IDF Increases Patient Education Meeting Outreach

The Immune Deficiency Foundation announces a commitment to increase patient education meetings throughout the country.

“As the national patient organization for primary immunodeficiency diseases, patient education is central to our mission,” said Marcia Boyle, President & Founder of the Immune Deficiency Foundation. “We know that patients and family members are hungry for knowledge about living with their diseases and we want to be there, in their cities to help.”

“Our Board of Trustees saw the value of this initiative and agreed to create a new position and dedicate more staff time devoted to enriching and increasing local patient education nationwide,” Marcia explained. “We are more than doubling our efforts to partner with our wonderful volunteers, physicians, and industry sponsors in geographic regions to reach more patients and enhance the content of the meetings. We are all excited about this improved outreach.”

**IDF Patient Education Meetings**

The day long, Patient Education Meetings not only present educational sessions and information about resources for living with primary immunodeficiency diseases (PIDD), but also offer the opportunity to interact with local healthcare professionals and other patients and families. Attendees can directly ask physicians’ questions during the “Ask the Expert” session and often benefit from several specialists’ responses.

Frequently, these gatherings of patients and families provide time for participants to exchange ideas and lend support. This has been formalized into the Get Connected Group time at the end of the meetings when participants are free to talk about more personal issues, person-to-person. This time has been so popular that now there are Get Connected Group meetings, scheduled separately from education meetings where local volunteers lead the networking session.

In fact, the work IDF volunteers do locally in their communities - providing peer support, developing relationships with medical professionals and creating awareness - is indispensible in laying the groundwork for these successful meetings.

**IDF Family Conference Days**, are similar to patient education meetings, but have the added component of a youth program for ages 5 and up.

**Operation Outreach** are patient education meetings held in areas where there may not be any IDF volunteer activity and are in early development stages of creating programming.

In 2012, IDF is hosting two IDF Family Retreats, offering more educational opportunities. These are full weekend events, with a fabulous youth and teen program. The next retreats are scheduled in Milwaukee, WI on June 22-24, and Houston, TX on September 7-9, 2012.

Of course, IDF’s next National Conference will be held in 2013 in Baltimore, MD, June 26-29!

IDF encourages you to attend a meeting near you. There is always something new to learn and someone new to meet! You can find out about upcoming IDF events in your area by checking the Calendar of Events on the IDF website www.primaryimmune.org.

Be sure to check out the Community in Action blog at www.idfcommunityinaction.org for accounts of educational meetings and other IDF volunteer events.
Rebecca Buckley, MD elected to National Academy of Sciences

The Immune Deficiency Foundation (IDF) is proud to announce that Rebecca H. Buckley, MD, Chair of the IDF Medical Advisory Committee has been elected a member of the National Academy of Sciences (NAS) for her life-saving research in pediatric immunological diseases. Dr. Buckley is the J. Buren Sidbury Professor of Pediatrics and professor of immunology at Duke University Medical Center.

The National Academy of Sciences (NAS) is an honorific society of distinguished scholars engaged in scientific and engineering research, dedicated to the furtherance of science and technology and to their use for the general welfare. Election to the NAS is considered one of the highest honors that can be accorded a scientist or engineer.

“Dr. Buckley’s contribution to the primary immunodeficiency community is immeasurable,” said Marcia Boyle, president and founder of the Immune Deficiency Foundation. “She has generously given her time and expertise to the IDF for years, particularly in the area of Severe Combined Immunodeficiency (SCID). For decades, her steadfast dedication to our community has been inspirational. Her leadership has been invaluable, and IDF is so fortunate to have her guidance and knowledge.”

Dr. Buckley has spent most of her career addressing genetic disorders of the immune system and has been a strong proponent of newborn screening for these types of diseases. She has been a pioneer in the use of bone marrow transplantation to provide immune reconstitution to infants with Severe Combined Immunodeficiency (SCID) and has been able to successfully provide this treatment to all SCID infants, regardless of whether they have a matched sibling donor.

