Largest Gathering of the PI Community in the World
IDF 2017 National Conference

The IDF 2017 National Conference, held in Anaheim, CA, June 15-17, brought together 1,276 attendees from 43 states, Washington D.C., and Guam as well as Canada, China, Germany, India, Israel, Italy, the United Kingdom and South Korea. This was the first IDF National Conference for 59% of attendees and the first IDF event for 46% of attendees. More than 60 educational sessions filled each day featuring 66 medical and life management experts who volunteer their time to help the primary immunodeficiency (PI) community.

From toddlers to teens, more than 150 children joined the IDF Youth Program, taking part in fun, educational activities throughout the conference. An interactive Exhibit Hall enabled participants to learn about the latest products, services and resources for the PI community. The exhibits allowed individuals and families to learn about the treatment resources available to them, helping them be their own best advocate.

Perhaps the most life changing moments of the conference occurred between individuals living with PI who were able to meet others going through similar experiences during networking sessions, social events or even the conversations in the hallways between sessions. Although PI is rare, those affected by these rare, chronic diseases need to understand that there is a strong community for them, and the IDF National Conference helps bring the community together.
“So my ask is this - my ask is ‘don’t be normal.’ You’re not anyways, let’s be honest; don’t be normal. Be powerful. Every single one of us, whatever our condition, can do it in the way that makes sense for them. Be powerful. So three things - get involved, stay involved, grow the community.” — Richard Low, Member IDF Board of Trustees, at the IDF 2017 National Conference Opening Session (pictured at right)

“I think connecting with other patients was the biggest positive for me. I’m happy to learn about my illness, but feeling like I’m a part of a community and not alone is huge. I have made lifelong friends just by going to a class.”

“Our family did a divide and conquer method to get as much information as possible. We are sharing information on the car ride home. We are exhausted, but happy … Our family works better as a unit because of the IDF. We took the tools that you’ve given us over the years and have been able to build successful lives for ourselves and our children. Our children are much better prepared for the future because of the information they have learned through the IDF. They are now working towards careers where they can go on to help others.”

“As a parent of a child with PI, I think my 4 year old benefited the most from being there. He really enjoyed learning and meeting people. I thought the speakers were interesting, but the biggest benefit was in watching him meeting people and networking.”

“I cannot express how much attending the conferences has helped me learn about my illness, improve my personal health, and deal with the emotional side of PI. The conference is the ultimate safe space. Meeting other patients, knowledgeable researchers, IDF staff, drug company employees who truly care - it is an experience I recommend to every patient and family member.”

“My 16-year-old daughter recently began IVIG therapy, and the conference was our first IDF event. We learned so much during informative sessions with Q&A, chatting with vendor reps in the Exhibit Hall, and meeting other people with PI.”

View Conference Presentations Online
IDF is pleased to provide various presentations from the IDF 2017 National Conference online. We appreciate the work of our presenters, and we hope the PI community can learn from the valuable content shared. To access available presentations, go to www.idfnationalconference.org/conference-presentations.

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See You in 2019!
The IDF 2019 National Conference will be held June 20-23, 2019 at the Gaylord National Resort and Convention Center outside of Washington, D.C.
Exceptional Members of the Medical Community Honored at IDF 2017 National Conference

At the IDF 2017 National Conference, outstanding members of the medical community were honored for their work. The IDF Art of Nursing Award and the Boyle Scientific Achievement Award were given to deserving clinicians.

IDF Art of Nursing Award

The IDF Art of Nursing Award, which pays tribute to a member of the nursing community who has extensively contributed toward improving the diagnosis and care of patients with PI, was presented to M. Elizabeth M. Younger, CRNP, PhD of Johns Hopkins University School of Medicine and member of the IDF Nurse Advisory Committee. Since 2005, Dr. Younger has been at the Johns Hopkins University School of Medicine. She is an Assistant Professor of Pediatrics, in the Division of Pediatric Allergy and Immunology. Dr. Younger’s clinical practice provides care to well over 500 patients with PI. She has authored or co-authored multiple publications and presented at countless meetings and conferences, sharing her knowledge of PI and treatment options. She became a member of the IDF Nurse Advisory Committee in 2006 and has served the committee both as chair and vice chair. Dr. Younger was the first nurse to serve as an editor of an IDF publication. Not only does she provide care to her own patients, but she also serves as a resource to nurses and nurse practitioners caring for the members and families in the PI community nationally and internationally.

Boyle Scientific Achievement Award

The Boyle Scientific Achievement Award pays tribute to a member of the medical or scientific community who has extensively contributed toward improving the diagnosis and care of people with PI. This year, two very deserving physicians, who both serve on the IDF Medical Advisory Committee, received the award: Jennifer Puck, MD of University of California, San Francisco and Kathleen Sullivan, MD, PhD of the Children’s Hospital of Philadelphia.

Jennifer Puck, MD has been a professor at the University of California San Francisco since 2006. Prior to moving there, she spent more than 10 years at the National Institutes of Health as Chief of the Genetics and Molecular Biology Branch and Head of the Immunologic Diseases Section at the National Human Genome Research Institute. She completed her pediatric residency and infectious diseases Fellowship at Washington University in St. Louis, and then continued as a pediatric infectious disease and immunology fellow at Baylor College of Medicine. Later she became an Assistant and then Associate Professor at the University of Pennsylvania School of Medicine. She has been elected to the Institute of Medicine, now the National Academy of Medicine, and she has published more than 300 peer review and scientific papers and book chapters, and received multiple grants from NIH and other funding agencies. Her research has the combined aims of improving diagnosis and treatment of PI and also understanding how the underlying gene mutations interrupt lymphocyte development and function. An important focus is on Severe Combined Immune Deficiency (SCID) and other disorders of lymphocyte development. Dr. Puck is currently developing lentiviral vector gene therapy for Artemis SCID. She pioneered SCID newborn screening with an assay using DNA from infant drawn blood spots to detect T cell receptor excision circles or TREC’s. The TREC assay has been widely adopted for newborn screening, not only in the U.S. but internationally. She serves as a medical advisor for the State of California Department of Public Health newborn screening program for SCID. She is also a member of the United States Immunodeficiency Network (USIDNET) Steering Committee, the IDF Medical Advisory Committee and the Steering Committee of the Primary Immune Deficiency Treatment Consortium (PIDTC).

