Letter from IDF’s President & CEO

In a Time of Distance, Stay Connected

Like many of you, I’ve had limited interaction with anyone outside of my immediate family since March. I’ve filled my car with gas a few times, gone to a handful of stores when delivery wasn’t practical, and even hit a drive-in movie theatre a couple of times. However, the majority of the last seven months for me has been spent within walking distance of my house.

But as school re-started for my son, and life outside has opened back up in other ways, it’s been harder to maintain that same level of protective distancing. While nothing has fundamentally changed in terms of the treatment of COVID-19, many of those around us are letting their guard down. I liken it to those in zombie movies who go stir-crazy and then do something self-destructive (“No! Don’t open the door!”). But as we want to make it to the end-credits of the movie, we’re just going to have to support each other in staying the course.

This is why it’s important, now more than ever, that we stay connected with each other online. While we can’t physically be together at the moment, we can stay connected. Between social media, Zoom, texts, emails, and good ol’ fashioned phone calls — there are ways of connecting (and commiserating) with others who are in the same boat as you. Folks who are grappling with these feelings of isolation and who are excited to connect with others who “get it.”

With all of that in mind, I hope you’ve had an opportunity to experience some of IDF’s many ongoing virtual events. They’re meant, of course, to provide you with information — but also with connection. Our IDF Forums have grown to allow hundreds to join us and hear medical experts speak and to engage in Q&A. Our IDF Get Connected Groups have grown to let each and every person receive the support they need. Our IDF Walk for PI is still going strong, but in individual neighborhoods instead of all in one location. Our IDF Advocacy Workshops are finding new ways to affect change for us all in terms of public policy issues.

These virtual events (and a number of others) have allowed us to serve more of you than ever before in our 40-year history. They allow us to provide you with important information about individual diagnoses, issues of interest to the entire PI community, and updates about what’s known about COVID-19’s impact upon our world. If you haven’t experienced one of these events yet, please consider joining us for one. It’ll provide you with information and connection that we think you’ll find helpful.

In order to make sure that you have the ability to stay aware of our online events and other opportunities that may be of interest during these unusual times, we ask that you make sure that your information in your IDF My Account is up to date: especially your email address and your diagnosis. If you have an old email address, you could be missing out on emails for events and ways to get involved. And if we don’t know what your diagnosis is, you might not be invited to special diagnosis-based events. We’re sending out news, invitations, and updates almost every single day (yes, we know that can be a lot, but like I said, we want you to have every opportunity possible). Updating/checking your information takes less than 10 minutes. So, if you have 10 minutes now or later tonight, please take the time to do so by logging into your account at: www.primaryimmune.org/my-account.

I hope to see you at one of the next virtual events that we’re hosting; we’re adding more and more each day. And remember, we may be alone, but we’re alone in this together.

Stay #zebrastrong, my friends!

John G. Boyle, IDF President & CEO
Where can I find all of the information you’ve shared about COVID-19?
Since the start of the pandemic, IDF has been dedicated to keeping our community informed on all things related to COVID-19 and PI. This has included many video updates from medical professionals, IDF Forums dedicated to the topic of COVID-19, and more. You can find all this information by visiting: www.primaryimmune.org/coronavirus.

Is IDF still hosting events in-person?
While everyone at IDF would love to be able to greet our community at an in-person event, at this time we are putting the health and safety of you first by going virtual. All of the events found on our Calendar of Events are virtual! This has allowed us to reach more of you than ever before. Find one you’re interested in joining at: www.primaryimmune.org/events.

I have some personal questions that I’d like to ask the PI community. How do you suggest I do this?
We know that part of living with PI means needing to connect with others who are in similar situations and have similar issues. To help, we created IDF Friends, an online platform for the PI community to connect, ask questions, get answers, and more. Create your IDF Friends account at: www.idffriends.org. For other questions, visit: www.primaryimmune.org/ask-idf.

I’ve heard on the news that plasma is being used to potentially help treat COVID-19 and want to encourage my friends and family to donate. How can I persuade them?
Now more than ever, we’re looking for individuals to step up and donate plasma. For many people, they had never heard of plasma donation before the COVID-19 pandemic began. IDF has created a website dedicated to those who are interested in donating plasma. Find out more at: www.plasmahero.org.

