Zebras Gather for Inaugural IDF Walk for Primary Immunodeficiency

This fall, IDF launched the first Walk for Primary Immunodeficiency in Chicago, Los Angeles and Philadelphia, and our community of zebras gathered herds of family and friends! Overall, nearly 1,300 walkers participated, and more than $430,000 was raised from walkers and sponsors. IDF Walk for Primary Immunodeficiency supports vital IDF programs and services, and increases awareness about primary immunodeficiency across the country.

Walkers showed incredible enthusiasm at the Greater Philadelphia Walk, held Sunday, September 29 at Penn’s Landing. Teams of walkers arrived in customized team t-shirts—some even wore fun hats and socks. Walkers registered online prior to the event and received their own online fundraising page to create teams, add members and easily spread the word and raise funds. There were teams of coworkers, teams of classmates—patients and families living with primary immunodeficiency really reached out and rallied those closest to them.

“Many in our community have asked how they can create awareness about primary immunodeficiencies and help IDF,” explained IDF President & Founder Marcia Boyle, “Walk for Primary Immunodeficiency gives them the opportunity to do just that. The response from this first year was extraordinary. We are grateful to our walkers and sponsors, especially our National Presenting Sponsor, Baxter Healthcare Corporation. Their leadership helped launch a phenomenal walk.”

In Philadelphia, more than 500 walkers helped raise over $75,000. The Greater Philadelphia Walk committee, including Chuck Lage, Terry Halper, Judy Kozulak and April Sica, were dedicated to making the first walk go smoothly, and it definitely did!

Continued on next page
On Saturday, October 19, IDF traveled to the West Coast for the Greater Los Angeles Walk at El Dorado East Regional Park in Long Beach. Like Philadelphia, the teams showed up in spirited gear with lots of energy. Special guest James Worthy, a former Los Angeles Laker and NBA Hall of Famer, attended to show his support and pump up the crowd. There were over 250 LA walkers and almost $65,000 was raised. Greater Los Angeles co-chairs Rich Low, and Kristy and Nick Cacucciolo did an amazing job!

IDF wrapped up in the Windy City for the Greater Chicago Walk on Sunday, October 27 at Cantigny Park in Wheaton, IL. The temperatures were a little cooler, but the crowds were just as motivated. There were more than 525 Chicago walkers, and over $90,000 was raised. There were many who made Greater Chicago walk a success including chair Amy Walsh, the Berryhill Family and the many members of the walk committee (too many to name).

In addition to the three national sites, Biotest hosted a local walk at their headquarters in Boca Raton, FL and many are participating in the Nationwide Virtual Walk, which runs until December 31, 2013. You can still create a team and start fundraising today. Go to www.walkforPI.org.

Get Involved in 2014
In 2014, Boston, Houston and New York will be added to our existing walk locations of Chicago, Los Angeles and Philadelphia, as well as the Nationwide Virtual Walk. Visit www.walkforPI.org or email walk@primaryimmune.org to find out how you can spread the word about IDF Walk for Primary Immunodeficiency in 2014!
Purchasing Health Insurance in the New ACA Marketplaces

A major provision of the Affordable Care Act (ACA), also known as the healthcare reform law, was the creation of health insurance marketplaces, which offers the new way to compare and shop for health insurance plans. The marketplaces give people not currently covered by insurance an opportunity to obtain insurance, as law will require it in 2014. The marketplaces can also be used to compare plan options. If you are a patient with primary immunodeficiency, you should carefully evaluate which health insurance plan is best for you. If you use the new marketplaces to purchase health insurance, there are key elements to consider before choosing a plan.

### Calculate OOP Costs

The plan categories are Bronze, Silver, Gold and Platinum with each of the metal levels representing a different patient cost sharing responsibility, which includes the amount of overall medical and drug costs the patient will be responsible for through out-of-pocket expenses (OOP), e.g. deductibles, co-payments and/or co-insurance. In general, the lower the premium is, the higher the OOP costs will be when a patient needs care. For example, the Bronze plans will have the lowest premiums and the highest cost sharing responsibility for OOP expenses, while the Platinum plans will have the highest premiums and the lowest cost sharing responsibility for OOP expenses.