Over 30 national committees and councils have been fortunate to have Dr. Buckley as a member. She was president of The American Academy of Allergy, Asthma and Immunology (AAAAI). She is a member of numerous medical organizations, including the Society for Pediatric Research, the American Pediatric Society (Council 1991-2001; President 1999-2000), American Association for the Advancement of Science, Fellow (2000); Chairman Section on Medical Sciences (2001-2003), American Association of Immunologists (Chairman, Clinical Immunology Committee 1984-87), American Academy of Pediatrics (Section on Allergy & Immunology; Executive Committee 1981-84). In addition to being Associate Editor of the Journal of Clinical Immunology, Dr. Buckley has also served on a variety of editorial boards including the Journal of Immunology and the Journal of Allergy and Clinical Immunology. She chaired the NIH Immunological Sciences Study Section and has been a member of NIAID’s Board of Scientific Counselors. Dr. Buckley serves on the ITN Data and Safety Monitoring Board for the National Institute of Allergy and Infectious Diseases (NIAID) and the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children.

Dr. Buckley has been actively involved in clinical and scientific research and is the author or co-author of almost 300 scientific publications. She has received numerous awards and honors for her contributions to medicine from organizations such as the National Institutes of Health, the Immune Deficiency Foundation, and the American Society for Microbiology and the American Academy of Allergy, Asthma and Immunology.

“Dr. Buckley’s tremendous scientific accomplishments have cemented her role in history as a leader in primary immunodeficiency research and treatment, and we are fortunate that she serves as Chair of our Medical Advisory Committee,” Boyle added. “We at IDF are so proud to be associated with such a distinguished and caring physician. IDF is also proud to sponsor the Immune Deficiency Foundation Duke Center of Excellence.”

Dr. Buckley joined 71 other new members and 18 foreign associates from 15 countries in recognition of their distinguished and continuing achievements in original research in NAS membership in April. Other renowned members of NAS include Albert Einstein, Robert Oppenheimer, Thomas Edison, Orville Wright and Alexander Graham Bell.

IDF & USIDNET LeBien Visiting Professor Program Accepting Requests for 2012

IDF is currently accepting Letters of Request for the IDF & USIDNET LeBien Visiting Professor Program for 2012. The purpose of this program is to increase knowledge about the diagnosis and treatment of patients with primary immunodeficiency diseases. It is available at no cost to teaching hospitals throughout the United States. We believe your medical education program will benefit by having a leading clinical immunologist lead grand rounds and other educational activities.

If you are interested in participating in this valuable program, please send a brief (one page) letter to the Immune Deficiency Foundation, Attn: IDF & USIDNET Visiting Professor Program, 40 West Chesapeake Ave. Suite 308, Towson, MD 21204 or email Diana Gill, Director, Program Services at dgill@primaryimmune.org by January 15, 2012, stating your desire to participate in the program. The letter should include a tentative list of teaching activities and information on how your training program would benefit from a visiting professorship.

Please direct any questions to IDF at 800.296.4433.
Are you prepared?

- For an insurance denial
- To change doctors if needed
- For a change in insurance coverage
- To go on vacation
- For a natural disaster
- For a product recall

For patients with a primary immunodeficiency disease (PIDD) it is critical to keep complete, up-to-date documentation of your medical status. Life is full of changes and you need to be ready for the twists and turns in your future.

That Is Where The IDF eHealthRecord Comes In!

It is designed to help you take control of your health information and make your life easier. You can track your symptoms, treatments, and check your progress, even schedule and review events in the calendar section. Use it to organize the health profiles for you and your family all in one place. Security measures keep your records safe, secure and ready for when you need them.

The IDF eHealthRecord, the first electronic personal health record for the primary immunodeficiency community, will help you organize and track:

- Lab reports that led to original diagnosis and corresponding documentation
- Explanation of benefits from your insurance provider
- IgG related blood work and other test reports
- Infusion log information such as lot #, manufacturer, infusion related notes, and side effects, pre, during, or post medication
- Family medical history
- Your own medical history
- And much more!

So Register today and be prepared!

The IDF eHealthRecord is for YOU! By tracking your medical history in the easy to use step-by-step process, utilizing the convenient infusion logs, or making use of the In Case of Emergency report (I.C.E.) you will be prepared for whatever comes your way. So do yourself a favor and take advantage of this free, unique software especially designed for the primary immunodeficiency community.

To learn more

- Check out the IDF website at www.primaryimmune.org
- Tune into the IDF eHealthRecord video channel at www.primaryimmune.org/idf-tv where you can learn how to get started and find tips and tricks on how to navigate the IDF eHealthRecord.
- Email us at info@idfehealthrecord.org or call 800-296-4433 (Toll Free) or 443-321-6647 (Direct).