Kathleen Sullivan, MD, PhD has been at the Children’s Hospital of Philadelphia since 1993. She currently serves as Chief of Allergy and Immunology there, and she oversees one of the largest North American clinics for PI. She completed her pediatric residency at University of California San Francisco and completed her Fellowship in Pediatric Immunology and Rheumatology at Johns Hopkins. Later she became an Assistant Professor, Associate Professor and Professor of Pediatrics at the University of Pennsylvania School of Medicine. Dr. Sullivan is a former President of the Clinical Immunology Society (CIS) and currently serves on the Basic and Clinical Immunology Committee of the American Academy of Allergy, Asthma, and Immunology (AAAAI) and the AAAAI Board of Directors. She directed the Clinical Immunology Society Summer School for Fellows, served three years on the Career Mentoring Program at the AAAAI and served on the University of Pennsylvania’s Center for Translational Immunology Executive Committee and the MD and PhD Selection and Mentoring Committee there. She currently serves on the National Institute of Allergy and Infectious Diseases (NIAID) Board of Scientific Counselors. She is Co-Principal Investigator of IDF PI CONNECT, and she is Vice Chair of the IDF Medical Advisory Committee. Dr. Sullivan co-edited the last edition of the widely used textbook, Stiehm’s Immune Deficiencies. Her basic science research interests include understanding inflammation and the mechanism of regulating gene expression in inflammatory diseases. Her clinical interests include the study of patients with the DiGeorge Syndrome and understanding the variables related to the outcomes of patients with PI. She is the author or co-author of more than 200 peer review articles or book chapters.
Following more than 37 years of skilled and passionate leadership, Marcia announced her plans to retire as IDF President effective August 11, 2017.

What started as an organization on a shoe-string budget, being run by a young mother from her kitchen table, has now evolved into an internationally-recognized patient organization dedicated to improving the diagnosis, treatment and quality of life of people with PI through advocacy, education and research.

Letter from Marcia

Even though I have officially retired as President of IDF, I assure you that I am definitely not retiring from our wonderful zebra community! It’s far too important to so many people. In 1980, after the diagnosis of our son with X-Linked Agammaglobulinemia (XLA), my husband and I wanted to do something positive for our son and the group of rare disorders known as the primary immunodeficiency diseases (PI). Fortunately, others agreed with our goal to create a national patient organization that would provide information and support to patients and their families, to advocate for these diseases, and to improve treatment and outcomes.

And now, 37 years later, when I look at what IDF has achieved since then, I couldn’t be prouder of our accomplishments. This organization has achieved more than I could have imagined all those years ago. I know that now, individuals and families confronted with a diagnosis of PI will all have the resources we’ve built over time – from our patient/family handbook…to our resources for children, our education meetings and peer support…to our advocacy.

Most importantly, they will have a true community. Others who understand so well what it means to live with PI. The people who know the mundane routines of infusion and the struggles of chronic illness. The people who know how frustrating it can be to sit on the phone for hours with insurance companies. These are the people who get it – this big, beautiful community of zebras. It gives me great comfort to know that this community exists – to know that in the future people will never feel as alone as John and I did when confronted with our son’s diagnosis.

Happily, this is a time when many exciting advances are happening in this field: improved diagnostics and treatments; better understanding of the genetic basis of many PI’s and individualized therapies; and improved bone marrow transplantation, gene therapy, and the hope of gene editing.

And yet I also feel concern over the future. I don’t have to tell you that access to quality, affordable healthcare remains challenging. Insurance seems to grow more complicated and costly with each passing year. The recent actions by Congress threaten people with pre-existing conditions and those who fall between the cracks in terms of affordable insurance.

IDF is here to make sure our community is not forgotten. That we are prioritized for our life saving therapies and quality healthcare. That we receive the benefits of gene therapy and other innovations. That our clinicians, insurers and legislators understand that one-size-fits-all solutions are inadequate.

Please know that IDF is here to serve you, whether that means going to Capitol Hill or fighting back when your insurer denies you the therapies you need. But we can’t do this work alone. We need you and the rest of the PI community to make sure that IDF is around for the next generation of patients and families. One of the ways you can do this is through your financial support of IDF. Your gifts to IDF really do matter and truly are appreciated.

And of course there are many other ways to support our work. My real “ask” is that you look at what needs to be done, and together help us with our next challenges. IDF is your organization, and none of us should ever take it for granted.
Farewell to Marcia Boyle, Founder of the Immune Deficiency Foundation

Take part in our walks, and get your friends to join in. Organize an IDF Get Connected Group with other people living with PI. Become a Health Access Advocate and help us with legislative issues. Offer peer support to help others in their journey.

Our volunteers have done tremendous work in these and so many other areas. From some of our earliest volunteers who still are giving to others, like Bonnie Doak and Susan Davis, to some of our youngest volunteers who have been members of the Teen Council. IDF has committed individuals throughout the country who are making a difference. Not only does it feel good to volunteer, you also meet lifelong friends, as have I. Happily, we even have a recent engagement amongst our volunteers – congratulations to Lucy Hicks and Mark Leventhal! To all of you, thank you.

