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GRIFOLS This newsletter is supported by Grifols.
Letter from IDF President & CEO
John G. Boyle - Imperfect Attendance

One thing that many of us with a primary immunodeficiency disease (PI) struggle with is this: perfect attendance. This year, we will host the 10th Immune Deficiency Foundation (IDF) National Conference, and I will have attended 9 out of 10—a fact of which my predecessor, IDF Founder Marcia Boyle, nudges me about each conference year. It’s a good reminder to me of the fact that sometimes you have to make tough decisions about your time and you simply can’t be everywhere for everyone—especially when you’re living with a PI.

I wasn’t able to make the IDF 2007 National Conference because I had the honor of officiating my friend’s wedding. Yes, I tarnished my conference attendance record to be a part of my friend’s special day, but I’m happy that I made that decision—although it was a tough one. My growing up with a form of PI has given me a lot of practice in making tough decisions. I’m fortunate to have a good healthcare team and been receiving regular immunoglobulin (Ig) replacement therapy as long as I can remember. But I have days when I feel rotten—not “zebra strong” at all. There are days when I have to change plans. Many of you know about the constant balancing act that comes with having a PI. Canceling on people when you know that you need another day (or ten) to recover from something you’re fighting off. Sometimes it’s not even your choice: maybe it’s a case of pneumonia that puts you in the hospital or a severe bout of bronchitis that sidelines your child. The issue is that a chronic illness makes life more challenging, and so we all have to get used to making tough decisions about where we spend our time and energy in part so we’re doing more than surviving—but actually living.

That’s part of why I chose to be part of my friend’s wedding 12 years ago. I’ve missed out on too many special moments with people I care about. And as much as I wanted to be at the IDF 2007 National Conference, I made the call that was right for me based on what was going on in my life at that particular time.

I know why Marcia wanted me there and why she pokes me about it every two years. The IDF National Conference is an event like no other for our community. It brings hundreds of people living with PI together to learn and (finally!) meet others with the same diagnosis who just get it. It gathers the best and brightest from the medical field to help us better understand how to manage our health and what’s on the horizon for our community. It allows us to discuss critical issues facing people with PI and determine what actions need to be taken. It serves as a time to unite and let our voices be heard.

Marcia wanted me there because every person in our community counts. Every voice counts. There are undoubtedly challenges our community will face in the years to come, but, at the risk of sounding cliché, we are stronger together.

I hope you will join us for the IDF 2019 National Conference, June 20-22 at the Gaylord Resort and Convention Center in National Harbor, MD, outside of Washington, DC. If it’s your first conference, I encourage you to take that first step and register. If you’re going for 10 out of 10, I applaud you for your perfect attendance.

John G. Boyle
IDF President & CEO

Read more from John about issues facing the PI community: www.primaryimmune.org/president.
I recently chose my health insurance plan, but I will likely have questions throughout the year. Where can I get answers?

Regardless of how you and your family obtain your health insurance, you need to understand your plan and get the answers you need. Health insurance can have an impact on both your health and your finances. To learn more and get answers, check out the IDF Patient Insurance Center. www.primaryimmune.org/insurance

Each year, there is always talk about the flu vaccination being dangerous or ineffective. What is the truth about the flu vaccine?

There is plenty of misinformation and myths surrounding the flu vaccine. We want to clear the air and keep everyone informed on why the flu vaccination is safe and vital. With the flu season running from October through February/March, it’s not too late to get a flu shot. www.primaryimmune.org/flu-vaccination-myths

I receive immunoglobulin (Ig) therapy. How can I encourage and support plasma donations to make sure I have this treatment for years to come?

Plasma donors are heroes! You can thank plasma donors through the IDF Plasma Partners Program, which gives you the chance to visit plasma centers and talk to donors and employees. You can tell your story of how their donations and jobs help keep you healthy: www.primaryimmune.org/plasma-partners-programs

I’ve thought about volunteering for IDF, but how would I fit it into my schedule?

There are many different volunteer opportunities that can fit your skills and schedule! IDF is always in search of passionate, dedicated and understanding individuals to step up and become a volunteer. www.primaryimmune.org/volunteer

I remember what it was like before I found IDF—I had so many questions. How can I help the next person searching for answers?

You found us, and now it’s your turn to help someone else find IDF! With the many IDF resources and programs, sharing our Learn More poster (available for download or order from the IDF website) in your immunologist’s office can direct others to IDF and help change someone’s life. www.primaryimmune.org/awareness

If you have questions, please contact:

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Immune Deficiency Foundation
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Towson, Maryland 21204

Toll-Free 800-296-4433
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SCID Newborn Screening: Leading the Way, Navigating the Future

As of December 10, 2018, all 50 states are now screening newborns for Severe Combined Immunodeficiency (SCID), life-threatening disorders and some of the most severe forms of primary immunodeficiency disease (PI). For the last decade, in collaboration with dedicated volunteers and partner organizations, IDF has worked to implement SCID newborn screening in all 50 states, ensuring that every child born in the U.S. has a chance at a happy and healthy life.