Remember, it is not always about the premium. The OOP costs for a patient with primary immunodeficiency can be much higher than the premiums in some plans. It is necessary for you to calculate the costs for your current immunoglobulin (Ig) replacement therapy, number of doctors’ office visits, emergency room visits, treatments for other conditions and any other costs including prescription costs. A Gold or Platinum plan which have higher premiums may be the better buy when OOP costs and premium subsidies are taken into account—especially if you have a primary immunodeficiency and need on-going and expensive treatments.

The IDF Health Insurance Toolkit includes helpful worksheets to help you calculate your OOP. Scan this QR code to download the toolkit:

www.primaryimmune.org/services/patient-insurance-center/idf-health-insurance-toolkit/

### Choosing the Right Plan

Once you determine what your OOP costs are expected to be, investigate how each plan will pay or not pay for services and Ig products that you will need. If your expected OOP costs are greater than the premium for any particular plan, that plan is probably not the right plan for you. Keep in mind the maximum OOP costs the law allows for individuals and families. In 2014, the maximum OOP costs that a plan can charge will be $6,350 for an individual, while a family could pay up to $12,700. Those totals include copayments, co-insurance and deductibles, but not premiums. The OOP limit may increase slightly every year.

As you search to find a suitable health plan, the answers to your questions may not be readily available. The summary description of benefits is usually not specific enough to learn what and how treatments will be handled, but questions can be submitted through navigators and certified application counselors. If these sources are not able to fully answer questions, directly contact the insurance companies that are offering qualified plans in the marketplaces to ask them, online or by phone.

With research and preparation, you will be able to make an informed choice of the plan that will best suit your individual healthcare needs.

### Stay Informed

For more information about the implementation of the ACA and how it relates to the primary immunodeficiency community, visit: www.primaryimmune.org/idf-advocacy-center/healthcare-reform.

For complete details about the marketplaces, visit www.healthcare.gov.*

*At press time, technical issues with www.healthcare.gov were being resolved. IDF will keep our community updated of any changes to the implementation of the ACA.
IDF Retreats are weekend gatherings for everyone in the primary immunodeficiency community — patients, parents, siblings, children and partners.

Whether you are newly diagnosed or have been living with a primary immunodeficiency disease for years, IDF Retreats offer an opportunity to connect with others to learn more about dealing with your disease. Leading physicians and healthcare professionals will present the latest information about the treatment and management of primary immunodeficiencies. Life management and everyday concerns will be featured in panel discussions led by experts in their fields. The youth and teen programs offer both education and fun, and are designed to help the younger members of our community better manage their diseases.

Perhaps, most importantly, these weekend gatherings offer an atmosphere to build relationships with others who share common experiences, therapies and feelings.

So, save the date and plan to attend an IDF Retreat in 2014! You can connect with the IDF Community and have some fun while developing better approaches to live with primary immunodeficiency!

Registration will begin in March 2014!

Mom Learns Life-Changing Information at IDF National Conference

Patients and families living with primary immunodeficiency all have stories of hope — stories of overcoming recurrent, sometimes life-threatening, infections, stories of receiving the right diagnosis and treatment. One mom recently shared her story of hope on IDF Friends, www.idffriends.org, IDF’s social network designed exclusively for patients and families living with primary immunodeficiency.

The mom, her son and her daughter are all patients with Common Variable Immune Deficiency (CVID), and together they attended the IDF 2013 National Conference. They learned that many people with CVID have autoimmune diseases, and a biopsy is the best form of diagnosis if possible. “It turns out that this recommendation would be life-changing for our family,” explains the mom in her post on IDF Friends.

Over the summer, her son developed symptoms of meningitis. Last summer, he had spent two weeks in the hospital due to meningitis and missed his freshman year of college because of it. This time he was admitted, immediately began antibiotics and underwent testing for multiple organisms. After a high fever sent him to ICU, he started to develop a rash just like the previous year, began suffering from seizure-like spasms and showed no signs of improvement. The mom says, “After about a week of living this hell… I told the doctors what I learned at the IDF conference and asked, ‘Could this be autoimmune?’ I have lupus, and my daughter has juvenile idiopathic arthritis. Maybe my son has something too. Could some type of autoimmune process be attacking his brain?”

