It's time to get ready for the world's largest gathering of individuals and families living with primary immunodeficiency! The Immune Deficiency Foundation (IDF) will host the IDF 2015 National Conference at the Hyatt Regency New Orleans, June 25-27, 2015. Individuals and families affected by primary immunodeficiency diseases (PI), clinicians, life management professionals, industry representatives and other members of the community will gather for three days to learn, share ideas and discover the latest about PI.

Attendees can choose from 40 healthcare and life management sessions conducted by dedicated experts. From learning about the advancements in the diagnosis and treatment of PI, to gaining the skills needed to manage healthcare, there are valuable experiences for everyone. For many, it is life-changing to meet and connect with others who are going through similar situations.

The conference will serve as a great opportunity for the community to learn more about PI CONNECT, the new IDF Patient-Powered Research Network—a tool for patients with PI to make their voices heard in research. Members of PI CONNECT can pose their research questions during a Live PI CONNECT Research Forum. In addition, we are pleased to announce that the Opening Session will feature Joe V. Selby, MD, MPH, the Executive Director of the Patient-Centered Outcomes Research Institute (PCORI). He will share information about the National Patient-Centered Clinical Research Network (PCORnet) of which PI CONNECT is proud to be a part of. This network focuses on the real-time experiences of patients to help advance research.

Be sure to visit the IDF 2015 National Conference website for all the details: www.idfnationalconference.org.

Conference Highlights

Healthcare and Life Management Presentations

World-renowned healthcare professionals will share their time and expertise to help you better understand and manage your primary immunodeficiency disease. Take advantage of the opportunities to learn from life management professionals who will provide helpful ideas you can use to help improve your daily life.

Welcome to New Orleans Reception

Join IDF on Thursday evening to celebrate our 8th National Conference and the gathering of the PI community. In the tradition of New Orleans, we will celebrate with a “second line” or a brass band parade where everyone is invited to enjoy the music and walk in the parade, twirl a parasol or handkerchief in the air! Sponsored by Baxter International Inc.

IDF Zebra Gala

Few cities know how to celebrate as well as New Orleans, so catch the spirit and maybe some beads, and join us Friday evening for a great night of music, food, libations, and recognitions. Of course, the always amazing THINK ZEBRA! silent auction will get the evening underway. This year, you can even place your bids on your smartphone! Sponsored by CSL Behring.

Young Adult Reception

For individuals with PI, ages 19 to 30, this is an opportunity to kick off the conference by getting to know others your age in a fun atmosphere.
IDF Order of the Zebra members are the elite fundraisers whose efforts make the greatest impact on the success of each IDF Walk for Primary Immunodeficiency, and on IDF itself. Benefits of being a member of the Order include:

- A medal signifying your Order membership that can be worn with distinction
- Listing of your name as an Order member on the Walk website
- Special recognition in IDF publications and at select IDF events
- And now, free IDF 2015 National Conference Registration!

By registering for the 2015 IDF Walk for Primary Immunodeficiency and raising $1,000 or more prior to the conference, you will earn a refund of your conference registration fee and be recognized as one of the walk’s top fundraisers as a member of the IDF Order of the Zebra. Whether you live near one of our nine Walk sites or want to participate in our Nationwide Virtual Walk, the funds that you raise as a member of the Order of the Zebra will make an enormous impact upon IDF. We are thrilled to offer the registration fee refund as a little reward for achieving so much so early in the year.

**HERE’S WHAT YOU NEED TO DO TO GET STARTED:**
1) Go to www.walkforpi.org
2) Register for the Walk of your choice
3) Customize your fundraising page
4) Start asking your community to support you and your Walk!

Once $1,000 has been recorded on your individual fundraising page (not your team page), IDF will be automatically notified. Funds must be recorded on your page by June 22, 2015 in order to qualify for the registration fee reimbursement.

For more information, please e-mail walk@primaryimmune.org.

*Reimbursements for Conference registration fees will be processed approximately two weeks after the National Conference concludes.*

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**Conference Highlights**

**IDF Night at Mardi Gras World**

Take a tour of Mardi Gras World’s float-building warehouse where you will see awe-inspiring parade floats. Then, go back in time to the magnificent Grand Oaks Mansion, right next door. The Mansion is a vintage Louisiana, indoor replica of an antebellum mansion, complete with towering columns, magical footbridges, magnificent oak trees and a starlit sky. You will be treated to a New Orleans style buffet dinner and great music.