Sponsored in part by an unrestricted educational grant from CSL Behring.
The idea was simple enough: develop a program that would help teenagers – age 12 to 19 – who are living with a primary immunodeficiency disease (PIDD) develop coping skills, nurture friendships and provide an opportunity to network with others who are facing the same challenges. But a funny thing happened on the way to the Immune Deficiency Foundation’s Teen Escape Weekends: the parents of the teens with PIDD seem to enjoy – and benefit – from the gatherings almost as much as their kids.

“Oh, absolutely,” says Deborah Sclafani-Toski, a Louisiana mom who attended a gathering in Atlanta. “The Escape really helped me a lot. Not only did I learn so much, but I left those sessions feeling more empowered than I ever have. I was definitely more confident in my ability to talk to medical professionals.”

Deborah’s 18-year-old daughter, Laurin, was diagnosed with Hypogammaglobulinemia more than two years ago, and mom’s plan was to use the retreat to “help bring [my] daughter out of her denial about having the disease.”

Mission accomplished – and although she described the act of getting Laurin to Atlanta as “like pulling teeth,” Deborah found the experience not only “rewarding” and “well worth it,” but it also increased her and Laurin’s interest in activism and “getting involved.”

“It was the best thing we could have done,” agrees Ricardo Ramirez, whose son, Robert (16), was diagnosed with CVID a few years ago. “The Escape allowed our son to become much more aware that he wasn’t alone, and he met other kids who were succeeding in many aspects of life regardless of their condition.”

But Ricardo and his wife, Lupe, weren’t just thrilled with what Robert took away from the Teen Escape in Minneapolis, they were also “incredibly impressed” with the entire program.

“We certainly appreciated the positive reinforcement we received from other parents [in the sessions] and from the Foundation,” Ricardo states. “It seemed like the parent program covered a great portion of the PIDD landscape.”

At its most basic, an IDF Teen Escape is an opportunity to acquaint teens diagnosed with PIDD with others like themselves. Healthcare professionals and life skills experts present valuable information to the teens and encourage them to discuss what it means to live with PIDD. This is all done with an element of fun and entertainment while encouraging the teens to play a major role in improving their own quality of life.

For parents, separate Saturday morning sessions are held at Teen Escapes that offer an environment to learn, exchange ideas, and make contacts.

Cindy Ross, a Colorado mom who – with husband Mike and daughter Kendra – also attended the Minneapolis Escape. Her 17-year-old daughter was diagnosed with Complement Deficiencies approximately one year ago.

“Three major benefits [of attending] come immediately to mind,” Cindy reveals. “The Escape was a blessing because it helped us better understand our daughter’s type of PIDD; allowed us to trade experiences with other adults; and went a long way in helping us be better parents. Just having the extended adult contact was wonderful. After dealing with teachers, school administrators, insurance issues, doctors’ visits, worrying about the health of houseguests, losing friends and providing care for Kendra, PIDD can make it rather isolating for a mother, too.”
In all, the three parents who shared their personal stories had much more in common than simply having a child with primary immunodeficiency disease. The trio agreed that attending an IDF Teen Escape led them to discover aspects of PIDD they had no idea existed, and that sessions such as “Insuring Your Teen” and “Empowering Your Teen to Take Control of Their Own Health Care” offered much needed - and greatly appreciated – advice.

The three also unanimously acceded that the concern, generosity and accommodating nature of the attending medical professionals, IDF Teen & Young Adult Council members and mentors made the experience both pleasurable and instructive.

At the core, IDF Teen Escapes provide a setting in which teen patients and their families can get away from the day-to-day challenges and medical concerns that come with primary immunodeficiency diseases. The additional layers surrounding these gatherings – beyond the obvious educational value – consist of an immeasurable number of success stories that were sometimes unexpected.

“I honestly didn’t know what to expect,” Deborah admits, “but as the weekend went on I was totally blown away by the whole program.”

“Boy, there sure is a learning curve when it comes to these diseases,” Cindy Ross says, “but finding IDF and attending these meetings has been very helpful.”

“In all, an outstanding experience,” Ricardo Ramirez concludes. “These weekends provide us with a great opportunity to become engaged.”