She insisted on a skin biopsy, and it came back and indicated Lupus.

“I am so grateful that we went to the IDF National Conference,” says the mom on IDF Friends, “I would have neither thought to advocate nor had the information to back it up without hearing the doctors at the conference.”

“I am so grateful that we went to the IDF National Conference,” says the mom on IDF Friends, “I would have neither thought to advocate nor had the information to back it up without hearing the doctors at the conference. My son is now on maintenance immunosuppressants to keep this from happening again. I am happy to say he made it to college this year!”

This story of hope illustrates not only how important it is to advocate for yourself and your loved ones but also how inspiring sharing your story on IDF Friends can be. IDF Friends is safe, secure, and members understand what you are going through.

You can share your story of hope and help inspire others. Simply log onto IDF Friends, www.idffriends.org, and go to Stories of Hope.

Look for a new IDF Friends in early 2014! The site is currently being redesigned for an enhanced user experience.
IDF Volunteer Judy Kozulak, like many patients living with a primary immunodeficiency, keeps track of her medical information on paper. “Piles. Yes, piles of paper,” she explains with a smile, “You know, there might just be a better way than having cartons in the kitchen, in my office and in the basement.”

So when Judy told IDF she would like to create an account in the IDF eHealthRecord, www.idfehealthrecord.org, the online personal health record designed for the primary immunodeficiency community, we asked her to give us some feedback on her experience.

**Why do you want to create an eHealthRecord account?**

> It takes a minimum of two hours to find anything anymore. I used to think I was smart keeping a Word document of my meds, until I realized the list of documents was now 24 pages long. For the first time, in years, I forgot my med lists for a recent appointment. Once I got to work, I couldn’t access the files on my home computer, and I was dead in the water.

**What did you notice about entering your basic information?**

> It was easy entering the information—easier than doing Turbo Tax but still just about as much fun. However, the payoff is I don’t have to enter the basic information again. Even though I only just started keeping the record by entering meds and physicians, I can now grab my med list anywhere I have internet access! Instant gratification!

**How long did it take you?**

> I probably spent a total of 90 minutes getting the basic information entered. I had to remind myself that it doesn’t have to be perfect, but I wanted the information to be accurate. Fortunately, the eHealthRecord allows you to edit your entries to correct the mistakes.

**When did you start?**

> I worked on the record after dinner but before watching The Daily Show. That kept me from trying to enter too much information at once so I don’t burn out before I get my long history in. My goal is to have my entire pile of papers scanned in. Then I won’t have to worry about losing them, and it will be easier to retrieve them as necessary. That is my long term goal. My short term goal is to get my basic medical history in, start logging infusions and add allergies.

**What would you say to other users about the first steps?**

> When you start your eHealthRecord, just remember the old question which asks, “How do you eat an elephant?” The answer: “One bite at a time.” It’s the same for the eHealthRecord. Trying to do too much at a time will burn you out. You can put in a little or as much information as you want to keep stored. It isn’t as much fun as sitting on the beach in the Bahamas or even just going to a movie, but the end result is far greater and longer lasting. You only have to do this once, and your records are safe and accessible no matter where you travel.

Like Judy, you can start turning your piles of paper into useful information with the IDF eHealthRecord. It can help you keep track of: medications, supplements, diagnoses, infections, symptoms, infusions, medical visits and medical history. You can conveniently access your account from your computer, tablet or smartphone, and easily print and share your information. Rest assured your information is safe, secure and private.

**Need help?** IDF staff can provide answers to your questions and provide personalized assistance: info@idfehealthrecord.org or 800-296-4433.
Typical influenza is characterized by abrupt onset of fever, aching muscles, sore throat, and non-productive cough. Additional symptoms may include runny nose, headache, a burning sensation in the chest, and eye pain and sensitivity to light. Although many people think of influenza as the “flu” or just a common cold, it is really a specific and serious respiratory disease that can result in hospitalization and death.

