After passing by an overwhelming majority in the House and unanimously in the Senate, President Obama signed the Medicare IVIG Access Act into law on January 10, 2013. The long road to this historic milestone was paved with challenges, but we succeeded because of the relentless efforts of the Immune Deficiency Foundation’s community of supporters and the tremendous leadership of our Congressional champions. Over the past 10 years, thousands of patients and family members made their voices heard in Congress by sending more than 25,000 letters and participating in over 500 meetings. If not for the unwavering spirit of the IDF community, the Medicare IVIG Access Act would not have been introduced and become law. This law creates a demonstration project supporting access to all products in all sites of care for Medicare beneficiaries with primary immunodeficiency diseases by addressing a problem in the Medicare law and allowing beneficiaries access to intravenous immunoglobulin (IVIG) in the home. It is important to understand the evolution of the law and the power of our community who made it a reality.

The Medicare Modernization Act (MMA) of 2003 created a new benefit for Medicare patients with primary immunodeficiency diseases to receive IVIG infusions in the home, in addition to the other covered settings, such as hospital outpatient departments, infusion clinics and physician offices. This was a critical achievement for our community, giving Medicare patients with primary immunodeficiency diseases the choice for the optimal site of care when their immunity is at the lowest. However, the law as written only provided coverage and reimbursement for the immunoglobulin product, not the items and nursing services needed to infuse it, essentially rendering the IVIG home infusion provision an “empty benefit.” A separate provision in the MMA changed the reimbursement methodology for IVIG and other Part B drugs in 2005. The unintended consequence of this change was to reduce IVIG reimbursement to the point where it was less than the cost of infusing IVIG in many settings. Concerned providers and patients flooded IDF with calls and e-mails. Very few physicians wanted to take our patients; hospitals were not always an option, and virtually no infusion companies wanted to take Medicare patients on IVIG, creating an unsettling time for our community.

IDF took steps to educate Members of Congress and the Centers for Medicare and Medicaid Services (CMS), including countless meetings and testimonies. IDF mobilized grassroots volunteers to sign up for the first IDF Action Alert to directly contact their legislators to help in the effort, and we had an overwhelming response. In fact IDF surpassed the milestone of 10,000 letters sent through IDF Action Alerts in June 2008. To increase our visibility on Capitol Hill, IDF retained the services of Hart Health Strategies, a bipartisan consulting and lobbying firm specializing in legislative and regulatory healthcare issues. To provide data behind the calls and anecdotes received, IDF conducted patient, physician and pharmacy surveys in 2006 to document their Medicare and IVIG experiences. Again, our community responded well and participated in the surveys, resulting in vital data. The patient component of these surveys found that patients on Medicare, when compared to their private pay insurance counterparts, were much more likely to report having IVIG therapy postponed, treatment intervals increased and their IVIG dosage decreased. IDF survey data was cited in the 2007 report published by the Department of Health and Human Services (HHS) Office of the Assistant Secretary for Planning and Evaluation (ASPE), documenting the access problems for Medicare patients. Months later a report published by the HHS Office of Inspector General, confirmed the information provided by IDF surveys.

During this time, Representative Kevin Brady (R-TX) became personally involved. His leadership began after meeting with his constituent, Carol Ann Demaret, member of the IDF Board of Trustees and mother of David Vetter, diagnosed with Severe Combined Immune Deficiency and known around the world as the “boy in the bubble.”

In 2007, Representative Brady introduced the first of several bills in subsequent years that would allow better access for our Medicare patients as continued on next page
Medicare IVIG Access Act Passes

continued from page 1

well as allow Medicare to reimburse for the items and services needed to receive IVIG infusions in the home. Senator John Kerry (D-MA) became involved after his constituents and IDF Volunteers Stefani Bush and Michelle Fox, along with their family and friends, advocated for the bill. During the healthcare reform debate in 2010, Senator Kerry introduced an amendment creating a demonstration project as an intermediate step to solving the home infusion problem. The idea of a demonstration project gained some political traction and that same year Representatives Doris Matsui (D-CA) and Brady introduced a Medicare IVIG demonstration bill based on Senator Kerry’s amendment. The project would allow Medicare beneficiaries with primary immunodeficiency diseases to receive IVIG infusions in the home and gather data to work toward permanent reimbursement for IVIG in the home.