I’d also like to thank the many people at the companies that make the lifesaving therapies and services needed by our community, who do so much to support IDF and our programs.

I will miss working with the incredible and talented members of the IDF professional staff. Thank you to Kathy Antilla, who 11 years ago was willing to leave her career in teaching to share her talents with our community. And to Christine Belser, I don’t know what I would have done without her incredible abilities. And, the other wonderful members of my management team, Larry LaMotte, Sarah Rose, Christopher Scalchunes, and now Kara Moran. Special thanks to my wonderful Executive Assistant, Lorraine O’Brien. And, of course, John Gordon Boyle, IDF’s new President & CEO, I know I leave IDF in good hands.

It’s impossible to recognize everyone who made a difference along the way, yet I would be remiss if I didn’t highlight a few other special people. Of course, Dr. Jerry Winkelstein and Dr. Rebecca Buckley, the first and second chairs of our Medical Advisory Committee. Dr. Kate Sullivan, our Vice Chair. The members of our Medical Advisory Committee and Nurse Advisory Committee, and all the medical professionals who give their precious time and expertise to our community.

The amazing members of the IDF Board of Trustees: John Seymour, Chair. Steve Fietek, Vice Chair, who was brought to us by long-time volunteer Sonia Vohnout. Barb Ballard, my dear friend Carol-Ann Demaret, Joel Buckberg, Terry Halper, Chuck Lage, Rich Low, Brian Rath, Yvette Shorten, John Smith and his amazing wife Heather, and Amy Walsh.

I want to give a special acknowledgement to Bob and Sara LeBien. Bob joined the kitchen table in the very early 80’s and has provided his wisdom ever since, and his presence on the Board will be missed. I also want to remember Mary Hurley, who, sadly, passed away recently, and who gave so much to the CGD community. And, IDF would not exist without the support and involvement of my wonderful husband, John Michael Boyle, who has given his time and talents to IDF from the beginning. And our inspiration for starting IDF, our son, John Gordon Boyle, who makes me proud every day. IDF could not have a more ardent advocate.

And now, as I pass the baton and resume my original role as a volunteer with IDF, it’s up to all of you to ensure that this zebra community remains strong. You are not alone. You are a strong, resourceful and tremendously dedicated group of people, and together you can achieve great things.

I am so thankful to be a part of this remarkable group, and to know that you’ll continue this work that we’ve started. From the bottom of my heart – thank you.

Thank you, Marcia!

“Thanks to Marcia and her idea, and with the help of hundreds, maybe a couple of thousand over the decades of dedicated, hardworking volunteers throughout the United States and the world, some of whom are here tonight, the PI patient landscape has changed forever.”

— Bob LeBien, Former Member of IDF Board of Trustees and Founding Member of the International Patient Organisation for Primary Immunodeficiencies (IPOPI)

“Marcia is an amazing woman. She had a vision and she followed the vision. She is very persistent and she used that persistence to accomplish her ultimate goals. She has been able to recruit people who have special talents that help to improve the overall function of the organization, as well as the running of the organization.”

— Rebecca Buckley, MD, the J. Buren Sidbury Professor of Pediatrics and Professor of Immunology at Duke University Medical Center, Chair of the IDF Medical Advisory Committee and a member of the IDF Board of Trustees

“Organizations come and go but Marcia has been a consistent driving force in this community. She built this organization from her kitchen table and today it is world renowned. In any country the PI community knows IDF and very specifically they know Marcia, so it’s important to understand her role in IDF, not just as the founder but as the leader who returned to save IDF in 2005. IDF would not be here today if it were not for Marcia coming back to it.”

— Kathy Antilla, IDF Vice President of Education and Volunteer Development

“We must know too that all heroes are not just those who have performed some deed; a hero must first have formed an attitude. It is from our attitudes, our beliefs that we form deeds, and from deeds we form habits. From habits grow character, and on our character we build our destiny and affect the destiny of others. And so tonight we pay tribute to our hero, Marcia Boyle. We gather here to thank you, Marcia, for sharing your character, your spirit with us, for functioning at a high level, no matter the difficulties and never taking, no, as the final answer.”

— Carol Ann Demaret, Member of the IDF Board of Trustees Mother of David Vetter
The Immune Deficiency Foundation (IDF) is walking together to create better lives and find cures for people with primary immunodeficiency diseases (PI). IDF Walk for Primary Immunodeficiency 2017 took place across the country in 16 cities this fall, and funds raised from the dedicated walkers continue to be raised at www.walkforpi.org. The walks bring together all those affected by PI and help people living with these rare, chronic disorders know that they have a strong community there for them!

During the walks, all individuals affected by PI are encouraged to come together to increase awareness of these rare, chronic diseases and raise funds to support vital research. Since 2013, IDF Walk for PI has raised more than $3.5 million. Because of the dollars raised by IDF walk teams and their supporters, the Foundation established the IDF Research Grant Program. Ranging from research on Common Variable Immune Deficiency (CVID), Severe Combined Immune Deficiency (SCID), XMEN and Selective IgA, these researchers are identifying and understanding the underlying issues of these chronic diseases. On the following pages, learn more about the grant recipients.
Identification of T cell receptor clonotypes important in the pathogenesis of CVID
Sara Barmettler, MD
Allergy Immunology Fellow, Department of Allergy and Immunology, Massachusetts General Hospital

“We are interested in looking at the T cells in patients with Common Variable Immune Deficiency (CVID) to try to determine if there are differences between the T cells of patients with CVID compared to healthy patients. We also want to investigate if there are specific T cells that are causing the disease. Some patients with CVID have gastrointestinal complications, including problems with absorbing nutrients, diarrhea, and weight loss. We will evaluate patients who have gastrointestinal complications with CVID (called CVID associated enteropathy) to see if we can evaluate their T cells to better understand why this disease occurs. We will compare the T cells in the gastrointestinal (GI) system to the T cells in the blood. We will also be evaluating the T cells in patients with the GI complications in CVID to those without GI complications. Our hope is that if we could identify specific T cells that are causing this disease then we could potentially target these T cells to protect patients. We would try to prevent the disease from occurring or getting worse if we can identify them early on in the course of the disease.”