The most frequent complication of influenza is bacterial pneumonia. Other complications include inflammation of the heart and worsening of pulmonary diseases (e.g., bronchitis). Reye’s syndrome is a complication that occurs almost exclusively in children—patients suffer from severe vomiting and confusion, which may progress to coma because of swelling of the brain. To decrease the chance of developing Reye’s syndrome, infants, children, and teenagers should not be given aspirin for fever reduction or pain relief.

Viruses cause influenza. There are two basic types which can cause clinical illness in humans, A and B. Influenza A can cause moderate to severe illness in all age groups and infects humans and other animals. Influenza B causes milder disease and affects only humans, primarily children. For most people, the flu lasts only a few days, but some people get much, much sicker. Influenza is of particular concern in people with pre-existing heart and/or lung conditions, the elderly, children under 2 years of age and pregnant women.

**Prevention**

The most effective way to avoid an infection with influenza is to receive the influenza vaccine annually. The Centers for Disease Control and Prevention (CDC) regularly updates its guidelines and now recommends that everyone over the age of six months be given the influenza vaccine every year. Influenza vaccines are safe and effective, and, contrary to a common misconception, they do not cause the flu. Because the influenza virus characteristically changes or mutates from year to year, each year it is necessary to prepare a new vaccine for protection from the new flu strains that are present that year. For this reason it is essential that everyone get immunized against the seasonal flu every year because last year’s vaccine may not be protective against this year’s virus strains. Currently there are two different types of seasonal flu vaccine available in the US – the inactivated or “killed” flu vaccine (the “flu shot”) and a live attenuated influenza vaccine (nasal spray). Both are highly effective in preventing influenza in normal individuals.

**FluMist**

The other vaccine is a live attenuated influenza virus (LAIV) vaccine that is administered by droplets given into the nose (FluMist). Attenuation means that the virus has been weakened so that it does not cause illness in normal healthy people. FluMist is approved for individuals ranging from 2 to 49 years old. Administration does not require any injections. However, since it is a live virus vaccine, it has some theoretical risk for patients with defective immunity. It is the general recommendation that patients with severe T-cell disorders, such as Severe Combined Immune Deficiency (SCID) and DiGeorge Syndrome, and B-cell disorders with hypogammaglobulinemia/agammaglobulinemia, such as X-Linked Agammaglobulinemia (XLA) and Common Variable Immune Deficiency (CVID), not be given this form of influenza vaccine (FluMist). There is no reason to expect that FluMist poses any risk for patients with CGD or complement disorders.

The CDC issued the following recommendation concerning FluMist (LAIV) use in individuals in close contact with patients with impaired immune systems: “The flu shot is preferred for people (including health care workers and family members) in close contact with anyone who has a severely weakened immune system (requiring care in a protected environment, such as a bone marrow transplant unit). People in close contact with those whose immune systems are less severely weakened (including those with HIV) may get LAIV.”

For more, updated information on the flu, visit the CDC website: www.cdc.gov/flu/ or www.flu.gov.
Primary Immunodeficiency Family Plan for Flu Season

For families with a member who has a primary immunodeficiency, it is recommended that all members of the family should be given the inactivated (killed) vaccine. Why should everyone be immunized? First, some patients with a primary immunodeficiency may benefit from the vaccine. Even if they do not, there is little down side to receiving the inactivated vaccine. Family members who are able to respond to the vaccine will be protected. Even if the patient with primary immunodeficiency does not respond to the immunization, he or she will benefit from having everyone else in the family protected from infection and not susceptible to bringing the virus home with them. We want to create a “protective cocoon” of immunized persons surrounding our patients so that they have less chance of being exposed. Immunization of other children in the family is especially important for this protective cocoon effect.

If influenza infection does happen, the same type of anti-viral medicine, i.e., Tamiflu or Relenza, which is effective for people with normal immune systems, would be effective for patients with primary immunodeficiency diseases. Note that Ig replacement therapy may not protect against new strains of the influenza virus since the Ig contained in the currently available lots of IVIG or SCIG was obtained from donors several months ago, probably before the newer strains of influenza had circulated thru the donor population to result in antibody formation.