Where We Started

In 2008, Wisconsin became the first state to screen for SCID, and every year since then new states have joined in implementing this lifesaving screening. In 2010, thanks to IDF advocacy, supported by members of the medical community and families affected by SCID, the federal government added SCID to the Recommended Uniform Screening Panel. Since then, state by state, IDF worked with local organizations, legislators and statewide public health officials to break down the barriers and have SCID added to the newborn screening panel in each state. Finally, in December 2018, Louisiana became the 50th state to implement SCID newborn screening.

This monumental moment was made possible through hard work and persistence. Advocating for SCID newborn screening required dedication, much of which came through grassroots organizations that worked with IDF to advocate for these issues, doctors who pioneered diagnosis and treatment, and volunteers and families of those with SCID who have shared their personal stories of struggle to raise awareness on why this important issue deserves the attention of lawmakers.

Where We’re Going

“It is gratifying to see all 50 states now testing for SCID, but the challenge does not end with universal testing,” said John M. Routes, MD, Section Head, Allergy/Clinical Immunology, Medical College of Wisconsin/Children’s Hospital of Wisconsin, a pioneering advocate for SCID newborn screening and a member of the IDF Medical Advisory Committee. “Many infants who test positive for SCID face a challenging road to firm diagnosis and successful treatment. I am proud to be working with IDF to help ensure clinicians and patients throughout the U.S. get the resources they need.”

IDF recently began work under a grant from the Health Resources and Services Administration (HRSA) to launch a two-year program—SCID Compass—to improve outcomes for infants detected through newborn screening. The SCID Compass program is designed to increase awareness and knowledge about SCID, support state newborn screening programs, link families, especially those living in medically underserved areas, to services and develop long-term follow-up strategies for infants identified through newborn screening.

To read the press release about SCID Newborn Screening in all 50 states, please visit: www.primaryimmune.org/SCID-50.

To learn more about SCID, please visit www.primaryimmune.org/SCID.
Remembering William T. Shearer, MD, PhD

The primary immunodeficiency (PI) community lost one of our greatest champions. William T. Shearer, MD, PhD, passed away Tuesday, October 9, 2018 in Houston, TX at the age of 81. In addition to serving as the lead physician offering innovative and compassionate care for David Vetter, affectionately known as the boy in the bubble, Dr. Shearer was responsible for numerous pioneering and meaningful discoveries that transformed the testing and treatment of PI during his illustrious four-decade career at Baylor College of Medicine and Texas Children’s Hospital.

Throughout the Immune Deficiency Foundation’s history, Dr. Shearer made many important contributions that helped to shape and advance the mission of our organization. In addition to serving as an engaged and highly respected member of our Medical Advisory Committee, Dr. Shearer played an important role in the success of a wide variety of IDF’s major initiatives, including the IDF Patient & Family Handbook. In reaction to our patient community’s concerns about the importance of immunization, he was the lead author of the landmark article, “Recommendations for live viral and bacterial vaccines in immunodeficient patients and their close contacts.” His tangible leadership within the PI community included regular participation in and presentations at our national conferences and meetings, participation in our annual Walk for PI events, and taking part in media interviews on a national level on behalf of IDF on numerous occasions.

Dr. Shearer was an amazing person and the PI community will forever be grateful for the advancements he fostered in the testing and treatment of these rare diseases. He will also be remembered for the expert care he provided in the diagnosis and treatment of many members of our community over the years. His legacy will live on in the hundreds of thousands of people with PI who are leading healthier, more active lives because of his work.

If you would like to read more about Dr. Shearer and his life and career, visit www.primaryimmune.org/WilliamTShearer.

Giving for the Future

The way that you donate is constantly evolving as new technology is introduced. Where you used to give through pen, paper and mail, you now can give through the click of a button online. And while the methods of giving may change, the reason behind the donation does not. You give to provide hope and assistance to the future.

As a member of the primary immunodeficiency (PI) community, it’s likely that you’ve received information, publications, resources, support, etc. from the Immune Deficiency Foundation (IDF).

The generosity of our donors help make the availability of these resources possible.

You give to provide hope and assistance to the future.

By donating, you ensure that the next generation of those living with PI will receive the support that you have received. You can help provide access to the crucial resources that helped you to understand your diagnosis.

No matter what you choose to give, donating is easy, and now you can select your gift designation to give towards IDF initiatives of interest to you. Whether donating to support diagnosis-specific programs or helping to fund our core services, you can find all the ways to give: www.primaryimmune.org/give.