The June 2012 report from the Medicare Payment Advisory Committee (MedPAC) also helped our cause. At the behest of Congress, MedPAC looked at home infusion, including the access problem for Medicare beneficiaries with primary immunodeficiency diseases. MedPAC reported to Congress that “a targeted expansion of home infusion coverage focusing on a subset of drugs would have more likelihood of savings… Drugs with a narrow indication and precise diagnostic criteria (e.g., IVIG for PID) would be less subject to a woodwork effect than drugs with broad uses or less precise diagnostic criteria…” We were encouraged by this report and IDF volunteers shared it with their legislators.

Our community was optimistic of the bill’s success but remained vigilant and continued to advocate for it. In mid-December 2012, the bill, with provisions of the Strengthening Medicare and Repaying Taxpayers (SMART) Act included, began moving. After passing in the House, we prepared for the Senate vote. Nearly 700 letters from patients and their families were sent via IDF Action Alerts. Physicians, plasma centers and manufacturers of immunoglobulin were called upon to contact Senators. The bill passed unanimously in the Senate.

Some say the way the Medicare IVIG Access Act passed is amazing. We acknowledge the significance of it passing as its own bill maintaining its original name. The fact that “IVIG” remains, an acronym that is such an important part of our community, is extremely meaningful. But the most amazing and meaningful aspect is the power of our community. When Representative Brady with continuing work and advocacy, it is our hope that the demonstration project will prove what we have expected all along and a permanent resolution will become law.

What Does Passing the Medicare IVIG Access Act Mean for Patients

The Medicare IVIG Access Act gives the Centers for Medicare and Medicaid Services (CMS) up to a year to implement the demonstration project that will allow patients with primary immunodeficiency disease across the country to receive home infusions of IVIG. This means that CMS has until January 10, 2014 to set up the demonstration project. Patients cannot currently access the benefit. IDF has initiated conversations with CMS about implementation of the demonstration project to ensure that it meets the needs of our patients. When we know more information about how the project will work and when patients can enroll, we will let the community know through our website and publications.
The IDF 2013 National Conference returns to Baltimore, Maryland, June 27-29 where IDF began in 1980 and where we held our first two national conferences in 2001 and 2003. This is the only meeting in the U.S. that brings together the primary immunodeficiency community for three days of learning, discussing and sharing.

IDF created a special website to cover all the details of the IDF 2013 National Conference, and we encourage you to visit it: www.idfnationalconference.org.

Some highlights you can look forward to:

- **IDF Advocacy Day** – Come a day early on Thursday and travel with IDF to Washington, D.C. to meet with your Congressperson and spread awareness of primary immunodeficiency diseases on Capitol Hill.

- **Orientation for First Timers** – Get an overview of conference activities and events.

- **Healthcare and Life Management Presentations** – Choose from almost 40 sessions to learn about advancements in the diagnosis and treatments, and gain skills needed to manage healthcare.

- **Welcome Reception** – Renew old friendships, meet new acquaintances and help us launch the conference! Hear about what opportunities the conference offers as you meet presenters, industry sponsors, IDF volunteers, board members and staff. Heavy hors d’oeuvres will be served.

- **Stars and Zebra Stripes Gala** – Join us on Friday night in the Francis Scott Key Ballroom, named for the American lawyer and amateur poet who wrote the words to the “The Star-Spangled Banner” in Baltimore, for an evening of music, dinner, recognitions and an amazing silent auction.

- **IDF Exhibit Hall** – Allow enough time in your schedule to visit the Exhibit Hall, filled with services and products for the primary immunodeficiency community, and you could be the winner of an iPad®.

- **IDF Night at the National Aquarium** – Enjoy dinner overlooking the dazzling Inner Harbor and discover aquatic treasures with your family at the National Aquarium in Baltimore.

- **Youth Program** – Fun, age-appropriate activities and educational sessions for everyone in the family, even as young as 6 months old. Kids and teens, ages 5-18, can attend an off-site trip to the Maryland Science Center Saturday afternoon.

- **Professional Medical Education Program** – IDF and the Clinical Immunology Society invite healthcare professionals to attend an Update in Diagnosis and Management of Primary Immunodeficiency program on Saturday, June 29, featuring sessions about primary immunodeficiency diseases and offering Continuing Medical Education (CME) credits for participants.