Influenza can be diagnosed rapidly by a test done in physician offices. If the test is positive, it is recommended that persons immediately begin anti-virus treatment. Speed is important in this situation since the antiviral medications are most effective if begun within 48 hours of the onset of the illness. It would be a good idea to discuss with your physician plans for dealing with influenza before you get sick so that you are prepared.

What do I do if there is influenza in the schools or at my workplace?

There is no single recommendation that is applicable to every situation. Some medical advisors recommend that unless influenza is in their classroom children with primary immunodeficiency diseases should go to school. If there is a known direct contact with secretions from a flu-affected child or adult by the child with primary immunodeficiency, some medical advisors suggest that the child should go on Tamiflu once a day for 10 days. If the child with primary immunodeficiency disease develops symptoms of influenza, that child should go on Tamiflu twice a day for 5 days. Relenza could also be used as the anti-viral treatment. The same treatment recommendations should apply to adults with CVID or other primary immunodeficiency disease. In all cases, please first consult your healthcare provider.
Richard Hong, MD, longtime IDF Medical Advisory Committee member, began working with IDF when the Foundation first started in the early 1980’s. IDF President & Founder Marcia Boyle acknowledges the integral role he played in the early years, “Dr. Hong referred some of the first patients to IDF. He really helped get us off the ground.”

Reflecting on those early years, Dr. Hong explains that patients would receive a diagnosis of primary immunodeficiency and suddenly they were alone in a land that was unfamiliar to their families and physicians. He wanted more for his patients, “IDF became a part of my initial chats with parents, describing the support they could get. I thought it was important that they get perspective and knowledge from individuals experiencing the same challenges and fears that had been thrust into their lives. IDF has grown into this wonderful organization, dealing with all sorts of diseases and providing education in a meaningful way. It is part of the therapeutic program of treating patients.”

Dr. Hong retired in 2006 after a remarkable career. He attended medical school at the University of Illinois in Chicago and received his pediatric training at the Cincinnati Children’s Hospital. During his residency years, he developed an interest in immunodeficiency disorders and began postdoctoral training with Clark West and continued with studies of protein structure in the laboratories of Alfred Nisonoff. He then joined the laboratory of Robert Good at the University of Minnesota. While there, he participated in the first successful bone marrow transplant in humans, resulting in the cure of a child with severe combined immunodeficiency disease. Shortly thereafter, he moved to the University of Wisconsin where he spent the next 23 years of his academic career. In 1976, he performed a thymus transplant, using an organ culture technique for preparation of the tissue, in a small child with severe combined immunodeficiency disease. Although the patient acquired some benefit from the treatment, the improvement was only short lived and is no longer used for combined immunodeficiency disorders. Nonetheless, the technique is now the treatment of choice for another immunodeficiency disorder, the complete DiGeorge anomaly, resulting in a complete cure for approximately 30-40 patients a year.

In 1992, Dr. Hong moved to the University of Vermont to be closer to one of his major passions, his grandchildren. He served as Professor of Pediatrics at the University of Vermont, Burlington up until his retirement.

Dr. Hong thinks that he had more global perspective of doctor-patient relationships because he was a patient—he had tuberculosis when he was a resident, so he suffered from a chronic condition for a year. This made it easier for him to put himself in the patient’s position. He believes that for this same reason IDF has been successful, “IDF is the perfect example of how something can be well done by people who understand.”

Dr. Hong served as a member of the IDF Medical Advisory Committee for many years, and he commends the work of so many to build IDF to what it is today. “IDF has been successful and moved with modern times, becoming increasingly more proactive,” he says, “To watch this has been a great pleasure.”

Each year, Dr. Hong donates to IDF, and his continued support is much appreciated. He says, “I think it is important to give because I always felt that IDF was a part of my medical team and deserved to be included in my budget as much as my office personnel, professional associates, and research group. As that was a personal conviction, that part of the budget came from my own funds. As IDF became more of a force for patient advocacy, their contribution to the whole national picture has become absolutely critical to survival in increasingly more difficult times. I simply could not say ‘no.’”