Author Joyce Maynard once wrote that ‘it’s not only children who grow, parents do too.’ And that observation offers yet another dynamic in which these three parents find themselves in agreement.

To learn more about the IDF Teen Program and Teen Escapes, contact IDF at 800-296-4433 or e-mail eferguson@primaryimmune.org.

Teen Escape is sponsored by an unrestricted educational grant from Baxter Healthcare.

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**Health Insurance Changes Could Affect YOU**

There is a growing trend among insurers that could hurt patients with primary immunodeficiency diseases! Some insurers are creating single-brand, restrictive formularies for immunoglobulin replacement therapy that would force patients to switch from the product they currently use to another product chosen by the insurance company. This is a safety issue for patients.

If you are a plan member of Coventry HealthAmerica in Pennsylvania or Coventry Group Health Plan in Missouri, we understand there are changes coming on December 1st that could force you to change your current Ig therapy. If you want more information, please contact IDF at info@primaryimmune.org.

Please sign up for IDF Action Alerts to stay informed of initiatives to protest harmful insurance practices. It could happen to you.

[http://primaryimmune.org/action-alerts-sign-up](http://primaryimmune.org/action-alerts-sign-up)

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**Pregnancy and Primary Immunodeficiency Disease**

If you are the mother of a child with Primary Immunodeficiency Disease (PIDD), or a woman, of any age, with a PIDD, IDF needs your help!

IDF has received an unrestricted educational grant to perform a ground-breaking survey. This survey will be conducted in the Fall of 2011 and we need to make sure we can get in touch with you in the most effective manner.

If you are not sure that you have provided IDF with your current e-mail address, please go to the “Get Connected” page on www.primaryimmune.org and fill out this contact form.

Contribute to this important research and help IDF make a difference!

If you have any questions regarding this upcoming study, please contact IDF’s Director of Survey Research at: 800.296.4433.
There’s a familiar saying – “the proof is in the pudding” – that, while shortened over time, still retains its original meaning: that the quality of something is uncertain until it has been tested directly.

The “pudding” – in this instance – was provided by Elena Bojorquez, a 19-year-old resident of Fresno, California, just one short year after the Golden State began a pilot program that screens newborns for Severe Combined Immune Deficiency (SCID) disease.

After years of resolute advocacy and dogged lobbying of legislators, the medical community, patients and families, and organizations such as the Immune Deficiency Foundation won a major victory by convincing more than a dozen state governments that the inclusion of SCID testing in newborn screening programs was essential in saving lives.

Unbeknownst to Elena – who had given birth to a seemingly healthy seven pound, one-ounce little girl – was the role she was about to play in proving just how crucial the California pilot program would become.

“I had never heard of SCID or primary immune deficiency disease until last year,” Elena explains. “The whole process really opened my eyes.”

Elena, now 20, was just as excited as any new mother when she gave birth to little AnnaLou 11 months ago. So excited, in fact, that she was out showing off her little girl when her pediatrician made the phone call that would change their lives.

“Given the initial screening at birth showed a potential problem, Elena’s pediatrician requested another blood draw.

“There’s good reason for the expansion of SCID screening to all 50 states,” says Dr. Jennifer Puck, Department of Pediatrics and the Clinical and Translational Science Institute at the University of California San Francisco, who created the TREC test used to identify SCID and also oversees the follow up of the infants in California picked up by the screening. “Without screening, four out of five cases of SCID are identified only after the child has suffered from numerous illnesses and infections. It is then that these babies are often in very serious trouble.”

Elena, naturally more interested in the health of her baby than in medical data and mechanisms, would not allow her new family to become a late diagnosis statistic. She would, however, face the most frightening time in her young life when the pediatrician confirmed that further blood tests had revealed the presence of SCID.

“When my doctor started explaining what was happening all I was hearing was ‘bone marrow transplant’,” Elena continues.

“There was a lot of crying and a lot of worrying. I just couldn’t imagine doing a transplant on someone so small.”

While a bone marrow transplant is the only ‘cure’ for SCID, there remains a myriad of steps between initial diagnosis and the actual procedure.

“When they told us it was SCID they also told us to isolate her and keep her in a controlled environment,” Elena shares. “We did get to spend [last] Thanksgiving at home, though, but for the first time in my life I wasn’t around my family for the holidays.”