Learn more about the IDF 2013 National Conference and register online at www.idfnationalconference.org. See you in June!
# IDF 2013 National Conference

## Conference Presenters

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution/Medical Center</th>
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<tbody>
<tr>
<td>Alessandro Aluti, MD, PhD</td>
<td>San Raffaele Telethon Institute for Gene Therapy, Milan, Italy</td>
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<tr>
<td>Michael Albert, MD, PhD</td>
<td>Dr. von Haunersches Kinderspital, Germany</td>
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<td>Mark Ballow, MD</td>
<td>State University of New York at Buffalo</td>
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<td>Mira Bada-Saad, PhD</td>
<td>Bar-Ilan University</td>
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<td>R. Michael Blaese, MD</td>
<td>Immune Deficiency Foundation</td>
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<td>William Blouin, MSN, ARNP, CPNP</td>
<td>Miami Children's Hospital</td>
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<td>Francisco Bonilla, MD, PhD</td>
<td>Boston Children's Hospital</td>
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<td>Christian Braun, MD</td>
<td>National Human Genome Research Institute – NIH</td>
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<td>Amy Brower, PhD</td>
<td>Massachusetts Institute of Technology</td>
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<td>Rebecca Buckley, MD</td>
<td>Duke University Medical Center</td>
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<td>James Bussel, MD</td>
<td>Weill Cornell Medical College</td>
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<td>Fabio Candotti, MD</td>
<td>National Human Genome Research Institute – NIH</td>
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<td>Charlotte Cunningham-Rundles, MD, PhD</td>
<td>Mt. Sinai School of Medicine</td>
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<td>Joie Davis, PNP-BC, APNG</td>
<td>National Institute of Allergy and Infectious Diseases - NIH</td>
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<td>Maggie Dodds, CPNP, RN</td>
<td>Texas Children's Hospital</td>
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<td>Carla Dufi, CCNP, MSN, CCRP</td>
<td>University of South Florida</td>
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<td>Kristin Epland, FNP-C</td>
<td>Midwest Immunology Clinic</td>
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<td>Lisa Filipovich, MD</td>
<td>Cincinnati Children's Hospital</td>
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<td>Alexandra Freeman, MD</td>
<td>National Institute of Allergy and Infectious Diseases - NIH</td>
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<td>Ramsay Fuleihan, MD</td>
<td>Northwestern University's Feinberg School of Medicine</td>
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<td>Laura Guenther, LCSW</td>
<td>University of Illinois, Chicago</td>
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<td>Adi Gundlapalli, MD</td>
<td>University of Utah School of Medicine</td>
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<td>Terry Harville, MD, PhD</td>
<td>University of Arkansas for Medical Sciences</td>
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<td>Vivian Hernandez-Trujillo, MD</td>
<td>Miami Children's Hospital</td>
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<td>Michael Hershfield, MD</td>
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<td>Steven Holland, MD</td>
<td>National Institute of Allergy and Infectious Diseases - NIH</td>
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<td>William P. Leach</td>
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<td>Howard Lederman, MD, PhD</td>
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<td>Peter Mannon, MD</td>
<td>University of Alabama - Birmingham</td>
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<td>M. Louise Markert, MD, PhD</td>
<td>Duke University Medical Center</td>
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<td>Donna Marie Meszaros, PhD</td>
<td>Abaris and Apex Behavioral Health Clinics</td>
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<td>Josh Milner, MD</td>
<td>National Institute of Allergy and Infectious Diseases - NIH</td>
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<td>Hans Ochs, MD</td>
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<td>Sung-Yun Pai, MD</td>
<td>Boston Children's Hospital</td>
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<td>Jennifer Pate, MD</td>
<td>St. Luke's Episcopal Hospital</td>
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<td>Jennifer Puck, MD</td>
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<td>Marc Riedl, MD</td>
<td>UCLA David Geffen School of Medicine</td>
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<td>Joseph Roberts, MD, PhD</td>
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<td>Debra Sedlak, CPNP</td>
<td>Duke University Medical Center</td>
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<td>John Seymour, PhD, LMFT</td>
<td>Minnesota State University - Mankato</td>
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<td>Ralph Shapiro, MD</td>
<td>Midwest Immunology Clinic</td>
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<td>Ricardo Sorensen, MD</td>
<td>LSU Health New Orleans - School of Medicine</td>
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<td>E. Richard Stiehm, MD</td>
<td>University of California - Los Angeles</td>
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<td>Kathleen Sullivan, MD, PhD</td>
<td>Children’s Hospital of Philadelphia</td>
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<td>Jodi Taub, LCSW</td>
<td>Private Practice Social Worker</td>
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<td>Troy Torgerson, MD, PhD</td>
<td>Seattle Children's Hospital</td>
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<td>James Verbsky, MD, PhD</td>
<td>Medical College of Wisconsin</td>
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<tr>
<td>Becky Wang, MA, LLPC</td>
<td>Private Practice Therapist, Shepherd, MI</td>
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<tr>
<td>M. Elizabeth Younger, CPNP, PhD</td>
<td>Johns Hopkins Hospital</td>
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## EARN YOUR STRIPES & EARN YOUR KEEP!