Thank you!
Make the Most of Your Appointment

Have you ever left a healthcare appointment and suddenly remembered that you forgot to ask a question or mention a symptom, or even worse, you didn’t understand what you were supposed to do next? Here are tips that can help you to make the most of the time you spend with any of the healthcare providers you see, from primary care physicians to nurse practitioners to immunologists and other specialists.

BEFORE YOU GO

**Take Control**

You are in control of your health. It’s up to you to schedule your appointments, ask for help, and most importantly care for yourself. Don’t ignore signs of illness or hesitate to notify the appropriate provider about a new problem. You don’t have to suffer in silence. Develop an action plan before you have a problem.

**Understand Your Diagnosis and Keep Track of Your Health**

By understanding your specific primary immunodeficiency (PI) diagnosis, you’re already taking steps to take control of your health. Know your personal health history and details; gather the data regarding your initial diagnosis, maintain a list of all your medications and doses, and all drug allergies. Make sure to track any symptoms you have, especially unusual ones, and add them to your list.

Keep this information with you at all times so it’s readily accessible. Consider using a personal health record, like IDF ePHR. IDF ePHR makes keeping track of all necessary health information simple, and it allows you to track symptoms, make notes and more. www.idfePHR.org

**Prepare for Your Appointment**

Write down any and all questions that you have in between appointments. Compile them into one list and take it with you. Go over the list, and make sure you’re not missing anything. Check your personal health record, like IDF ePHR, to make sure you’ve inputted the most recent information. Check all your medications and prescriptions to see if any of them will run out soon or if any will be out-of-date before your next appointment.

**Who’s on Your Team?**

The people on your team help you stay healthy, and even though it may not seem like it, they’re all interconnected. Your primary care provider may send you to a specialist, who then in turn sends a prescription to your pharmacist, who may have to contact support staff with any questions, and so on. Here are the people who are on your team. Make sure you know who they are and how to reach them. Add them to the contacts in your phone.

- Healthcare Providers
- Therapists
- Primary Care
- PT, OT, Counselors
- Specialists
- Support Staff
- Nurses
- Social Workers
- Pharmacists
- Family/Friends

**Know Your Rights**

As a patient, you have the right to have your condition and treatment explained so that you can understand it. You have the right to a second (or more) opinion. You can make decisions about treatment and to refuse treatment, if you so choose. You may request copies of medical records and lab reports. You should always be treated courteously and with respect, and you always have the right to privacy.

Looking for a Healthcare Professional?

**Take Advantage of the IDF Physician Finder**

Have you moved? Did your physician retire? Are you looking for someone who is experienced in dealing with primary immunodeficiency diseases (PI)?

**Check out the new Physician Finder!** Finding a physician who understands PI can be difficult. IDF has long maintained a database to help patients and families locate a specialist, but now for the first time ever, that information is available 24/7 with the click of a button. Log in to your IDF My Account to access the IDF Physician Finder. Search for physicians by geographic location, last name, specialty and more. For support or questions regarding how to create an account or update an existing account, contact support@primaryimmune.org.

**Already have a physician you like?** See if they’re listed! Our list of physicians is a collaboration, and you can help someone else find the treatment they need by making sure your physician is on our list. Visit www.primaryimmune.org/my-account.

Let us help you find the right physician. www.primaryimmune.org/my-account
WHAT YOU CAN DO DURING THE APPOINTMENT

**Take Notes**
Share your list with your provider first. Have paper and pen with you and write down what they're saying so you don't forget. Or take notes on your smartphone or tablet. If you’ve tried this before and couldn’t get everything down; ask your healthcare professional if you may record your appointment so that you won’t miss something important. If you have a paper list, ask your provider to write the important details down. You can also request a visit summary from the office either printed or e-mailed to you.

**Bring a Trusted, Supportive Family Member or Friend**
This person can take notes for you, or just be an extra set of ears to hear what is said. Prepare them beforehand with what questions you want to ask or symptoms you want to mention. If on the chance you forget something, they can bring it up.

**Communication Is Key**
All of your providers need to know about your health including your diagnosis, medications and plans for care. Your team needs to be on the same page, and you’re in charge of keeping them informed. You should also let family members and people who matter know about your condition and how they can help you. Let them know how you are feeling. Ask your providers to talk to each other as necessary but, again, make sure you confirm that they communicate. The healthcare team you put together should be comprised of those you trust to care for you, and each team member should have a designated role in your care.

AFTER AND IN-BETWEEN APPOINTMENTS

**Review Your Visit**
Once your appointment ends, take some time to review what happened in the appointment. By doing this, you can confirm that you understand any follow-up actions that you need to take and that you had all your questions answered. If there is something you don’t understand, don’t hesitate to contact your team in whatever way you’ve previously agreed upon.