**IDF Exhibit Hall**

Be sure to allow enough time in your schedule to visit the Exhibit Hall where companies and organizations are ready to show you the newest products and services available to the primary immunodeficiency community. If you visit them all, you even have a chance to play the Visit and Win game and win an iPad.

**Youth Programs**

Fun, age-appropriate activities and educational sessions are planned for everyone in the family, even as young as six months old! A trip to the Audubon Aquarium will be included for all children in the youth programs, ages 5 and older. Youth programming is available on Friday and Saturday, June 26 and 27.

**Chronic Granulomatous Disease Symposium**

For the first-time, IDF will host a special symposium for those living with Chronic Granulomatous Disease (CGD). This is an exclusive in-depth opportunity to learn more about CGD treatment, news and research from top medical experts during sessions held Thursday afternoon and Friday morning. Participants can attend general sessions Friday afternoon and Saturday. **Sponsored by Horizon Pharma.**

**Wiskott-Aldrich Syndrome Symposium**

Individuals and families living with Wiskott-Aldrich Syndrome (WAS) can take part in a special symposium held Thursday afternoon and Friday morning. Healthcare professionals will present the latest information regarding diagnosis and treatment of WAS, and participants can attend general sessions Friday afternoon and Saturday.

**Professional Medical Education Program**

On Saturday, June 27, the Clinical Immunology Society (CIS) will host the Professional Medical Education Program Update in Diagnosis and Management of Primary Immunodeficiency Disease for healthcare professionals, featuring sessions about primary immunodeficiency diseases and offering Continuing Medical Education (CME) credits for participants.

**New Sessions**

This year, IDF looks forward to presenting several new sessions:

- Complementary and Alternative Medicine
- Young Adults - Life Beyond High School
- Practical Q&A on the Administration of Ig Therapy
- Taking Care of Ourselves: Women Getting it Done!
- For Men Only
- Nutrition and Immunity

Learn more about the IDF 2015 National Conference and register online at www.idfnationalconference.org.

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**See you in June!**

**IDF 2015 National Conference Sponsors**

**Legacy Sponsors**
- Baxter International Inc.
- CSL Behring
- Grifols

**Silver Sponsors**
- Biotest Pharmaceuticals
- Horizon Pharma
- IgG America/ASD Healthcare/US Bioservices
- Sigma-Tau Pharmaceuticals
The Immune Deficiency Foundation challenges you to **POWER UP YOUR HEALTH** with IDF ePHR, the electronic personal health record designed for the primary immunodeficiency (PI) community. IDF ePHR features innovative tools to help you improve your health and organize your info—even on the go!

The first 1,000 people to sign up for IDF ePHR in 2015 will receive a free portable electronic charger*, and you’ll also be entered to win one of three incredible prizes:

- iPad® Air 2, 16GB
- iPad® Mini 3, 16GB
- $100 American Express® Gift Card!

The drawing will be held during National Primary Immunodeficiency Awareness Month and World PI Week, **April 29, 2015**. Winners will be announced via IDF social media, and winners will receive an e-mail. See official rules for further details: [www.primaryimmune.org/challenge](http://www.primaryimmune.org/challenge).

**IDF ePHR can help you improve your health!**

- Track your health and fitness goals, set reminders and notifications.
- Easy-to-use tools to help organize your info.
- Access IDF ePHR from anywhere—your computer, tablet or phone.
- Keep your medical info safe, secure and private at no cost to you.

**Take this challenge to **POWER UP YOUR HEALTH** with IDF ePHR!**

**Questions?** Contact IDF: **800-296-4433 or info@idfephr.org.**

**Tell us how you **POWER UP YOUR HEALTH**—use #idfephr and share your story!**

IDF Friends: www.idffriends.org | Twitter & Instagram: @IDFCommunity
Facebook: www.facebook.com/ImmuneDeficiencyFoundation

*The IDF ePHR is sponsored in part by CSL Behring.
April: National Primary Immunodeficiency Awareness Month

April is National Primary Immunodeficiency Awareness Month! Join IDF, in partnership with World PI Week celebrated April 22 to 29, to promote awareness of primary immunodeficiency diseases (PI) in your community.

