Need You!
Update Your “My Account”
Sign Up for IDF Action Alerts

Make your voice heard for the “herd”

- You sign up to receive notification of action alerts.
- When we need your voice heard regarding public policy issues, we will e-mail you with the information you need to make a difference.
- Easy to forward to friends and family.

www.primaryimmune.org/action-alerts
Help Advance Research

Funded through Patient-Centered Outcomes Research Institute (PCORI)
Participate in IDF Surveys

Excellent: 0%  
Very good: 10%  
Good: 20%  
Fair: 30%  
Poor: 40%  
Very Poor: 50%  
Blank: 0%
Join the IDF Volunteer Network

- Health Access Advocates
- IDF Liaisons
- Plasma Awareness Coordinators
- IDF Get Connected Leaders
- Peer Support Coaches

www.primaryimmune.org/volunteer
IDF Walk for Primary Immunodeficiency

2018 National Walks

Atlanta: 10/27  Kansas City: 10/27
Boston: 9/30  Los Angeles: 11/4
Chicago: 9/30  New York City: 10/21
Cleveland: 9/23  Philadelphia: 10/14
Dallas: 11/10  St. Louis: 10/13
Ft. Lauderdale: 11/17  Tampa: 11/17

www.walkforpi.org
Help Us Reach More People

Are you living with a primary immunodeficiency disease?

Contact the Immune Deficiency Foundation

Learn More

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

Primary immunodeficiency diseases are a group of more than 200 rare, chronic disorders in which part of the body's immune system is missing or functioning improperly. While not contagious, these diseases are caused by hereditary or genetic defects and can affect anyone, regardless of age or gender. Many people with primary immunodeficiency can lead healthy, productive lives with early diagnosis and appropriate treatment.

Contact IDF for more information about programs and services for patients and families living with primary immunodeficiency.

800-298-4433
www.primaryimmune.org

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

If any of these words describe your infection, the Immune Deficiency Foundation (IDF) recommends that you ask your physician to check for the possibility of a primary immunodeficiency disease. These diseases are caused by genetic defects and can affect anyone, regardless of age or gender. People with primary immunodeficiency are more susceptible to infections and health problems that lead to serious and debilitating diseases. It is critical to get an early diagnosis and proper medical care.

Questions? Contact IDF to learn more. www.primaryimmune.org • 800-298-4433
Final Thoughts

- Find out how IDF can help you
- Learn how you can help the PI community
- Learn from everyone you meet this weekend
- Be your own best advocate
Follow IDF on Social Media

- IDF Friends
- Facebook
- Twitter @IDFcommunity
- Instagram @IDFcommunity
- LinkedIn

#IDFretreats
Thank You, Presenters!

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Johns Hopkins University School of Medicine
Thank You!

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