**Establish a Relationship**
Establish a relationship with all the members of your personal health care team. Your benefits from these relationships, will include:

- All parties know up-to-date and accurate information about all of your diagnoses;
- All parties participate in making decisions about your health care;
- Making it easier to manage your symptoms and get good follow-up care;
- Helping you make the most of the time you have with your healthcare team;
- Reducing your stress by making sure your questions are answered and your concerns are addressed;
- And most importantly, you can feel confident that you are getting the best care.

**Stay Routine**
You need to keep up with your appointments. Make sure you have an annual wellness visit (physical) with your primary care provider. You should be taking all your medications regularly as prescribed, get all recommended immunizations, especially an annual influenza vaccine (if applicable). Schedule routine health maintenance screenings as recommended (i.e., monitoring labs, colonoscopy, mammography, etc.).

**When You Get Sick**
You never know when you're going to get sick, so make a plan for what to do when you get sick. Develop an “illness protocol” by asking your healthcare professional “how will I get my questions answered between scheduled appointments,” “what do I do after hours or when the office is closed” and “when and where I should go when I get sick?”

You should also prepare for possible emergency room and/or urgent care visits. Have your immunologist contact information and/or a letter from your immunologist. Like you do for your scheduled appointments, you should have a record of your health records (it’s easy with IDF ePHR). You can also go the extra mile and bring your copy of the IDF Patient and Family Handbook and/or IDF Diagnostic & Clinical Care Guidelines.

Keeping track of your health isn’t always easy while you’re living with PI, but by maintaining regular appointments with your providers, establishing a relationship with your healthcare team and getting your prescribed treatment and medications, you will be a better informed and prepared individual.

*This content should not be used as a substitute for professional medical advice. In all cases, patients and caregivers should consult their healthcare providers. Each patient’s condition and treatment are unique. The benefits and risks of any treatment should be discussed with the patient’s provider.*
Bringing the Community Together

For all those living with a primary immunodeficiency disease (PI), meeting someone who either shares their experiences, has the same diagnosis or can simply understand what they’ve been through can be life changing. For attendees of IDF events, often it is the first time they are able to meet someone else with PI—the first time they truly feel understood. In 2018, IDF hosted a variety of events for our community, providing education, support and fun for those living with PI of all ages.

IDF Retreats 2018
This summer, 485 individuals and families of all ages came together at the IDF Retreats in Cleveland, OH and St. Augustine, FL. Since IDF began IDF Retreats 20 years ago, we’ve had thousands of people join us, bringing together the PI community, and this year was no different. With informative educational sessions and meaningful opportunities to meet others in the community, this year was one of the best for the IDF Retreats.

IDF Retreats 2018 were supported by CSL Behring, Grifols, Shire, Horizon Pharma, Octapharma, and Leadiant Biosciences.

IDF Teen Escapes 2018
IDF Teen Escapes give those ages 12-18 who are living with PI a weekend getaway. During this weekend, teens develop coping skills, promote and nurture friendships, learn how to live with PI, and have some fun with teens just like them. (And parents get their questions answered and have fun too)! In 2018, teens and parents gathered in Minneapolis, MN and Chandler, AZ, and 146 attended.

IDF Teen Escapes 2018 were supported by CSL Behring, Grifols, Horizon Pharma, and Shire.

IDF Get Connected Groups
There are over 30 IDF Get Connected Groups across the country overseen by our devoted IDF Get Connected Leaders. These volunteers truly take the time to bring those living with PI in their local areas together to have the opportunity to talk, gain support and more.

IDF Get Connected Groups 2018 were supported by Lead Sponsor Shire.

IDF Education Meetings
Each year, we have thousands of families and individuals join us across the country for IDF Education Meetings and Family Conference Days (which are meetings with a youth program), and in 2018 alone, we’ve seen close to 1,500 members of our community at these events.

IDF Education Meetings 2018 were supported by CSL Behring, Grifols, Shire, Leadiant Biosciences, Octapharma, ADMA Biologics, BPL, Horizon Pharma, Kedrion Biopharma, Accredo Healthcare, CVS Specialty/ Coram CVS Specialty Infusion Services, Diplomat Specialty Infusion Group, Kroger Specialty Infusion, RMS Medical Products, EMED Technologies, and Soleo Health.

FROM THE COMMUNITY

“It was an amazing weekend! A great opportunity to build upon our knowledge and share hope for the future. Thank you!”
– An IDF Retreat Attendee

“Thank you for all you did for our son. Your support and encouragement changed his life.”
– A Mother of a Teen Escape Attendee

“I really valued the opportunity to interact with others! I’ve learned so much useful information.”
– An IDF Get Connected Group Attendee

“I am always so surprised at how much I learn at these events, even though I have been to quite a few now!”
– An IDF Education Meeting Attendee

Thank you to all those who either attended, volunteered, gave presentations or supported these events!