If you live with primary immunodeficiency or you have a significant relationship with someone who is affected, you know how important it is to raise awareness and understanding about these rare diseases. You have the power to educate and inform people about primary immunodeficiency, and this knowledge may lead to early diagnosis and appropriate treatment.

To get you started, below are ways you can help. Have fun, be creative and help increase awareness of primary immunodeficiency!

Get the Word Out and Help Others

“Learn More” Poster

IDF programs and resources produce benefits for thousands of people living with PI, but people need to find IDF first! IDF developed the Learn More – IDF Awareness Poster to lead patients and family members to IDF to use our services and innovative materials. Awareness Month is the perfect time to distribute it.

Start in your community! Are you a member of Facebook groups or other online communities related to PI? Share the Learn More – IDF Awareness Poster with them! You can download or order awareness posters, information cards and IDF publications to distribute at libraries, doctor’s offices, infusion centers, home healthcare companies, places of worship, schools and other civic organizations. No matter how or where you decide to get your message across, IDF has the resources you need. Download materials at www.primaryimmune.org/awareness, or order copies by contacting IDF at idf@primaryimmune.org or 800-296-4433.

Use Social Media

Use social media to share basic facts and information about primary immunodeficiency.

• Log into IDF Friends and connect with others living with primary immunodeficiency diseases in discussion forums and groups. Find others in your area to organize your efforts: www.idffriends.org.

• Teens can share what they are doing to promote awareness in IDF Common Ground, IDF’s social network just for teens: www.idfcommonground.org.

• Share your story with your own video at IDF Reel Stories: www.primaryimmune.org/idf-reel-stories.

• Like IDF on Facebook, follow @IDFCommunity on Twitter and Instagram and encourage your friends and followers to do the same! #primaryimmune #PIawareness
In celebration of Volunteer Awareness Week, we want to extend our gratitude to our nationwide network of dedicated IDF volunteers. If you have been helped by an IDF volunteer, reach out to them during Volunteer Awareness Week and thank them! Whether you send them a note or mention them on social media, let them know how much their assistance was appreciated.

Thank you to our amazing volunteers and all you do!

Interested in volunteering for IDF?
Learn more at www.primaryimmune.org/volunteer.
The Immune Deficiency Foundation Diagnostic & Clinical Care Guidelines for Primary Immunodeficiency Diseases has been one of the Foundation’s most popular publications, and the new third edition is now available.

In partnership with expert immunologists, IDF developed these guidelines to enhance earlier diagnosis, improve health outcomes and increase access to specialized healthcare and optimal treatment for patients with primary immunodeficiencies.

“The Guidelines were developed as a guide to help treating physicians, patients and their families,” explains Editor Rebecca Buckley, MD, the Chair of the IDF Medical Advisory Committee and the J. Buren Sidbury Professor of Pediatrics and Professor of Immunology at Duke University Medical Center, “They include recommendations, strategies and other information to assist patients and physicians in making early diagnosis of primary immunodeficiency and educated decisions about appropriate healthcare for patients with these diseases. This new edition has the latest recommendations and treatment information.”

Dr. Buckley led a working committee of contributors: Mark Ballow, MD, University of South Florida; Thomas Fleisher, MD, National Institutes of Health; Sergio D. Rosenzweig, MD, PhD, National Institutes of Health; R. Michael Blaese, MD, Immune Deficiency Foundation; Steven Holland, MD, National Institutes of Health; William T. Shearer, MD, PhD, Texas Children’s Hospital; Francisco A. Bonilla, MD, PhD, Boston Children’s Hospital; Hans D. Ochs, MD, Seattle Children’s Hospital and University of Washington; and Jerry Winkelstein, MD, Johns Hopkins University School of Medicine.

Marcia Boyle, IDF President & Founder, expressed her gratitude to the team, “The Immune Deficiency Foundation is extremely grateful to Dr. Buckley and all the contributors for their time and expertise. Their knowledge is so critical in developing this valuable resource which is bound to help save lives.”