Win up to THREE FREE HOTEL NIGHTS at the IDF National Conference, along with free registration.

2013 marks the 5th Anniversary of THINK ZEBRA!, Immune Deficiency Foundation’s spectacular campaign to raise funds and promote awareness of primary immunodeficiency diseases.

This year, for the first time, funds and awareness can be raised online.

It is easy for participants to create their own Personal Campaign Page, and then e-mail friends, neighbors and family members, with information about primary immunodeficiency diseases and IDF. We will provide all the information and even text for you to use. Simply add your personal story, then your contacts can easily make contributions through your Personal Campaign Page.

So what will you win?

**Raise $1,000** - and you will receive reimbursement for your registration fee for the IDF National Conference.

**Raise $2,500 - $3,499** - and you will receive one free hotel night at the Baltimore Hilton during the Conference, in addition to the reimbursed registration fee.

**Raise $3,500 or more** - and you will receive three free hotel nights at the Baltimore Hilton during the Conference, in addition to the reimbursed registration fee.

Visit [www.idfnationalconference.org/zebra](http://www.idfnationalconference.org/zebra) for more information and to create your personal campaign page.

IDF cannot succeed without your help! Gifts at all levels are greatly appreciated and ALL participants, no matter how much they raise, will be recognized.

**THINK ZEBRA!**

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!
EARN YOUR STRIPES &
EARN YOUR KEEP!

Donations are tax deductible as allowable by law, and all auction proceeds will directly benefit IDF’s mission. In appreciation of this support, donors’ name will be recognized in the Silent Auction Program and displayed with the item at the auction. If you would like to donate, please visit www.idfnationalconference.org/idf-auction to submit the form.

If you have questions, please contact IDF: 800-296-4433 or info@primaryimmune.org.

Long-requested by members of our community, IDF officially announces the launch of Walk for Primary Immunodeficiency. IDF’s national walk program will be a game-changing fundraising initiative, and an incredible opportunity to raise awareness of primary immunodeficiency diseases in the U.S.

This inaugural year of Walk for Primary Immunodeficiency will feature walks in the greater Chicago, Philadelphia and Los Angeles areas, all scheduled for the fall. For those who live elsewhere, resources are being developed that will allow for participation no matter where you live.

More details will become available in coming months, but we encourage you to start thinking about the role that you might play as this important initiative expands. For more information, please e-mail walk@primaryimmune.org.

Special thanks go to:
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April is National Primary Immunodeficiency Awareness Month! So this April, join with IDF, in partnership with World PI Week, celebrated April 22 to 29, to promote awareness of primary immunodeficiency diseases in your community.

If you live with primary immunodeficiency diseases or you have a significant relationship with someone who is affected, you know how important it is to raise awareness and understanding about these diseases. This is a perfect opportunity to educate and inform people and hopefully, this knowledge will lead to early diagnosis and appropriate treatment.

To get you started, below is a list of ways you can help increase awareness. Have fun, be creative and get the word out!

**Distribute Educational Information**
One of the easiest ways to promote awareness is by spreading the word in your community. You can download or order posters, information cards and IDF publications to distribute to libraries, doctor’s offices, infusion centers, home healthcare companies, places of worship, schools and other civic organizations. To get your message across in the most effective manner possible, it is important to have some basic facts and information ready for anyone that asks, including:

- Talking Points on Primary Immunodeficiency Diseases
- Frequently Asked Questions
- IDF Information Sheet

Download materials at [www.primaryimmune.org](http://www.primaryimmune.org), or order copies by contacting IDF at info@primaryimmune.org or 800-296-4433.

**Contact the Media**
If you are interested in telling your story to the local media, download our Media Kit at [www.primaryimmune.org](http://www.primaryimmune.org). The kit includes steps on how to go about contacting the media, sample letters and press releases, FAQs about primary immunodeficiency diseases and other helpful information to use when reaching out to your local media.

**Take Action and Advocate**
Advocacy gives you a voice! You do not need to be a professional lobbyist to influence how policy and legislation is created. Grassroots advocacy helps to personalize an issue and begins to help solve some of the problems that the primary immunodeficiency community faces. Visit the IDF Advocacy Center [www.primaryimmune.org/idf-advocacy-center](http://www.primaryimmune.org/idf-advocacy-center) to view advocacy priorities for our community. Be sure to sign up for the Action Alerts and get your IDF Advocacy Toolkit to start getting involved.