Save the date for June 20-22, 2019 for the IDF 2019 National Conference in National Harbor, MD, outside of Washington, DC. As the world’s largest gathering of people with PI, the IDF 2019 National Conference will have more than 40 educational sessions from experts in the field, opportunities to connect with others in the PI community and so much more.
Walk with Us in 2019!

Thanks to all those who supported IDF Walk for Primary Immunodeficiency 2018! Whether by donating, creating a team and raising funds, volunteering, walking, or cheering from the sidelines, you’ve helped make a difference for those living with PI. Since the walks began in 2013, the PI community has raised more than $4 million to fund educational resources and help support research of PI. IDF is now awarding research grants because of the funds raised through IDF Walk for PI. And we couldn’t have done all this without you!

It’s never too early to start planning your 2019 walk team, getting together with members of your team for an outing and raising awareness for PI.

Share your efforts on social!

#WalkforPI  
@idfcommunity  
@TZtheIDFZebra  
www.walkforpi.org

Registration opens for next year in Spring 2019!

2019 WALK LOCATIONS

NATIONAL
Boston, MA  
Chicago, IL  
Los Angeles, CA  
New York City, NY  
Philadelphia, PA

REGIONAL
Atlanta, GA  
Baltimore, MD  
Cleveland, OH  
Dallas, TX  
Detroit, MI  
Orange County, CA  
San Francisco, CA  
St. Louis, MO  
St. Paul, MN

COMMUNITY
Indianapolis, IN  
Kansas City, MO  
Omaha, NE  
Portland, OR  
San Antonio, TX  
Tucson, AZ  
Waco, TX

More to come!
Interested in organizing your own Community Walk?
Contact
walk@primaryimmune.org.

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PromptCare Ig Programs*  
US Bioservices***

*One walk, **Two walks, ***Six walks, ****Ten plus walks

World’s largest gathering of people with PI  
More than 40 educational sessions  
Opportunities to connect with others

Register at:
www.idfnationalconference.org

W i n t e r  2 0 1 9
How to Reach Your Elected Officials
Getting through to Those in Office

The midterm elections are well behind us, and it is a great time to consider reaching out to your elected officials. Establishing and maintaining relationships with those who represent you, at all levels of government, is vital to securing their support in the future. We want to make sure all elected officials know about primary immunodeficiency diseases (PI) and how these disorders impact your everyday life. From your local city council to Senators in Washington, DC, meeting with your elected officials is easier than you may think.

Creating a strong relationship can help enact change. These relationships are built much the same way as any other relationship—by being friendly, helpful and informed on the issues at hand. There is no guarantee for how much time you will have with an elected official. You need to be prepared to tell an effective story, something that inspires them, addresses the greater good and makes them want to take action.

Elevator Pitch
If your meeting with an elected official ends up being quick or rushed, you need to be ready to pitch your story. Here are the key points you need to hit to be effective:

- **Introduction** – You want them to know your name and your face.
- **Tell your story** – Your story is who you are; it is how they will see you.
- **Explain the challenges you face** – Use details in order to paint a picture for them to understand your stance.
- **Describe the outcome you hope to achieve** – Take a stand on the issue you are addressing.
- **Shareable materials** – Have a one-page handout that’s easy to read and digest but hits all the important points. Once you leave them, this will be what they have to remember you. Reach out to IDF before your meeting for materials.
- **Conclusion** – The conclusion to your story may be inspiring or heartbreaking, but it should lead to action and build up to your “ask.”

- **Make the ask** – You want something from them, and this is your time to tell them exactly what it is. Be sure to focus on the greater good.
- **Thank them** – Even if it was quick, they took the time to hear from you, be courteous and thank them.

Conducting a Meeting with an Elected Official
Taking the time to visit your elected officials can send a powerful message about what you care about as a constituent. Here are some tips for your visit:

- **Start on a positive note** – As we mentioned, the elected officials with whom you are speaking are likely busy, so be sure to be courteous.
- **Be direct** – State your position and what you are asking the legislator to do. Do not let the meeting stray.
- **Shareable materials** – Reinforce your meeting with the one-page handout mentioned earlier. Remember: one to three facts make an impact, any more can be overwhelming.

- **Capture the moment** – Take a group photo to post or share. It is a reminder of who you are.
- **Speak with the aide** – When you make a trip to meet an elected official or legislator, you expect to speak with them. If they are not available, always opt to speak with their aide or a member of their team.
- **Thank them** – Regardless of how the meeting goes, thank them for taking the time to hear your concerns. Courteousness can go a long way.

The Follow-Up
Following up after an elevator pitch or a formal meeting is not only polite, but it also gives you another opportunity to advocate. Take the time to follow-up in writing, be it e-mail or letter. Thank them again, remind them of your issue, add at least one key fact, include links to where they can find additional information and once again make your request for action.