In preparation for her bone marrow transplant, AnnaLou was admitted to the UCSF hospital when she was just one-month old.

“I couldn’t imagine not being there for her,” Elena explains. “I was so thankful they let me stay with her almost from the time she was admitted until after the transplant.”

With AnnaLou’s admission to the hospital came what is normally an exhaustive search for a bone marrow donor who would provide the best match.

“I think everybody in my family volunteered to get tested,” Elena says proudly, “but it turned out that AnnaLou had the best chance if I was the donor. I think that’s when I really started freaking out.”

The young mother would spend the next few months in the hospital with her daughter, and would then undergo a series of shots – four days worth, to be exact.
that would prepare her for the bone marrow removal and transfer.

“The shots really burned,” Elena exclaims, “and they really made my bones hurt – head, kneecaps, elbows. It was worse than the worst flu I’ve ever had.”

Fortunate, then, that one does not remain awake for the entire process.

“Oh, no… I watched the whole thing play out,” Elena says excitedly. “From the arm withdrawal to watching the [IV] bags hanging in the corner of the room fill up – I was awake for the whole thing and just laying there kind of chillin’.”

For the first time during the course of the interview, Elena used the sort of slang normally associated with a young, carefree mother, and not like the worried woman who had been describing the seriousness of the situation she faced. Yet, she was so impressed with the professionalism of the medical teams she encountered that as soon as AnnaLou had responded favorably to the transplant, Elena enrolled in college and embarked on an inspirational career path.

“After watching those nurses and doctors and people like Dr. Puck do what they did for me and AnnaLou I decided to enter the medical field,” Elena admits. “I want to be a nurse in San Francisco and work with people who are as wonderful as they are.”

Not only successful in detecting the potential presence of SCID, the newborn screening method has also alleviated fears that such a test would result in a large percentage of “false positives.”

“After pouring over the data for the whole first year – and keep in mind that’s nearly 500,000 births – there were only 50 instances of an irregular screening,” Dr. Puck clarifies. “Of those 50 only 20 revealed the low level of T-cells that is associated with SCID.”

Those numbers reveal why California was such an important addition to the roster of states that screen - the state is not only responsible for 10 percent of this country’s newborns, but also sees approximately a dozen infants born each year with the disease.

Though she eventually discovered that SCID had taken the life of one of her family members, Elena Bojorquez never imagined that her child would become the first one whose life was saved thanks to the newborn screening pilot program.

Babies in the state will continue to be screened for SCID beyond the current pilot thanks to legislation that was signed into law October 4, 2011 making SCID a part of the state’s newborn screening panel. Dr. Puck and Elena both participated in advocacy efforts to see AB 395 become state law along with the Immune Deficiency Foundation.

“This is something that is going to continue to save lives,” Elena says, wondering aloud why any state legislature wouldn’t add SCID testing to the roster of diseases now screened for at birth. “Do they really want children to die because of not having this simple test?”

As for the star of this story, little AnnaLou is now no different than any other healthy 11-month-old.

“She has two teeth now,” Elena says, “and she hasn’t been sick at all. She did run a fever not long ago, but it was just from teething. I have to admit, though, I was ready to get on the phone and call Dr. Puck.”

That a young mother can attest to her child’s very survival thanks to newborn screening should not only validate that aforementioned saying, but it should also provide all the proof that anyone could possibly need.

Visit www.idffriends.org/reelstories to see Elena tell her story on the IDF Reel Stories page!
The sweet tea and chocolate bundt cake may have sweetened the offer, but it was the dedicated connection between a Member of Congress and constituent that spurred Congressman Kevin Brady of the 8th District in Texas to choose to spend a Saturday afternoon at Carol Ann Demaret’s house. Carol Ann, who lives in Texas’s 8th District and is a member of the IDF Board of Trustees, welcomed Representative Brady to her home to film the latest IDF Advocacy Channel video. The goal of the video was to focus on tips for being a successful IDF advocacy volunteer, emphasizing how to effectively communicate with your legislators. Carol Ann’s relationship with Congressman Brady is the perfect example of the power of creating a strong bond with your Members of Congress.