Prevalence of Fatigue in Common Variable Immunodeficiency
Joud Hajjar, MD
Assistant Professor, Pediatrics, Allergy and Immunology, Baylor College of Medicine

“This research project was born in our clinic, where our patients with CVID often reported having fatigue. Fatigue is not often discussed or treated by providers. We believe that understanding fatigue in CVID is important because researchers have shown that patients who have fatigue, report lower quality of life compared to patients who do not have fatigue. This is especially relevant to patients with CVID, in which studies have shown that having a poor quality of life predicted shorter life span compared to patients who reported a good quality of life.

Persons with CVID have more fatigue compared to the general population and that some of the complications that result from having CVID such as lung or gastrointestinal damage were associated with having fatigue. Our goal is to determine how common fatigue is in CVID, who is at risk to develop fatigue, and what are the effects of immunoglobulin therapy on fatigue. The results from this proposed research have the potential to significantly alter how doctors evaluate fatigue in subjects with CVID, and how they prescribe immunoglobulin therapy in a way that notably decreases fatigue, improves the quality of life and potentially survival in the CVID population. Importantly, identifying the risk factors to develop fatigue will allow health care providers to recommend specific therapies to treat it.”
Characterizing T cell lymphopenic infants identified on routine newborn screening

Artemio Jongco III, MD, PhD, MPH
Assistant Professor, Pediatrics and Medicine, Allergy & Immunology Feinstein Institute for Medical Research

“Severe Combined Immune Deficiency (SCID), a life-threatening but curable PI, belongs to a category of conditions where early detection and treatment can significantly improve morbidity and/or mortality. Patients with SCID have decreased number and function of T cells, which play a crucial role in the immune system, such as fighting viruses and fungi. All but three states in the U.S. screen or plan to screen for SCID. All these programs rely on quantifying T cell receptor excision circles (TRECs), circular pieces of DNA that are produced during normal T cell development and maturation. Individuals with aberrant T cell development resulting in reduced T cell numbers, will have low TREC counts. These programs identify infants with other non-SCID PIs that primarily affect T cells, such as DiGeorge Syndrome. They also detect infants with low T cell counts (known as T cell lymphopenia (TCL)) for whom the underlying cause is unknown and evidence-based management guidelines are lacking. A better understanding of TCL is desirable because it will improve our knowledge and facilitate the development of evidence-based guidelines for diagnosis and management of this condition. Thus, these studies can guide the development of best practices to maximize patient outcomes in a cost-effective manner.”

A new pathobiological basis for the treatment of XMEN primary immunodeficiency

Sonia Sharma, PhD, BSc
Assistant Professor, Cellular Biology, La Jolla Institute for Allergy & Immunology

“Immunodeficiency is a state in which the immune system’s ability to fight infectious diseases or cancer is compromised or entirely absent. The study of these rare diseases has been instrumental in providing valuable insight into the biology underlying the proper function of the immune system, and is critical for developing specific therapies to treat these debilitating diseases. In this proposal, we are exploring a new molecular basis for X-linked immunodeficiency with Magnesium defect, Epstein-Barr Virus (EBV) infection and Neoplasia (XMEN) disease, which is caused by genetic mutations in the gene encoding magnesium transporter 1 (MAGT1). We propose to shed valuable new insight into the role of MAGT1 and magnesium as a regulator of the early or innate immune response to bacteria, viruses and tumor cells. Our new insight into the pathobiological basis of XMEN immunodeficiency could be therapeutically beneficial for the treatment of XMEN disease, as patients with XMEN may benefit from anti-biotic, anti-viral or interferon-based therapies to treat their early immune deficiency.”

IKAROS deficiency and CVID: Disease biology and specific therapeutic approaches

Sergio Rosenzweig, MD, PhD
Chief Immunology Service, Department of Laboratory Medicine, National Institutes of Health

“CVID is the most common, treatable primary immunodeficiency. Treatment is usually focused on replacement of dysfunctional immunoglobulin. Approximately half of the patients with CVID exhibit autoimmune disease or lymphoproliferative disease and this further dictates therapy with an emphasis on immune suppression or anti-inflammatory treatment. Over the past 10 years, it has been revealed that 10-20% of patients with CVID have single gene defects that contribute to the evolution of their immune deficiency. IKAROS deficiency is one of the most recently described single gene defects. The goal of this proposal is to understand how IKAROS deficiency impacts the patients’ DNA and to pilot treatments that would uniquely be able to treat IKAROS deficiency.”

Deciphering function of HLA encoded microRNA in primary immunodeficiency

Nilesh Chitnis, PhD
Postdoctoral Fellow, Pathology and Laboratory Medicine, Children’s Hospital of Philadelphia

“Selective IgA deficiency patients suffer from increased incidences of respiratory diseases and are at greater risk of anaphylactic shock during blood transfusions. Our data shows that expression of a noncoding RNA, miR-6891-5p is elevated in selective IgA deficiency patient cell lines. Suppression of miR-6891-5p increased IgA secretion. We propose to confirm these observations in primary B cells obtained from blood of selective IgA deficiency patients. We will decrease the expression of miR-6891-5p in patient cells and determine whether IgA secretion can be restored. Many therapies targeting microRNAs are already in clinical trials. This research may uncover miR-6891-5p as a target for therapeutic intervention.”