To be more involved in advocacy for the PI community, visit www.primaryimmune.org/advocacy-center.

IDF Advocacy Workshop 2018
An IDF Advocacy Workshop took place in Annapolis, MD in late September. Those living with PI from the Mid-Atlantic region and beyond came together for a chance to become informed, skilled volunteers who can be the voice of the community. Thank you to the elected officials from Maryland, including Delegate Terri Hill, Delegate Clarence Lam, and Delegate Robbyn Lewis who spoke at the workshop and to all who attended! Weren’t able to make it? We’ll be hosting two more state advocacy trainings in 2019! Be on the lookout for more information on these.

The IDF Advocacy Workshop 2018 was supported by CSL Behring.
New Data from IDF 2017 National Patient Survey

Analysis of the IDF 2017 National Patient Survey results are beginning to reveal interesting findings. This information, given by members of the primary immunodeficiency disease (PI) community, can help us better understand your experiences, which can make an impact on the quality of life and treatment for those living with PI. Taking part in research and participating in surveys provides information that is vital to continuing our mission.

In October of last year, the IDF 2018 National Ig Treatment Experiences and Preferences Survey was mailed to randomly selected households.

The IDF 2018 National Ig Treatment Experiences and Preferences Survey specifically focuses on your experiences with intravenous immunoglobulin replacement therapy (IVIG) and subcutaneous immunoglobulin replacement therapy (SCIG). Co-developed with immunologists, the purpose of this survey is to learn more about how immunoglobulin (Ig) replacement therapy affects the lives of those living with PI.

We encourage you to share your experiences with IDF! To learn more about the IDF National Ig Treatment Experiences and Preferences Survey, please visit www.primaryimmune.org/2018-Ig-Treatment-Survey.

Now is the time to make sure your contact information is up-to-date, so we can contact you to share your experiences. We can’t e-mail you about our surveys unless you have an IDF My Account and are subscribed to “IDF Surveys.” If you do have an IDF My Account, log in, scroll down to “My E-mail Subscriptions” and subscribe to “IDF Surveys.” If you have not created an account yet, go to www.primaryimmune.org/my-account.

IDF National Ig Treatment Experiences and Preferences Survey Winners

Congratulations to those who completed their surveys by December 31, 2018 and were entered into our first lottery for Amazon gift cards!

• Jennifer S. from Minnesota ($700)
• Susan D. from Alabama ($200)
• Clover H. from California ($100)

What Should I Know about Clinical Trials before Agreeing to One?

Clinical trials are necessary to develop safe and effective products with limited side effects, while also providing the most therapeutic benefit. The safety and effectiveness of these potential new medications and new medical devices depends on clinical research to provide the Food and Drug Administration (FDA) with enough information to decide to approve or reject these products.

There are many opportunities for individuals living with primary immunodeficiency diseases (PI) to partake in clinical trials. Before doing so, make sure you know all the facts and can make an informed decision that is best for your health. Deciding to take part in a clinical trial is something that only you can decide with information from the investigators and their teams. There are many possible benefits, as well as drawbacks to partaking in a clinical trial.

Participation allows you the benefit of a treatment option that may not otherwise be available, and you have a chance to help others by advancing science.

There is always a chance of the treatment or medicine not working, and even if side effects are known, you may experience other side effects unknown to the study team at the time you start. You may need frequent monitoring depending on how the medicine or treatment is taking affect.

Randomization is used in some trials to reduce different sources of bias. Bias occurs when results are affected by other factors that are not related to the treatment(s) being tested in the clinical trial. In some randomized clinical trials, one group receives the new treatment, and the other group receives the most widely accepted treatment. Though rarely used in PI drug studies, inactive drugs called placebos may also be given as the alternative to the new treatment. When participating in a clinical trial there’s always, however, a possibility of not being selected in the group that will receive the new treatment — this will be unknown to you until the study concludes. At the conclusion of the study, the results from each group are compared to show which treatment is more effective.

As a participant in any kind of research study, you have rights. If you are approached about participating in a study, you can decide to participate or not without any effect on your regular care. If you decide to participate, you will be told about important risks and benefits that are known about what is being tested. You will learn how long participation will take, what is expected of you, including any costs, and/or if you will receive any payment for participating.

Clinical trials are crucial to the medical community in finding more effective treatments. To learn more about clinical trials, please visit www.primaryimmune.org/clinical-trials.
What’s Your Story?
Share It with the IDF Community and Inspire Others

We all have a story to tell, and it’s important for those who are living with a chronic, rare disease, like primary immunodeficiency disease (PI) to share their experiences with others. It lets others, like you, know that they aren’t alone. They can listen to what you’ve gone through and think, “that is exactly what I needed to hear today.”