The original Guidelines was published in 2006, and minor revisions were made in the second edition in 2009. The third edition has been thoroughly reviewed and updated, and contains information on:

• Selected Primary Immunodeficiency Diseases
• Antibody Production Defects
• Cellular or Combined Defects
• Phagocytic Cell Immune Defects
• Mendelian Susceptibility to Mycobacterial Disease
• Complement Defects
• Genetic Counseling: General Considerations and Practical Aspects
• Health Insurance
• Glossary

It also includes a new section on Mendelian Susceptibility to Mycobacterial Disease and updated International Classification of Diseases (ICD) codes.

These guidelines are not only intended to better educate physicians on the recognition, diagnosis and optimal treatment of these diseases, but they are also intended to provide patients with resources to deal more effectively with their physicians and with insurance providers.

This publication, like all IDF materials, is available at no charge to individuals. Download or order a copy of the Guidelines at www.primaryimmune.org/idf-publications.
IDF developed a new website dedicated to individuals and families living with Chronic Granulomatous Disease (CGD), LivingwithCGD.org. The website provides the latest news and information regarding diagnosis and treatment and serves as a platform to connect individuals and families living with CGD. The site features videos from individuals living with CGD and an integrated blog with news, events and patient stories.

CGD is a rare primary immunodeficiency disease (PI) in which one group of the body’s white blood cells, called neutrophils, fail to make the hydrogen peroxide, bleach and other chemicals needed to fight bacterial and fungal infections. CGD affects an estimated 1,200 people in the U.S. and approximately 25,000 people worldwide.

IDF launches the website at a pivotal time for CGD, as more treatment options are available today, enabling patients to lead healthier and more active lives. To further educate and generate awareness, IDF will host its first two-day CGD Symposium at the IDF 2015 National Conference in New Orleans on June 25-27, 2015. More details are available at LivingwithCGD.org.

We welcome individuals and families with CGD to share their story in video or on the site’s blog. Contact IDF if you are interested: 800-296-4433 or info@primaryimmune.org.

Visit IDF’s new website today! LivingwithCGD.org

This site is made possible by an unrestricted educational grant from Horizon Pharma.

Parents and Students: New IDF School Guide Available!

The Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases – Third Edition is now available! IDF developed this guide to help facilitate effective communication between parents, students and school personnel. When primary immunodeficiency affects a student’s education, the parents or the student (if appropriate) can use this guide to work with school personnel and develop a plan to address issues that might arise during the school year.

This Third Edition has been revised and updated and includes new information regarding federal laws and health insurance, and it incorporates helpful information about transitioning from high school to post-secondary education. Plus, more sample letters and forms were added.

To download or order a copy, go to www.primaryimmune.org/idf-publications.
What Is a Biosimilar and Why Should Patients Care?

What Is a Biosimilar Drug?
In simple terms, a biosimilar drug is a partial copycat drug that is similar but not exactly the same as an existing biologic drug, called a reference drug. Brand name drugs, like many found in your local drugstore, can have exact copies called generic drugs. However, a biosimilar drug cannot exactly copy a specific biologic drug. Immunoglobulin, for example, is a biologic.

It is important that biosimilar drugs, while not identical, can be manufactured to be as safe and effective as a brand named reference product. And the hope is that these biosimilar drugs will be significantly less expensive allowing patients greater access to them. The first biosimilar drug in the U.S. is on its way to being approved in the next few months.

It would be great to have cheaper drugs for patients with primary immunodeficiency diseases. IDF supports less expensive drugs. But, we are concerned about the rules of the FDA approval process as to whether these new drugs will be as safe and effective as the existing biologic drugs.

At this time, the approval rules are not finalized – and thus not known. The FDA has published draft “Guidance” documents, but they have not been finalized and they do not tell exactly what the process is and how patients will have the opportunity to be involved in the process.

Critical Questions
There are many critical questions the FDA has not answered. Will these new drugs have distinct names that allow patients and physicians to know what they are? If a biosimilar shares the same name as the referenced product drug, it makes it hard for patients to know what drug they are taking. This is a major issue because states are already passing legislation that would allow a pharmacist to substitute the biosimilar drug for its reference drug without notifying either the patient or the prescriber. Safety is always an issue and IDF believes that patients have the right to know before their treatment whether or not the drug is the biologic drug prescribed by a healthcare provider. Some states have laws that patients and providers don’t have to be notified. Most allow for notification, but after the substitution has occurred.