With research comes better diagnoses, lives and potentially cures for those with PI. For more information and to learn more about the grants awarded, go to: www.primaryimmune.org/research-grant.
Connect Online with the IDF Community

Ways to Interact and Build Relationships with the PI Community

Because primary immunodeficiency diseases (PI) are so rare, it can be difficult for those living with one to find someone else who has similar experiences and situations to talk with. The Internet has changed how we all connect and communicate with people. It allows us to reach those who are a million miles away in an instant. It’s easier than ever for those in the PI community to get connected to someone else who is living with PI. IDF provides many opportunities and ways you to get involved in the PI community. Here’s how:

Customize Your Communications: New IDF Website

It is now easier than ever to access IDF’s vast reserve of valuable programs, resources and services at www.primaryimmune.org. Whether you’re newly diagnosed or have been living with PI for years, the new website was designed for you and allows you to customize your experience. The site includes a My Account feature where you can create an account, update your information, easily order publications, register for events, submit questions through Ask IDF and more. My Account is a new feature, so if you haven’t created an account since the launch of our new website in August 2017, you will need to create an account first.

The site also features updated information on various topics related to living with PI, a regularly updated calendar of events and more ways to stay informed. Create your account today: www.primaryimmune.org/my-account.

Discuss Living with PI: IDF Friends

IDF Friends, www.idffriends.org, is exclusively for individuals and family members who are living with PI. There are more than 5,000 members contributing to conversations about diagnosis, treatment and day-to-day life with a PI. This exciting online community gives you a chance to connect with others, learn from group conversations, share your experiences while giving and receiving support. To benefit from a network of others who understand what you’re going through, go to www.idffriends.org.

Find Others with Your PI: Diagnosis Specific Facebook Groups

Sometimes individuals and family members simply want to talk with someone who understands what it’s like to live with PI. They find value in meeting others online and discussing their diagnosis. Official IDF Facebook Groups were designed to provide a welcoming and safe environment to individuals diagnosed with a specific type of PI and their loved ones.

These groups, moderated by trained IDF volunteers, create online networking opportunities designed to bring together individuals with similar experiences. IDF Facebook Group Moderators facilitate a welcoming environment conducive to sharing ideas and support, so that group participants feel a sense of belonging, assuring them that they are not alone. Currently, there are two IDF Facebook Groups.

• X-Linked Agammaglobulinemia (XLA)
• Common Variable Immune Deficiency (CVID)

We will create more groups for more diagnoses in the future, and we need volunteer moderators to help us!

If you’re interested in becoming an IDF Facebook Group Moderator, please contact us: volunteer@primaryimmune.org.

Looking for the Donation Envelope?

Make Your Gift to IDF Online

To improve efficiency and maintain the utmost fiscal responsibility, the IDF ADVOCATE will no longer include a donation envelope. We’ve invested in a new user friendly website where you can make your gift online, update your contact information and customize your communications preferences to ensure you receive the information you are interested in: www.primaryimmune.org/my-account.

If you would like to receive a donation envelope, please contact IDF at 800-296-4433.

No matter how you give, your donation to IDF helps make a difference in the lives of people with primary immunodeficiency diseases.

Thank you so much for your support!

Fall 2017
Public Policy Update

Medicare IVIG Demonstration Project Extension

IDF is happy to announce that, after months of intense work from our organization and the PI community, the Medicare IVIG Demonstration project has been extended to December 31, 2020 or until allocated funds are spent, whichever comes first. Beneficiaries who were enrolled in the demonstration project as of September 30, 2017, when the project was originally slated to end, have been automatically re-enrolled for the extension period and experienced no gaps in coverage. Medicare is now accepting new applicants and will continue to do so until the demonstration project reaches its limit on enrollment and/or funding. While extension of the project is a temporary solution, individuals with PI on Medicare will continue to have access to home administered IVIG while we advocate for Congress to make this a permanent benefit.

Medicare SCIG Access

In December 2016, Congress passed the 21st Century Cures Act (Cures) which, while increasing important research funding, unfortunately included reimbursement provisions that threaten access to treatment for people with PI on Medicare who receive subcutaneous immunoglobulin (SCIG) therapy. To “pay for” the provisions of Cures, effective January 1, 2017, Congress significantly reduced reimbursement for drugs, including immunoglobulin (Ig). At IDF’s urging, Congress included language that authorizes Medicare to develop reimbursement categories to pay for training and monitoring individuals who receive SCIG. Unfortunately, the start date is not until January 1, 2021, creating a four-year delay from when the payment reductions began. This gap in reimbursement has resulted in some providers no longer providing services, some refusing to take new Medicare beneficiaries, and some cautiously waiting to see if Congress will fix this problem.

Moving the start date to January 2019 will address this gap. The House has passed language that would temporarily fix the problem. Senate action is expected by the end of 2017.

IDF Health Access Advocate Program

Are you interested in advocating in your home state for policy change that affects the PI community? Apply to be a Health Access Advocate (HAA)!