Since primary immunodeficiencies are rare, you may not have heard from someone with your diagnosis. We want to fix that. We often hear from members of the PI community who had never met anyone else living with PI. Once they watched a video or read a blog on the IDF website, they realized that someone understands them.

Our stories are powerful. They inform, educate and reassure. Wondering what kind of story to share? It can be your life story, your diagnosis or one moment that stands out. It can be a time you felt alone, a time you felt strong or a time you weren’t sure what to feel. What matters is sharing it so others can find comfort that they’re not alone. Here are some examples of stories you can share:

- Your diagnosis journey
- Meeting a member of the PI community for the first time
- What/who helped you
- Advice for others living with PI
- How you advocate for the PI community
- Ways you help to raise awareness for PI

Make a difference for others living with PI and share your story with us by visiting www.primaryimmune.org/share-your-story or by contacting us at shareyourstory@primaryimmune.org.

Need some inspiration? We’ve got inspiration!

You can watch individuals and families living with PI speak about their experiences through IDF Reel Stories. IDF Reel Stories are patient-generated videos designed to encourage and empower fellow patients and their loved ones. In addition to general stories of hope and inspiration, you can select from a robust playlist of video testimonials that inspire us on some level – whether as individuals, families or as members of the IDF community. Watch them at www.primaryimmune.org/idf-reel-stories.

You can also hear stories from our community by reading blogs on the IDF website. Please visit www.primaryimmune.org/blog.

You Could See Your Story Here!

Want to see your story here? We’re always looking for empowering stories from those living with PI. By sharing your story with us, you could be featured in a future edition of the IDF ADVOCATE or on the IDF blog!

You don’t have to be a writer or a public speaker to step up and speak out—you just have to be you. We can’t wait to hear your story. Contact us at info@primaryimmune.org.
Primary Immunodeficiency Q&A is a series of podcasts created to answer questions and address topics to help members of the IDF community. Each episode will feature a special guest, from physicians and nurses to life management experts and individuals living with primary immunodeficiency diseases (PI). John G. Boyle, IDF President & CEO, hosts multiple specialists to discuss issues such as health, wellness and advocating for yourself.

The first three episodes of the Primary Immunodeficiency Q&A are now available for you to listen!

In our first episode, Taking Control of Your Healthcare Management, hear from Jennifer Heimall, MD of the Children’s Hospital of Pennsylvania as she discusses the best ways for young adults to manage their care with insight and tips.

Our second episode, Coping with the Emotional Dimensions of PI, we talk to special guest and psychotherapist Jodi Taub, LCSW, LLC about how young adults cope with the diagnosis and everyday life with PI, providing insight that is crucial for all young adults.

The next episode, Employment and PI, featuring Brian Rath, an attorney at law and member of the IDF Board of Trustees, we discuss how to find a job that you’re comfortable with, how to handle your PI while working and looking into how your health benefits are a factor in your employment.

This podcast series provides online learning opportunities allowing young adults across the country (and people of all ages with PI) to learn about managing PI from the comfort of their own home. Ready to take a listen? Visit www.primaryimmune.org/podcast. Already listened and loved it? Subscribe, rate and write a review for us on iTunes!

If you would like to submit a question or topic to be discussed on a podcast, email us at info@primaryimmune.org.

The IDF Young Adult Online Education Series is supported by CSL Behring.

Stay Informed about Your Health Insurance

Living with a rare, chronic disorder, there are certain questions you need to ask yourself about your health insurance. Regardless of how you and your family obtain your health insurance, it is ultimately your responsibility to understand your plan. Understanding your plan can have a huge impact on both your health and your finances. IDF is here for you! We can provide you with information and resources, including comparison worksheets, to help you understand health insurance plans and make the best possible choice in your selection. Get more information at www.primaryimmune.org/insurance.
Kim DiGangi experienced infections her entire life. She spent many years on antibiotics but never connected the dots. When Kim was finally told she may have a primary immunodeficiency disease (PI), she was in complete denial. She sought out second, third, and fourth opinions. Finally, she found a doctor that did not feel she had a PI and sided with him. Several years later, the complications continued, and she resigned herself to her diagnosis of Common Variable Immune Deficiency (CVID). “Once I finally accepted the diagnosis, I was scared and overwhelmed and kept asking, why me?” explains Kim. “My doctor knew of only one other person with the condition, which left me feeling pretty isolated.”

Receiving a diagnosis of a PI isn’t easy—it’s life-changing. It is normal to experience a range of emotions, and many people feel unsure where to turn to find someone who might understand what they are going through. The healthcare system can be helpful, but too often it can’t provide the type of emotional assistance needed with peer-to-peer support. Serendipitously, Kim saw a flyer in her doctor’s office about an upcoming Immune Deficiency Foundation (IDF) local meeting and decided to attend. There she met others like herself, coping with the same challenges. “The meeting showed me that I was not alone, and with that, I turned a corner,” says Kim. “Acknowledging your feelings turns out to be an empowering first step in coming to terms with your diagnosis.”