In IDF’s recent health insurance survey, patients with PI were asked, “Should a pharmacist have the authority to substitute a biosimilar for its reference drug if it is deemed interchangeable by the FDA?” Nearly two-thirds of patients responded “No.” And nearly 30% of other patients responded that they didn’t know or were not sure.

Patients for Biologics Safety and Access
Other regulatory issues regarding the approval testing procedures and product labeling also concern IDF. Because of these concerns, IDF is now spearheading a coalition of 23 national patient organizations who share similar interests. The Patients for Biologics Safety and Access (PBSA) coalition believes that patients must be a part of the FDA approval process for both biologics and biosimilar drugs. PBSA is seeking a Congressional oversight hearing to make sure patients are a part of the decision making process.

IDF will keep patients with PI informed and will call for patient action through IDF’s Action Alerts. Register for IDF Action Alerts at www.primaryimmune.org/action-alerts. Your voice is important!
SCID Q & A with Sung-Yun Pai, MD

Sung-Yun Pai, MD, a pediatric hematologist/oncologist at Dana-Farber/Boston Children’s Cancer and Blood Disorders Center, was lead author on two articles published last year on Severe Combined Immune Deficiency (SCID) in The New England Journal of Medicine: “Transplantation Outcomes for Severe Combined Immunodeficiency, 2000–2009” July 31, 2014 and “A Modified γ-Retrovirus Vector for X-Linked Severe Combined Immunodeficiency” October 9, 2014. The first reviewed outcomes after bone marrow transplantation; the second reported the first results of a new international gene therapy trial for X-linked SCID.

Q. What is SCID?

A. SCID is a group of disorders that compromise the blood’s T cells, a key component of the immune system that helps the body fight common viral infections, other opportunistic infections and fungal infections. They are also important for the development of antibody responses to bacteria and other microorganisms. A baby born with SCID appears healthy at birth. Once the maternal antibodies that the baby is born with start to wane, the infant is at risk of life-threatening infections. Unless diagnosed and treated with a stem cell transplant from a healthy donor or a more experimental therapy like gene therapy, babies with SCID typically die before their first birthday.

Q. How is stem cell transplant used to treat children with SCID?

A. Transplantation using healthy donor cells derived from a variety of sources has been described for SCID since 1968. The ideal donor is a healthy sibling donor with a matched tissue type. However, only 25 percent or less of siblings will be matched to the patient, and fewer siblings still will be healthy and suitable to donate. For most patients, the donor is a parent, an unrelated suitably matched adult or umbilical cord donor.

Q. Please describe your paper on transplant outcomes.

A. We examined outcomes for 240 patients transplanted in North America between 2000 and 2010. Virtually all patients with a matched sibling donor survived, but only half of babies who were actively infected at the time of transplant survived. Babies who had never suffered an infection or whose infection had resolved prior to transplant had excellent survival, regardless of age or donor source. Actively infected babies who got chemotherapy or immunosuppressive conditioning prior to transplant had lower survival compared to those who received no conditioning. While overall we found better immune system recovery in surviving babies who received chemotherapy conditioning, this benefit must be weighed against the long and short-term toxicities of chemotherapy. The longer you wait for transplant, the more likely it is that a baby with SCID will develop an infection, making it important to transplant babies as soon after birth as possible. Newborn screening in all 50 states is critical for this.

Q. What is gene therapy?

A. Gene therapy is an experimental treatment currently available for X-linked and adenosine deaminase deficient SCID (ADA SCID). Clinicians harvest the patient’s own blood stem cells, introduce a corrected copy of the gene using a specially designed virus called a vector, and give those cells to the patient through a transplant. Because the patient’s own cells are used, gene therapy eliminates the risk of graft-versus-host disease.

Q. Please describe your paper on gene therapy.

A. The new trial for X-linked SCID was designed to avoid the treatment-related leukemia that developed in one-quarter of patients in earlier European trials. We found that a redesigned vector is as effective in curing the SCID, and we have preliminary evidence that it is safer. Although our patients have not yet cleared the two-to-six year window in which the leukemia developed, molecular analysis shows that the new vector did not lead to the proliferation of cells driven by over-activity of cancer-causing genes that was seen in the earlier trials.