Carol Ann met Representative Brady many years ago after the death of her son David Vetter from Severe Combined Immune Deficiency (SCID). David became known around the world as the “boy in the bubble” due to his need to live in a sterile environment that was created by a bubble-like structure. Carol Ann explained SCID and issues surrounding living with primary immunodeficiency diseases to Congressman Brady and he was moved by Carol Ann’s story. They have kept in touch, and as a result of their relationship, Rep. Brady has become one of IDF’s most dedicated advocates in Congress. He is the cosponsor of the Medicare IVIG Access Act (HR1845/S 960) that, if passed, would allow patients with PIDD who are Medicare beneficiaries to receive their IVIG treatments in the home setting, an option that is currently unavailable to most of them.

It is because of his connection with Carol Ann that Representative Brady has come to know the IDF community and care so much for our issues.

“Because Carol Ann took the time to educate me both here at home and in Washington, DC, that’s why I learned about primary immunodeficiency diseases,” Congressman Brady explains, “That’s why I became engaged in IDF.”

In addition to the encouraging words from Representative Brady, the “Tips for Being an Advocate” video features Carol Ann presenting steps to help members of the PIDD community engage with their own policymakers.

“You don’t need to be a professional lobbyist to influence how policy and legislation are created,” Carol Ann affirms, “All you need is your personal experience and factual information to back up your personal experience.

The video takes viewers through the multiple ways to interact with policymakers and encourages them to become involved in public policy to make a difference for the whole primary immunodeficiency community.

Congressman Brady is just one of the many legislators who are supportive of IDF and our public policy efforts. However, when Members of Congress and other policymakers receive thousands of emails and phone calls every month on other issues, it takes that personal connection to really make an impact.

“It is so important that you talk to your lawmakers. Bring your story to life, bring this disease and give it a face to your local lawmaker,” prompts Representative Brady, “You, I am certain, can make a difference.”

Time to get inspired! Check out “Tips for Being an Advocate” and all of the IDF Advocacy Channel videos at http://primaryimmune.org/idf-advocacy-center.
Patient Notification System (PNS): Make Sure You Are Registered In Case of a Product Recall

Over a decade ago, the Plasma Protein Therapeutics Association (PPTA) and its members, working in collaboration with consumer organizations, developed a first-of-its-kind Patient Notification System (PNS). This model notification system is a rapid web-based tool that empowers patients with information about their medicines and is also available to physicians, nurses, and pharmacists. For our community, this system covers your Immunoglobulin therapies, IVIG or SCIG.

All you need to do is: Sign Up! Register at www.patientnotificationsystem.org. The PNS is a great source of trustworthy information; it provides confidential notification of therapy withdrawals and recalls. There is no charge to register.

There are many great features about the PNS. It’s easily accessible and it is the one place on the web that you can visit and log-in to receive comprehensive information about immune globulins, blood clotting factors, alpha-1 proteinase inhibitors and other lifesaving plasma protein therapies. Another important feature is that the PNS is confidential. Registrants, whether they be patients, physicians, family members, nurses, or pharmacists, are guaranteed that their information is never shared nor is it accessible by anyone other than the third-party company that houses the computers to run the system. The PNS was created to provide consumers, health care providers and others with a single, convenient source for up-to-date information about the plasma protein therapies they use and depend on.

Ensuring Confidentiality
Maintaining patient confidentiality was a major consideration when developing the system. A working group comprised of representatives from consumer organizations, including Alpha-1 Association, Alpha-1 Foundation, Committee of Ten Thousand, Hemophilia Federation of America, Immune Deficiency Foundation and National Hemophilia Foundation, helped to design the system to safeguard sensitive registrant information. To ensure confidentiality, the PNS is operated by Stericycle, Inc., an independent organization that specializes in informing the public of pharmaceutical withdrawals and recalls (notifications). All registrant information is kept strictly confidential.

Register Online or Toll-Free
Anyone interested in registering with the PNS can go online at www.patientnotificationsystem.org or call the toll-free number, 1-888-UPDATE-U (1-888-873-2838). When you sign up, some basic contact information will be required, such as your name, address, email and phone number. You’ll set up your own log-in and receive a password.

Notification Methods
During the registration process, you will be asked to select your “primary” method of notification. Registrants currently have the option of being notified by email, telephone or fax. We think you’ll agree that email is a great choice for your “primary” method of notification because it is instantaneous and it is accessible anywhere, even if a registrant is traveling. It is very important for patients to receive this information about recalls or withdrawals; don’t delay in registering and consider email as your “primary” choice for how to be notified.