The aim of the IDF HAA program is to identify and cultivate advocates nationwide who can work within their local and state communities to enhance access and remove barriers to care for the PI community. HAAs contribute to our public policy program by contacting local legislators on behalf of IDF, testifying at legislative hearings, working with other patient organizations on state and federal issues, mobilizing other members of the PI community and participating in various activities that further IDF’s mission on behalf of our community. IDF currently has 24 designated HAAs from 20 different states, with the long-term goal of having representatives in all 50 states. Currently, HAAs are needed in the State of Iowa to assist IDF’s effort to pass legislation that expands insurance options with predictable co-pays and without high up-front prescription costs.

To become a Health Access Advocate, please go to: http://bit.ly/HealthAccessAdvocate.

Co-pay Choice State Advocacy

IDF is leading patient coalition activities in Iowa and Nevada and providing support to state efforts throughout the U.S. to address insurers’ increased use of coinsurance for individuals with PI and other chronic conditions through specialty tier coinsurance practices. Under these practices, people may have to pay up to 40% of the cost of their treatment. To address these practices, IDF is proposing legislation and state administrative policies to ensure people in need of specialty medications have the choice to purchase pre-deductible flat fee co-pay only plans. This will allow people in need of specialty medications, including immunoglobulin (Ig) therapy, to predict and plan for their yearly healthcare costs and will reduce the likelihood that they would forgo necessary treatment. We are seeking patient stories that highlight the challenges people face with high coinsurance to assist in our advocacy in various states. Please tell us your story at info@primaryimmune.org.
Immunoglobulin (Ig) therapy is a critical, lifesaving treatment for people living with primary immunodeficiency diseases (PI). Missing or forgoing treatment altogether can mean a quick deterioration of the immune system and overall health, even if you have been feeling “OK” without treatments.

In January 2017, IDF was contacted by a North Carolina woman with Common Variable Immune Deficiency (CVID), a type of PI, who wanted to share her story in hopes that others will not make the same choices she had. The woman was in her 40s and had been living with CVID for several decades. Due to personal financial constraints and numerous insurance challenges, she had not received regular, monthly treatments in almost three years.

She had Medicare through disability but was not eligible for Medicaid after she was required to spend more than $5,000 in medical bills within six months to qualify. After realizing she would be unable to afford these bills, she made the decision to forgo Ig therapy, and it quickly took a serious toll on her health.

She suffered repeated severe lung infections, which further damaged the already compromised organs. She began receiving care from hospice and, after six months, was finally referred to IDF through a social media group. After communicating with her, IDF worked to connect her to whatever resources we could, going so far as to reach out to her U.S. Congressional Representatives to see if they could help with her Medicare challenges.

Unfortunately her health has continued to decline and as of this writing, she has been placed in residential hospice care. Her outlook is not good. This distressing story and others like it are stark reminders that people with PI should never forgo treatment. No matter the circumstance, reaching out for help just may save your life.

We encourage those who are struggling to reach out to us as early as possible so that we can leverage a variety of resources and information to help those living with this disease, as well as their families. The earlier IDF is contacted, the more potential there is for us to help. The resources IDF provides can help people with PI find treatments or doctors, even if they feel like they have run out of options.

With changes in healthcare occurring on a national level and patients at risk of losing treatment, we would like to call on every member of our community to share our mission in an effort to touch those who may not know about IDF and potentially save lives.

And for those of you in our patient community, we cannot stress how essential treatments are. If you are ever in a position where you are unable to receive your infusions, never hesitate to reach out. Our patient advocacy team will work with you one-on-one to try to find a solution.

Contact IDF at: www.primaryimmune.org/ask-idf or 800-296-4433.

For Medicare Beneficiaries: Understanding the Importance of Supplemental Insurance

There are many options when it comes to Medicare coverage, and you will have to do a little investigative work to determine what is going to work best for you. Medicare Part B covers at 80% so many enroll in a supplemental/medigap plan (Part F) to help with the remaining cost.

Another option is a Medicare Advantage plan (Part C). These plans are sold as an “all in one policy” and act more like a private insurance. According to Medicare regulations, the managed care plans must provide enrollees with all Part A and Part B benefits.

Medicare Advantage plans are not required to provide enrollees the same access to providers that is provided under original Medicare.

Over the past few years, patients with Medicare Advantage plans have reported to IDF that most have a 20% to 30% coinsurance for their treatment. It is important to keep in mind that if you choose an Advantage plan, you are not eligible to obtain a secondary policy so make sure you know the advantage plan coverage details.

Speak with Someone Who Understands PI

The IDF Peer Support Program is a free resource that connects people with those who share similar relationships to PI. Our trained Peer Support Coaches are members of the PI community of all ages with varying experiences. These individuals are ready to listen to your cares and concerns, offer skilled emotional support and will share their experiences and offer their understanding.

Contact IDF today to request a Peer Support Coach: www.primaryimmune.org/ask-idf or 800-296-4433.

Have You Seen This Poster in Your Doctor’s Office?

If not, then IDF needs your help! Volunteers are needed to get these posters into doctors’ offices! You can generate awareness and build relationships with healthcare professionals.

Visit the IDF Volunteer Connection Center and sign-up to do this in your area as an IDF Liaison: www.primaryimmune.org/volunteer

Questions? Contact the IDF Volunteer Development Manager: 800-296-4433 or volunteer@primaryimmune.org.

IDF Liaisons are part of the IDF Outreach Initiative. The IDF Outreach Initiative is supported by Lead Sponsor Shire.

Want to Meet Others Living with PI in Your Area?

Join or Start an IDF Get Connected Group!

IDF Get Connected Groups are designed to connect individuals diagnosed with primary immunodeficiency diseases (PI) and family members in their local communities. The groups can occur at a local community room, library, coffee shop or other venue. Through IDF Get Connected Groups, individuals and families living with PI can connect to share experiences, receive information and gain support. These groups do not include medical presentations or industry exhibits.