Having a support network that you can turn to for advice and encouragement during challenging times is critical throughout the PI journey. Many people with PI find the support offered by others with a similar diagnosis to be just as important as the healthcare team. “Connecting with others like myself helped put my own experiences living with PI into perspective,” adds Kim. “You can get a much better sense of the journey from others who have trodden the same path and found the way through.”

Kim’s experience nudged her to become an IDF Peer Support Coach, sharing her own story to help others. IDF established the Peer Support Program to connect people who share similar relationships to PI. Participation in the program gives you the opportunity to interact with an IDF Peer Support Coach, who is a trained volunteer with personal experience living with PI. This free resource is for anyone personally affected by PI—a patient, parent or another family member, friend or caregiver. Kim has been volunteering in this program for more than five years and has spoken to many people during that time. “It’s been very gratifying to help others.” As a Peer Support Coach, she has made some special connections with people and hopes her story provides them with the encouragement they need. “I wanted to help people accept their diagnosis, move ahead, and discover new ways to live an affirmative and fulfilling life,” concludes Kim. “Becoming a peer support coach allows me to do that.”

Are you a caregiver, family member or someone with PI and would like to speak with someone about your journey? It’s easy… just contact IDF through Ask IDF on the website (www.primaryimmune.org/ask-idf) or call 800-296-4433.

Would you like to make a positive difference in someone’s life? It might be as simple as sharing your story and listening. To learn more about becoming an IDF volunteer, visit www.primaryimmune.org/volunteer.
TZ’s Corner

What’s In Your Bag – TZ the IDF Zebra

TZ the IDF Zebra is a VIZ (Very Important Zebra) and often has to carry many things when traveling around to see friends. Let’s take a look at what you can find when you look into TZ’s bag.

Hi, friends! TZ here,

Here’s an inside peek at what you can find inside my THINKZEBRA! bag that I take with me on every trip to make sure I can stay happy and healthy. Hopefully I didn’t forget anything!

Stay Germ Free – Hand Sanitizer: It’s important for those living with PI to make sure they stay away from germs, and hand sanitizer is a must for my hooves.

Fuel – Zebra Cake, Something Healthy and Water: Snacking helps keep my energy up, especially when I’m traveling for walks. I like to keep a few Little Debbie Zebra Cakes in my bag for a sweet treat, and usually something healthy, like carrots or celery to keep my trim, striped figure. I also take water with me everywhere so I can stay hydrated.

Take Note – Pen and Paper: I always like to keep a few pens in my bag, plus a notebook so I can write down important information, and be reminded to THINK ZEBRA! I may be biased, but I carry extra THINK ZEBRA! pens with me to hand out and spread PI awareness.

Stay In Touch – Smartphone: I always want to be able to reach my fellow zebras, check in Twitter and Instagram accounts (@TZtheIDFZebra), snap pictures and more!

Is there anything you suggest I should start carrying or that you carry that you want me to know about? Let me know by sharing a picture on social media and tagging me (@TZtheIDFZebra) and IDF (@idfcommunity).

Tag TZ!

It’s been a busy time for our pal, TZ! With walks all over the country, TZ has been traveling all over to see his friends and members of the IDF community. If you’ve seen TZ at an IDF event near you, share your pictures of you with our favorite zebra on social media by tagging TZ in your pictures.

By tagging TZ, you could be featured in an upcoming IDF ADVOCATE Newsletter, like our friends below!

TZ the IDF Zebra – Official Mascot of the Immune Deficiency Foundation

The primary immunodeficiency (PI) 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. People with PI are the zebras of the medical world. So IDF says THINK ZEBRA!

A few years ago, the saying truly came to life through the official IDF mascot, TZ the IDF Zebra. The name “TZ” comes from THINK ZEBRA! TZ travels across the country to promote awareness of PI and meet fellow zebras. Children, young and old, can’t help but smile when they see TZ, serving as a reminder to members of the PI community that they are not alone and together we are #zebrastrong.

Follow TZ the IDF Zebra!

Twitter: @TZtheIDFZebra

Instagram: @TZtheIDFZebra
Thank You

Thank you to the following companies for their 2018 support of the Immune Deficiency Foundation and the primary immunodeficiency community!

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Interested in supporting IDF? Contact us:
info@primaryimmune.org.

For an Updated IDF Calendar of Events, Visit
www.primaryimmune.org/event-calendar.

See you there!
Registration and more information:
www.idfnationalconference.org

World’s largest gathering of people with PI
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