PNS in Action
Here’s how the PNS works. If a therapy is withdrawn or recalled, the company involved immediately contacts Stericycle, Inc., which then notifies the registrant. Every effort is made to notify registrants within 24 hours. Registrants are notified twice. First, you will receive an email, phone call or fax from Stericycle depending on your designated “primary” notification. Second, you will receive a U.S. mail letter containing the same information. The reason you will receive two notifications is because this is important information – you need to know before you infuse or inject your therapy that there has not been a recall or a withdrawal. The redundancy of two types of notification is intended to ensure that you have received your notification.

Consumers also can go online to www.patientnotificationsystem.org or call a 24-hour, toll-free number 1-888-UPDATE-U (1-888-873-2838) for current information on product recalls or withdrawals. To maximize the usefulness of the system, it is important for consumers to keep accurate infusion logs and record the lot number, therapy and manufacturer for all therapies they use.

PPTA’s Role
The system is administered by the Plasma Protein Therapeutics Association (PPTA). The PNS is a comprehensive web-based system that is funded by manufacturers including: Baxter BioScience, Bayer Healthcare LLC, Cangene Corporation, CSL Behring, Grifols USA, Novo Nordisk Pharmaceutics, Octapharma, and Pfizer.

The Perfect Place to Keep Your Infusion Log!
Keeping an infusion log on the IDF eHealthRecord will help improve your quality of healthcare by finding the product that works best for you, helping you keep a regular infusion schedule, and protecting you in the case of a product recall. The IDF eHealthRecord is specifically designed to track all details related to your infusion.

You will be able to track:
- Product
- Product lot numbers
- Dates
- Dosage amounts,
- infusion sites,
- total time of infusion,
- reactions,
- physician notes
- and more.

To get started, make sure you know these three things:
- type of treatment and product
- total volume
- frequency of infusions

Sign on to the IDF eHealthRecord at www.idfehealthrecord.org and track your next infusion!
To make your gift online, please visit www.primaryimmune.org. Thank you!

In medical school, many doctors learn the saying, “when you hear hoof beats, think horses, not zebras” and are taught to focus on the likeliest possibilities when making a diagnosis, not the unusual ones. However, sometimes physicians need to look for a zebra. Patients with primary immunodeficiency diseases are the zebras of the medical world. So IDF says THINK ZEBRA!

In Memory - Lisa Codispoti, IDF Board of Trustees Member

Lisa Codispoti passed on October 6, 2011. She is survived by her husband, Shawn Wilson, parents Joseph and BettyAnn Codispoti, sisters Annette and Laura, and good friends. She will be remembered for her compassion, beaming smile and the fierce passion she brought to her quest to bring equity and accessibility to health care and women’s issues. Lisa was a valuable member of the Immune Deficiency Foundation (IDF) Board of Trustees, and dedicated IDF volunteer.

Lisa served as Senior Counsel at the National Women’s Law Center in Washington, DC with their Health and Reproductive Rights Team. In that capacity, she helped lead the Center’s work on Women and Health Reform.

Lisa especially excelled when it came to patient advocacy. She had a tremendous wealth of information and advice on health policy issues for IDF. At the IDF 2011 National Conference Lisa gave an outstanding presentation on healthcare reform and how it would impact our community at the Saturday Breakfast Symposium.

Lisa was remembered for her work as a tireless healthcare advocate at the Congressional level with remarks made by Congresswoman Janice Schakowsky (IL) on October 12, 2011. To read the commemoration in the Congressional Record go to: thomas.loc.gov, click on the congressional record link, and search for “Lisa Codispoti”.

Lisa will be missed. There is a memorial fund to honor Lisa’s legacy at the Immune Deficiency Foundation.
For an updated IDF Calendar of events, visit www.primaryimmune.org/event-calendar.

IDF Store

Do your holiday shopping at the online IDF Store this December! Visit www.primaryimmune.org/idf-store, and you’ll find gifts for everyone on your list! A portion of the proceeds from every purchase benefits IDF. Happy shopping!

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In honor of IDF’s 30th Anniversary, be sure to check out the new “30 Years of IDF” interactive timeline, and the 30th Anniversary Video at www.primaryimmune.org/30-years-of-idf.