I haven’t seen anything posted about the IDF Retreats. Are they still happening this year?
The IDF Regional Conferences are going by a new name! Our IDF National Summit will be held virtually November 5-8, 2020, and we hope that you’ll be able to join us from the comfort of your own home. To learn more, go to page 5, or visit: www.primaryimmune.org/idfsummit.

Are you still hosting the IDF National Conference in Dallas in June?
We are still hosting a National Conference, but it will be virtual and held from June 22-26, 2021, using the same immersive platform that will be used for the IDF National Summit. Stay tuned for more details!
What’s Going on in the IDF Community?

IDF Events & Updates

IDF has always strived to deliver educational, valuable, and fun events for the PI community. And during this time of uncertainty, we’re still putting forth our best efforts to give you events that you can enjoy and look forward to. It’s our hope that now, you can participate in even more IDF events than you could in the past. Each IDF event is now 100% virtual! You can join us from the comfort of your own home, knowing that you don’t have to risk your health by venturing out.

We hope that you’ll join us at one (or many) of our upcoming events: www.primaryimmune.org/events. We also know how important it is to update you on the goings on and exciting news here at IDF. We have new announcements coming out regularly!

COVID-19 Can’t Stop Us!

IDF Walk for PI 2020

IDF Walk for Primary Immunodeficiency (PI) 2020, an initiative of IDF, is taking place this fall. This season is shaping up a little differently than past walks due to COVID-19. Instead of coming together and walking physically side by side, the PI community has started opening up their laptops and whipping out their cell phones to unite online. Zebras, family, and friends are participating from Coast to Coast raising awareness and funds for those living with PI, and so far, we’re still having a great time walking.

It’s not too late to join us and make a difference. Register now and donate or fundraise at least $25 towards IDF Walk for PI to receive a free IDF swag bag that will include your 2020 Walk for PI t-shirt. In addition, you’ll gain access to a variety of online puzzles and games and have the chance to make an impact on those affected by PI. You’ll also be able to join us on December 15 at 7 PM ET via Zoom to connect with fellow zebras and celebrate all the fundraising successes we’ve accomplished. It is an event you don’t want to miss! We can do great things when we all come together and Stride with IDF Pride.

Register for IDF Walk for PI at: www.walkforpi.org

IDF SCID Compass Update

Continuing Our Journey with SCID Compass

IDF has received a $2.97 million grant extension from the U.S. Health Resources and Services Administration (HRSA) to fund screening and education programs for people with Severe Combined Immunodeficiency (SCID) through the SCID Compass program. This one-year grant is an extension of an original two-year grant awarded in 2018 to IDF from HRSA to improve outcomes for infants with SCID, which lead to the creation of the SCID Compass program.

We are thrilled to have the opportunity to build upon the work done in the first two years of the grant and the SCID Compass program. This includes increasing awareness and knowledge of SCID; supporting state newborn screening (NBS) programs; linking families, especially those in rural and underserved areas, to clinical services; and identifying and developing long-term follow-up strategies. In addition, the grant supports IDF’s goal of access and inclusion for all by addressing disparities in knowledge and barriers to services that portions of the underserved population may experience.

To learn more about SCID Compass, visit: www.scidcompass.org.

HRSA Acknowledgement/Disclaimer: This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $2.97 million with 0% financed with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.
IDF Forums and IDF Get Connected Groups

We have seen a great turnout from the PI community over the last few months for our IDF Forums (formerly IDF Education Meetings) and IDF Get Connected Groups. These now virtual events have been flourishing and we’ve seen more participants at these events than ever before. We hope that you continue to tune in to these one-of-a-kind meetings to hear from medical experts and support others who are living with PI. No longer limited to geographic location, we’ve been able to expand our programming to include diagnosis-specific offering for forums and Get Connected Groups.