Q. Which patients should consider conventional transplant, and which should consider gene therapy?

A. If you have a matched sibling donor you should go with that. These transplants are almost always performed without chemotherapy, so even babies with an active infection do well. These patients are at substantially lower risk of graft-versus-host disease and rarely get its severe form. Examples of candidates for gene therapy include patients who lack a matched sibling donor, as well as those with an active infection. While most patients who undergo transplant do not develop severe graft-versus-host disease, for those that do, the consequences can be debilitating. Gene therapy trials for ADA SCID have yielded positive results and are beginning to be covered by insurance.

Q. Looking ahead, what do you see?

A. Given the toxicity of chemotherapy conditioning, we would like to determine the minimal dose needed to give patients the best chance of having normal immune systems. In gene therapy, we are working on the next-generation vector, which we hope will be even less prone to the development of leukemia, and plan to introduce a low dose of chemotherapy conditioning to promote better immune system recovery. Both avenues of treatment are clearly advancing. It’s too soon to say whether one will take over for the other. Ultimately I hope to see that all babies with SCID can be cured.

IDF SCID Newborn Screening Campaign Update

For many years, the Immune Deficiency Foundation (IDF) has strongly supported and worked tirelessly toward establishing SCID newborn screening programs in all 50 states to save lives. With more than 40 states either currently screening or planning to begin screening, the goal is within reach, but much work needs to be done.

To stay up-to-date and learn how to get involved, visit the IDF SCID Newborn Screening Blog: www.idfscidnewbornscreening.org.

The IDF SCID Newborn Screening Blog is sponsored in part by PerkinElmer and Sigma-Tau Pharmaceuticals, Inc.

Spring 2015
Join us in 2015 for IDF Walk for Primary Immunodeficiency and help us raise awareness and power research! Whether you’re new to the PI community or have been part of it for decades, you can support IDF’s mission of improving lives of people with PI by helping us reach our 2015 goal of $1 million!

Create a Team

One of the most critical factors to reaching our $1 million goal is creating many teams for each walk. Our teams raise an average of $1,000 each, so it’s essential to have as many teams as possible. You can create your walk team for any of our walk sites.

2015 IDF Walk for PI Sites

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<th>City, State</th>
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<tr>
<td>Boston, Boston Common</td>
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<td>Cleveland, Wade Oval</td>
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<td>Fort Lauderdale, Huizenga Plaza</td>
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If you do not live near any of the nine sites, you can create a team as part of our Nationwide Virtual Walk!

Free T-Shirt and More

There is no cost to participate in the walks, although we hope every walker will help us raise funds in support of our goals. Our walkers raise $100 on average, and each walker who raises $100 or more will receive a free 2015 IDF Walk for PI t-shirt. There are a variety of other incentives and recognition opportunities for those who raise more.

Madison Shaw showing off her sweatshirt and medal. Megan Ryan sporting her jacket. Both walkers earned their incentives for their amazing fundraising totals.

Raise $1,000 and Receive Free IDF 2015 National Conference Registration

Join the Order and get your IDF 2015 National Conference registration FREE! IDF Order of the Zebra members are the elite fundraisers whose efforts make the greatest impact on the success of each IDF Walk for Primary Immunodeficiency, and on IDF itself. By registering for the 2015 IDF Walk for Primary Immunodeficiency, and raising $1,000 or more prior to the conference you will earn a refund of your conference registration fee, and be recognized as one of the walk’s top fundraisers as a member of the IDF Order of the Zebra. Whether you live near one of our nine Walk sites, or want to participate in our Nationwide Virtual Walk, the funds that you raise as a member of the Order of the Zebra will make an enormous impact upon IDF. We are thrilled to offer the registration fee refund as a little reward for achieving so much so early in the year. Find complete details on page 3.
The IDF Legacy Society recognizes those who have included the Immune Deficiency Foundation in their wills or who have created other types of planned/legacy gifts in support of IDF. This type of giving makes a lasting impact by helping future generations of individuals living with primary immunodeficiency.

If you have chosen to include IDF in your financial or estate plans, please contact us and become a member of the IDF Legacy Society. Membership involves no dues, obligations or solicitations, but it does allow us to thank and recognize you for the future plans you have made. And your plans may inspire generosity in others.

Each Legacy Society member will enjoy benefits including personal updates from IDF’s President as well as recognition in publications and at special events.

For more information about the IDF Legacy Society, contact John Boyle, Director of Development, at jboyle@primaryimmune.org or 800-296-4433.