There are more than 20 Get Connected Groups across the U.S. View upcoming IDF Get Connected Groups on the IDF Calendar of Events: www.primaryimmune.org/events.

Want to start a group near you? Visit the IDF Volunteer Connection Center and sign-up to become an IDF Get Connected Group Leader: www.primaryimmune.org/volunteer.

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New IDF Publications

Immune Deficiency Foundation Transition Guide: From Pediatric to Adult Care

The transition from childhood to adulthood has certain milestones, typically managing your own healthcare, going to school and moving away from home. There are many things to consider, especially for those who are living with a primary immunodeficiency disease (PI). The Immune Deficiency Foundation Transition Guide: Pediatric to Adult Care examines the transition from pediatric to adult healthcare, helping young people with PI prepare how to make their own decisions and manage their health on their own.

If you’re a teen or young adult (or a parent of a teen or young adult), use this guide to help you understand all the steps involved in managing your health.

This publication was made possible by a charitable grant from Shire.

Understanding the Low T Cell Results from Your Baby’s Newborn Screening (Brochure)

If your baby’s newborn screening came back with low T cell results, it’s hard to know what that means or what you should do next. The IDF brochure, Understanding the Low T Cell Results from Your Baby’s Newborn Screening: A Guide from the Immune Deficiency Foundation, can help explain what low T cell results can mean and why evaluation and continued visits with a specialist are important.

This publication was made possible by a charitable grant from Associated Public Health Laboratories (APHL).

Order these and any IDF publication at no cost to you at www.primaryimmune.org/idf-publications.

Updated Flu Information for 2017-2018

Nasal Spray Influenza Vaccine NOT Recommended for the Upcoming Flu Season

For the 2017-2018 Flu Season, IDF has published recommendations for patients with primary immunodeficiency diseases and their families, including prevention, vaccination and creating a family plan.

Also, please note, again this season, the Centers for Disease Control and Prevention’s Advisory Committee on Immunization Practices (ACIP) has recommended that the nasal spray influenza vaccine not be used.

To read IDF’s 2017-2018 Flu information, go to www.primaryimmune.org/flu.
Announcement of John G. Boyle as new IDF President & CEO

At the IDF 2017 National Conference, the IDF Board of Trustees announced that John G. Boyle will serve as the organization’s new President & CEO. John brings a wide base of non-profit management experience to his new role with IDF. John has devoted his career to serving non-profit organizations, most recently as Vice President of External Relations at IDF. John was instrumental in developing a number of new initiatives for the Foundation, including the IDF Walk for Primary Immunodeficiency that launched in 2013, which has now grown to 12 cities across the U.S., and raised in excess of $3.5 million to support vital IDF programs and resources, including funding a new IDF research grant.

Q & A with John G. Boyle, IDF President & CEO

John talks about his new role with the organization and what the priorities and challenges will be for IDF and the PI community in the future.

You officially became President & CEO of IDF in August, how have the first few months gone?
My first few months have been very smooth, a lot of that is thanks in large part to the IDF staff being so accommodating, welcoming and excited for what’s coming next. The transition was well thought out and organized, and it has given us the opportunity to look at and evaluate how we do things. Our team has had a chance to share their views about how we can better serve the PI community and how we might be able to reinvigorate some of our programs.

What can we expect from IDF for 2018 and beyond?
Well, we’re still the same IDF that you know and trust. We continue to be driven by making a long lasting impact on the PI community. Early 2018 will be focused on strategic planning with the Board of Trustees.

I am especially focused on several initiatives, including finding those who are diagnosed with PI but are not connected to IDF or who don’t know about us. We hear from many people that they have been diagnosed for years but had not heard of IDF—we need to change that to help improve the lives of all those affected by PI. Another initiative is working closer with plasma centers across the country. We hope to increase the number of volunteers within the PI community available to visit centers and serve as spokespeople to help raise awareness and share the importance of plasma to the greater community as well as the IDF community.

We have heard chatter about a website redesign, what can you tell us?
We redesigned our website, and it launched in August 2017. The redesign was based on anecdotal feedback and concrete data from our website users. Our team looked at the data and how our community was interacting with the site, the information they were searching for and their needs.

We have galvanized that feedback and data into tangible directives for our new website. We plan to continue connecting with our community while reaching the smaller and newer diagnoses as well. We will be launching more diagnosis specific initiatives and are exploring the concept of an online database that connects patients with immunologists in their geographic area. With some of the diagnosis specific pages, we are going to provide more resources, rather than just a description. We plan to incorporate video content, more medical journal articles and links to IDF Friends groups or IDF diagnosis specific Facebook groups.

What are some of the emerging areas of study and research that IDF hopes to engage with?
IDF has remained engaged in studies for gene therapy and other emerging cure based opportunities. As we learn more about these diseases, we are going to see some really interesting opportunities, and IDF is going to make sure it not only holds a seat at the table but that we are also promoting and encouraging exploration in these areas. We are working with new partners that are experimenting with personalized medicines and genomics that may benefit people with PI.

We are also going to be monitoring and helping to promote the status of the KREC test which could potentially identify PI in children at birth, which would otherwise be going years or decades without a diagnosis.

What are some of the threats that the PI community faces?
The biggest threat we are seeing now is our access to care. We are seeing many unforeseen consequences to insurance and Medicare from the legislation that is being pushed forward.

Other threats include the plummeting vaccination rates that we are seeing across the US. This actually puts our community at risk for some of these infections that had nearly disappeared, such as polio, measles and others. Our population is extremely vulnerable, and we do require that other people protect themselves from these diseases. Because of this, we are also engaging with the FDA to ensure that over the long term, the immunoglobulin, or Ig, provided to us is effective and that vaccination levels are not having a negative impact on the Ig that is donated.