IDF National Summit
November 5-8, 2020

The IDF National Summit, formerly known as IDF Retreats, is a weekend gathering designed with everyone in the PI community in mind—especially you! In the past, the IDF National Summit was two different events, on different dates, in different cities. Now, we can have everyone attend the exact same immersive online event!

Whether you’re a patient, parent, sibling, child, or partner, we encourage you to attend and learn how to develop better approaches to life with a primary immunodeficiency. Whether a person is newly diagnosed or has been living with PI for years, the IDF National Summit offers an opportunity for individuals and family members to connect with others to learn more about dealing with their diagnosis. The educational sessions feature leading physicians and healthcare professionals who address the treatment and management of primary immunodeficiency. Insurance specialists, public policy experts, and other qualified professionals discuss life management issues.

The youth and teen programs held during the Summit are both fun and educational. They’re designed to help the younger members of the IDF community better manage their diagnosis. With an ever-evolving, age-appropriate curriculum, medical and life skill experts present invaluable information for the younger participants with primary immunodeficiencies.

Register here: www.primaryimmune.org/idfsummit

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Protecting the Immunocompromised Collaborative

Throughout the COVID-19 pandemic, we have heard reference to “the immunocompromised,” leaving many to wonder who those people are and if it’s more than just the elderly or infants. IDF has been actively advocating on behalf of the primary immunodeficiency community during this time. We have reached out to Congress to ensure that patients have access to home infusions and have joined forces with other patient organizations to support issues including expanded telehealth services, increased access to health insurance, support for research, and federal promotion of plasma donations. In this, we realized that there is a need for a strong voice representing all immunocompromised patient communities at the federal, state, and local levels.

With all the mentions of “the immunocompromised” in the response announcements for COVID-19, there has been very little in the way of guidance to ensure protections for this group. It’s essential that as policies and regulations develop, that the voice of those who are immunocompromised is represented and listened to in decision making, both now in the future. We need to continue to fight for protections and responsive government action for those with compromised immune systems. Our solution? The Protecting the Immunocompromised Collaborative. IDF is now working with other patient organizations to advocate for the needs of those who are immunocompromised and are developing a steering committee. To find out more about this exciting collaboration, visit: www.primaryimmune.org/news/idf-leads-collaborative-effort-protect-immunocompromised

Encourage Your Loved Ones to Become a Plasma Hero

Over the last year or so, IDF has regularly spoken out about plasma, the plasma supply shortage, and what we can do to help. Now more than ever, we need more plasma donors. As plasma is being collected and used as a means to help those with COVID-19 and potentially protect some against COVID-19, we need donors dedicated to giving plasma for plasma derived therapies, like immunoglobulin (Ig) replacement therapies.

Many in the PI community rely on Ig replacement therapies like intravenous Ig replacement (IVIG) or subcutaneous Ig replacement (SCIG). In fact, it can take up to 8-10 donations to supply one person with PI treatments for one month, or more than 100 donations to treat one person for a year. This is why plasma donors are heroes. They help save lives.

To help people better understand plasma donation and how it can benefit the PI community (and many more people), IDF has created the Plasma Hero website. Here, you can learn about plasma donation, hear from Plasma Heroes who have donated, find a donation center in your area, and even share your own story of how plasma donation has helped you. Check it out at: www.plasmahero.org.

IDF Forums and IDF Get Connected Groups

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The Faces of IDF
The Stories of the PI Community

PERSONAL PROFILE

My name is Stephanie Aden, I am 49 years old, and I have a primary immunodeficiency (PI). I live on a farm in Nebraska with my husband and our two sons. I run a graphic/website design company from an office on our farm. I enjoy gardening, 3D printing, cooking, and watching my sons participate in their many activities.

I have been a member of the PI Community since I was diagnosed in 2012. As a person who struggled with illness for almost 30 years before receiving a PI diagnosis, I am grateful that the discovery of my condition led to an early PI diagnosis for my sons. I would like to use my experiences of living with a “mystery illness,” going through a long journey to a diagnosis, and helping my children learn to live positive lives in spite of PI, to help give support to others in the PI Community and understanding to those who are unfamiliar with PI.