IDF is grateful for Dr. Hong’s generosity and for his years of service to IDF and the primary immunodeficiency community. We wish him a happy retirement!

To help improve the diagnosis and treatment of primary immunodeficiency diseases, IDF invites teaching hospitals to benefit from its free educational program for teaching hospitals throughout the U.S.—The IDF & USIDNET LeBien Visiting Professor Program. This popular program provides a leading clinical immunologist to conduct Grand Rounds and present at educational activities, such as bedside rounds, house staff presentations and medical resident conferences.

Requests for the IDF & USIDNET LeBien Visiting Professor Program for 2014 are now being accepted. Simply write a brief (one page) Letter of Request stating your reason to participate in the program and how your students would benefit. Please include a tentative list of teaching and clinical activities. Submit this information to idfvisitingprofessor@primaryimmune.org by January 17, 2014. Contact IDF should you have any questions: 800-296-4433.
IDF Meets National Health Council Standards of Excellence

The Immune Deficiency Foundation Board of Trustees is pleased to announce that IDF has met all the requirements of the National Health Council Standards of Excellence Certification, ensuring that IDF maintains the highest levels of transparency, accountability and public stewardship. The standards cover the areas of governance, human resources, programs, fundraising, finance, accounting, reporting and evaluation.

“IDF has always maintained high standards and implemented best practices while working to improve the lives of those living with primary immunodeficiency diseases through advocacy, education and research,” said IDF President & Founder Marcia Boyle, “We are proud to become a member of the NHC to help raise awareness of rare and chronic diseases in a united voice.”

NHC Chief Executive Officer Myrl Weinberg said, “We are delighted that IDF has joined the list of the nation’s leading national patient advocacy organizations that meet the highest levels of transparency, accountability, and ethical practice.” She explained the NHC’s Standards of Excellence Certification Program® goes beyond the requirements of many charity watchdog groups and is unique to the patient advocacy community. “By meeting these Standards, IDF assures the public that it is an organization patients can trust and is worthy of the public’s support.”

The National Health Council is made up of more than 100 national health-related organizations and businesses. As a member, IDF will be able to work with other patient organizations and healthcare industry partners to bring attention to the needs of those living with rare and chronic diseases. For more information, visit www.nationalhealthcouncil.org.

IDF 4th National Treatment Survey

IDF is conducting the 4th National Treatment Experiences and Preferences Survey of Patients with Primary Immunodeficiency Diseases this winter, and we want members of our community to be a part of it. The goal of this survey is to obtain a current picture of patients with primary immunodeficiency who require immunoglobulin replacement therapy in the U.S. The three previous IDF National Treatment Surveys conducted in 1997, 2003 and 2008 provided the only national estimates of the experiences of patients with primary immunodeficiency diseases and Ig therapy, and it is time for an update.

This survey produces critical information to help understand and serve the primary immunodeficiency community. It will:

- Demonstrate the importance of early diagnosis and proper treatment with immunoglobulin for patients with primary immunodeficiency
- Describe in detail the health status of patients with primary immunodeficiency
- Provide detailed data on patient reactions to various immunoglobulin treatment regimens
- Identify problems in access to treatment in this population

There will be a sample of patients contacted. We need to make sure we can get in touch with you because your input and participation is vital. So we ask all patients to provide IDF with your current contact information, including mailing address and e-mail address by visiting www.primaryimmune.org/get-connected/ or scan this QR code to complete the form now.

It is important that we have your updated contact information because the survey will be mailed to a sample of patients this December. If you have any questions regarding this upcoming study, please contact Christopher Scalchunes, Director of Survey Research, at 800-296-4433.
Each year leading companies in the healthcare industry provide financial support to 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 are dedicated partners that support IDF at the highest level. They help fund direct services that offer peer support, help locate 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 our Consulting Immunologist Program and the IDF & USIDNET LeBien Visiting Professor Program, as well as IDF exhibits at medical meetings.