What might we be surprised to learn about you?
I am a geek at heart. I’m a gamer, and I watch far too many comic book movies and shows. I am a knowledge seeker, and I spend my commutes listening to podcasts that are relevant to how I approach everyday life. I love learning about human behavior, organizational leadership and other things that are relevant to our community, which is very diverse. I am always working to gain a better understanding of the world around us in order to be a happy, healthier person.

As a person with PI, I have a foundational understanding for what members of the IDF community are going through because I am one. If you’re on Ig, I can commiserate. I have been on all three forms at some point in my life. And after a busy day of leading the zebra herd, I am a husband and a father.
Immune Deficiency Foundation Sponsors 2017

Each year leading companies in the healthcare industry provide support to the Immune Deficiency Foundation (IDF). Without such funding, IDF would be unable to provide our community with many of the services, resources and programs that contribute to the improved quality of life for the individuals and families of those living with primary immunodeficiency diseases.

IDF Core Service Sponsors

IDF Core Service Sponsors are dedicated partners that support IDF at the highest level. They help fund direct services that offer peer support, help finding a specialist and offer information on dealing with health insurance issues. Local IDF patient meetings are offered throughout the country because of their generosity. They support medical and scientific programs like the IDF Consulting Immunologist Program and the IDF & USIDNET LeBien Visiting Professor Program, as well as IDF exhibits at medical meetings. Funding from sponsors allows IDF to provide services and publications free of charge to our community.

IDF Core Service Leaders

- AbbVie
- CSL Behring
- Grifols
- Shire

IDF Core Service Supporters

- AmerisourceBergen Corporation
- Leadiant Biosciences
- Octapharma

IDF Core Service Contributors

- ADMA Biologics Inc.
- BPL
- Horizon Pharma
- Kedrion Biopharma

IDF Sustaining Contributors

- Accredo Healthcare
- Coram CVS Specialty Infusion Services

IDF Sponsors

- Diplomat Specialty Infusion Group
- Kroger Specialty Infusion
- Orchard Therapeutics
- RMS Medical Products

Our sponsors understand the chronic nature of primary immunodeficiency. Because the diseases never go away, individuals and their families will continually rely on IDF, and the Foundation extends sincere appreciation to these companies for their continual support to make this possible.

IDF Legacy Society

IDF is fortunate to have members of our community who philanthropically support us in many different ways. Some support us through the walks. Some make end-of-year gifts. Some of the younger ones even create lemonade stands! Each of those gifts helps us advance our mission. There is, however, one type of gift that helps us do even more for our community: a legacy gift.

Everyone should have a will. It’s the way that you can make your intentions and values clear in a way that leaves nothing to chance. It’s a way that you can make a mark and create a legacy that truly impacts the next generation. IDF has been fortunate in that people have chosen to name IDF as a beneficiary of their will or other estate plans. Those commitments, when ultimately received, are transformative for what IDF can do for the PI community.

If you haven’t created a will or haven’t reviewed your plans in recent years, please consider the transformative effect that you could have by naming IDF as a beneficiary of your will, life insurance policy or other estate plans. If you do, IDF will gratefully recognize you as a member of the IDF Legacy Society.

If you have already chosen to include IDF in your financial or estate plans, please let us know so we can properly thank you. To let us know about your plans or to learn more about the IDF Legacy Society, please contact Roslyn Hannibal-Booker at: rhannibal-booker@primaryimmune.org.

Remembering Members of Our Community

To remember members of our community who have passed away, IDF has created a perpetual plaque. Individuals with PI, parents, medical professionals and caregivers can be honored through inclusion on this plaque. It is a tribute to memorialize those who were an important part of our community and is free of charge.

Some of the most recent additions include Kathy Lingo, Bonnie Robertson, Scott Solberg, Tim Tarulli and Benjamin Andrew Zubricki.

If you would like to submit a name to be included on the memorial plaque, please e-mail that person’s first and last name along with a little about their life to: development@primaryimmune.org.

WITH GRATITUDE
MEMORIAL GIFTS
January 1 – September 30, 2017

Luke Altobelli  Kasey Goodwin  Dominick Passalacque
Collin Anderson  Brian Greenlaw  Samantha Penn
Robert Armstrong  Jordan Grobelny  Pattiann Phillips
William Bausman  Brandon Grobelny  Janine Ravallo
Jacquie Becker Field  Baby Girl Hart  Logan Reddish
Varun Bhaskaran  Mary Hurley  Gavin Smith
Roland Borelli  Amarom Karney  Manny Sperling
Lillian Buske  Nicholas Kellar  J. Stahl
Bud Calkins  Rose Kellum  Patricia Stowe
Jeannie Costelow  Ronald Lewis  Tim Tarulli
Nick Faulkner  Kathy Lingo  Alan Vanderbloomen
Merritt Geiger  Richard Lund  Eric Weintraub
Delores Goldsmith  Thomas Marbach  Richard Weisbart
Savannah Goodman  Christopher Meddaugh  Louella Wunder
For an Updated IDF Calendar of Events, Visit www.primaryimmune.org/event-calendar.

Make Your Gift to IDF Online

We’re streamlining and reducing our costs while ensuring making your gift is easy! We will no longer include a donation envelope in the IDF ADVOCATE. We ask that you make your gift online: www.primaryimmune.org/give.

Prefer to receive an envelope? Contact IDF: 800-296-4433.

Your donation, whether submitted online or mailed to IDF, supports vital programs and resources for people with primary immunodeficiency diseases.

Thank you!