MY JOURNEY TO DIAGNOSIS

As a child and a teenager, I was often sick and prone to infections. Doctors treated my infections, but could never explain why I was always sick and tired. Eventually, my parents were told that my health problems were due to my inability to manage stress and were advised to take me to a psychologist. As a young adult, I went through phases of pushing for more medical testing, always arriving at another dead-end where another doctor would suggest that the problem was “in my head.”

In 1999, I was reading a magazine in a waiting room and found an article about a woman who had a “mystery illness” and many of her symptoms sounded like mine. I took the article to a cardiologist and asked to be tested for that illness. Though the test was positive, it didn’t explain all my health problems, but it gave me the confidence to push for more answers. 13 years later, a doctor tested me for allergies, looking for a cause of my recurrent sinus infections and discovered that I was completely missing one subclass of immunoglobulins. I was diagnosed with an IgG Subclass Deficiency and Specific Antibody Deficiency and began treatment which has improved my quality of life tremendously.

MY TREATMENT IS MY LIFELINE

My son, Sam, and I both receive intravenous immunoglobulin (IVIG) treatments every four weeks. They are costly, and we have always had to work through the “red tape” with insurance to be able to continue them. At the beginning of 2020, I had to quit my job of 20 years and become an independent contractor because it was the only viable way I could find to get my family health insurance that we could afford and that would cover our IVIG treatments. I want to share my story to help people who haven’t lived in fear over the next insurance premium hike, pre-authorization renewal, or Congressional vote on pre-existing conditions, understand why life-saving treatments like IVIG need to be accessible to the people who depend on them.

As a person who struggled with illness for almost 30 years before receiving a PI diagnosis, I am grateful that the discovery of my condition led to an early PI diagnosis for my sons.
Conducting Research on COVID-19 and Primary Immunodeficiencies

IDF Partners with Columbia University

IDF began a series of surveys on COVID-19 and PI earlier this year with questions related to COVID-19 to help us further understand how the pandemic has affected a variety of health factors. These factors included access to treatment, general health indicators, and whether they’d been tested for/ been diagnosed with COVID-19.

IDF is in collaboration with Columbia University in its research on how COVID-19 affects individuals with primary immunodeficiencies (PI). This will be the first study of its kind but will help us to better understand the differences between how those with a normally functioning immune system react to COVID-19 versus how someone with a PI reacts to COVID-19. Not only that, but this study will be able to help individuals with PI who don’t display average symptoms to hopefully get diagnosed easier, and help educate healthcare professionals on PI.

“The COVID-19 pandemic has brought a lot of uncertainty and anxiety in recent times. We are all facing very challenging times as we try to identify ways to move forward as safely as possible. We are very happy to collaborate with the Immune Deficiency Foundation to provide scientific expertise to better understand the impact of COVID-19 on individuals with primary immune deficiencies,” says a representative from Columbia University. “These surveys are unique in that they will study all individuals with primary immune deficiencies that respond regardless of whether they got sick with COVID-19 and help understand the impact of COVID-19 on the individuals with PIDs as a community with respect to their disease and access to care. We hope this information will help empower them by identifying ways to navigate this pandemic, but more importantly, the true reward will be that individuals with primary immune deficiencies can stay safe and healthy.”

Working with IDF on this study will be Deepti Deshpande, MD, MPH (Fellow in Allergy and Immunology) and Joshua Milner, MD (Division Chief, Pediatric Allergy and Immunology) from Columbia University.

“It’s so important that we understand how COVID is—or is not—impacting everyone who lives with PIDD. We are thrilled to be partnering with the IDF for such a critical project,” says Dr. Milner.

IDF will continue to keep the PI community updated as we further progress in this study. For more information about the research IDF is involved in, please visit: www.primaryimmune.org/research.
Update Your Contact Information

Not hearing from us? Your IDF My Account information might not be up-to-date! Don’t miss an opportunity from IDF, update your contact information today!

IT’S EASY

1. Go to: www.primaryimmune.org/my-account

2. Log-in

3. Update your information

Need help? Contact us at: info@primaryimmune.org.

Thank You

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

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- KORU Medical Systems

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