IDF does not charge for membership, so funding from sponsors allows IDF to provide services and publications free of charge to our community.

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

IDF Core Service Leaders
Baxter Healthcare Corporation
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RMS Medical Products

Lila Albin, Ph.D. of Lafayette, IN passed away April 10, 2012. Months later, IDF received a generous gift from her estate. The gift came as a surprise because IDF was unaware of Dr. Albin’s plans before her passing. She had been a member of the IDF community for years, attending meetings and programs, receiving communications and participating in surveys, but IDF did not know of her intentions.

“We regret not having the opportunity to properly acknowledge Dr. Albin’s incredible gift,” explains IDF President & Founder Marcia Boyle, “Her generosity will help IDF provide educational programs to individuals living with primary immunodeficiency.”

The Board of Trustees voted to use a portion of her gift to fund scholarships to the IDF National Conference, enabling patients and family members to attend who otherwise would not have been able to do so. “Dr. Albin’s gift truly makes a difference in people’s lives.”

Share Your Plans with IDF

If you have chosen to include IDF in your financial or estate plans, like Dr. Albin, please contact us and become a member of the IDF Legacy Society, which recognizes those who have included IDF in their wills or who have created other types of planned gifts in support of IDF. You may make a bequest or gift through your estate by including a provision in your will or living trust, or by naming the Immune Deficiency Foundation as a beneficiary of a retirement plan or life insurance policy.

Membership in the IDF Legacy Society involves no dues, obligations or solicitations, but it does allow us to thank and recognize you for the future plans you have made and it can inspire generosity in others. Each Legacy Society member will enjoy benefits including an annual conference call with the IDF President as well as recognition in publications and at special events.

When you leave a legacy that helps advance the work of IDF, you bring hope for a better future for the thousands living with primary immunodeficiency. Dr. Albin chose to support future generations of our community, and IDF acknowledges her remarkable kindness.

Let us know when you have included IDF in your estate plans, and it will be an honor to add you to the IDF Legacy Society. Please allow us to recognize your generosity.

For more information about the IDF Legacy Society, contact John Boyle, Director of Development, at development@primaryimmune.org or 800-296-4433.
Mail Your Gift
Use the enclosed envelope and mail your check, made payable to the Immune Deficiency Foundation, to IDF, 40 West Chesapeake Avenue, Suite 308, Towson, MD 21204.

Tribute Gift
A donation to IDF is a thoughtful way to honor someone whose life has been impacted by a primary immunodeficiency disease. Once your gift is received, IDF will notify the honoree or family acknowledging your gift. Complete the online donation form and designate your honoree or memorial. Go to www.primaryimmune.org/give.

Matching Gifts
Some companies will match the gifts of employees. Please visit www.primaryimmune.org/match to see if your company matches gifts, or contact your employer’s human resources department to ask if they participate and request the form to accompany your gift.

For more information about ways to give to IDF, contact the Development team development@primaryimmune.org or 800-296-4433.

Make Your Gift to IDF

Thousands of people living with primary immunodeficiency turn to IDF for education, resources and support. A gift to IDF can help us to continue to provide these vital programs and services to individuals, families and healthcare providers. We ask that you consider making a gift to IDF this year, and there are many ways for you to do so:

Donate Online
To make a one-time donation, visit our website:

www.primaryimmune.org/give

Mail Your Gift

In Memory of:
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Tamara Allard
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Dr. Daniel Boje
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The gifts listed here were received independent from IDF Walk for Primary Immunodeficiency. Those contributions will be recognized in the IDF 2013 Annual Report. All donations help IDF improve the diagnosis and treatment of patients with primary immunodeficiency diseases through advocacy, education and research. If you would like to make a donation, please go to www.primaryimmune.org/give or contact us:

Phone: 800-296-4433 or 410-321-6647
Monday - Friday, 9 a.m. - 5 p.m. (EST)
E-mail: development@primaryimmune.org
Mail: IDF, 40 W. Chesapeake Ave., Suite 308 Towson, MD 21204

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