**Host an Event**
Consider hosting an event such as a bowl-a-thon, bake sale or trivia night to raise funds and spread awareness. By getting a little creative, you can personalize your event in your own special way and make it a success.

**THINK ZEBRA! Fundraising**
This year, for the first time, funds and awareness can be raised online. It is easy for you to create your own Personal Campaign Page, and then e-mail friends, neighbors and family members with information about primary immunodeficiency diseases and IDF. We will provide all the information and even text for you to use. Simply add your personal story, then your contacts can easily make contributions through your Personal Campaign Page. Money raised will help fund patient and physician education and awareness. To get started raising funds online, visit [www.primaryimmune.org/take-the-zebra-challenge/zebra](http://www.primaryimmune.org/take-the-zebra-challenge/zebra). If you have questions or would like to order kits, contact IDF: 800-296-4433 or info@primaryimmune.org.

**World PI Week: April 22-29**
IDF will join the efforts of organizations across the globe to promote awareness of primary immunodeficiency diseases during World PI Week, April 22-29. IDF will participate in worldwide initiatives to improve the recognition, diagnosis, treatment and quality of life of people with primary immunodeficiency diseases. For more information about World PI Week, visit [www.worldpiweek.org](http://www.worldpiweek.org).
How One Volunteer Promotes Awareness
Assigns Her Students an IDF Research Paper

Nancy Nicholas beams with pride when she wears her zebra attire while teaching at Ivy Tech Community College in Goshen, IN. Rather than simply telling her students why she wears zebra, the adjunct professor, known for her bright smile and positive attitude, has them go a step further and research the Immune Deficiency Foundation (IDF) for themselves. Each semester, she asks students in her entry-level English class to write a research paper about IDF. As an enthusiastic IDF volunteer, it’s no wonder Nancy incorporated her dedication to IDF into her work.

“I appreciate the leverage from my supervisor to choose my own subjects and am not confined to a list of research topics that are old and boring,” explained Nancy, “I choose research projects involving current events and teaching a lesson as well as producing a properly written paper.”

Nancy’s “IDF Research Paper” helps the class learn how to research and cite for a 2-3 page paper. The adult students use IDF’s website as a source to explain primary immunodeficiency diseases and the work of IDF. Some discuss the diseases and treatment, and others write about the programs for patients, families and healthcare professionals. Overall, each student provides a different perspective. “Each semester I have 24 students, and I find it amazing. I normally receive 24 different concepts of what they researched through IDF,” said Nancy, “I even had one student try to cure the disease.”

It seems the most meaningful aspect of the IDF Research Paper is the increased awareness of primary immunodeficiency diseases and IDF resources—something Nancy values as a patient diagnosed with Common Variable Immune Deficiency (CVID) just four years ago. Nancy said, “I was diagnosed solely on the information that I ‘accidently’ received while attending the Orlando conference in June 2009 as a guest with my niece and nephew who both have CVID.”

After attending the sessions and learning more about the diseases, it did not take Nancy long to realize that she had the symptoms that her nephew, niece and most of the other attendees had. Nancy believed she had CVID. For more than 15 years, she had been living on antibiotics and hospitalized two to three times a year with pneumonia. “I returned home full of knowledge, determination. Against strong resistance, I maintained focus on finding help,” she said. After finding the right specialist, Nancy was diagnosed and began treatment in August 2009. She is doing well!

Nancy now wants to educate as many people as she can about primary immunodeficiency diseases, IDF, plasma donation and more. One of Nancy’s students shared the information she learned from the assignment with her son’s doctor. Her son had suffered from chronic ear infections, causing the young mom to often miss class. At 14 months old, he was diagnosed with a primary immunodeficiency disease and started receiving intravenous immunoglobulin therapy just weeks after his diagnosis.

Nancy’s work is making a difference. Students are learning more than writing skills. They are discovering a community of patients and families living with rare diseases who rely on IDF for support. One student wrote, “IDF has helped thousands to be educated and has been a place that feels like home to so many.”

Because of the incredible work of volunteers like Nancy, IDF is “like home to so many” — a home where proudly wearing zebra attire is encouraged.
IDF celebrated the passing of the Medicare IVIG Access Act with staff members of the Plasma Protein Therapeutics Association (PPTA) January 15, including Julie Birkofer, Senior Vice President, North America; Kym Kilbourne, Director, Federal Affairs; Joshua Penrod, Vice President, Source; and Bill Speir, Director, State Affairs. They presented Marcia Boyle, IDF President & Founder, with a silver champagne holder engraved with “Congratulations IDF – Medicare IVIG Access Act, January 10, 2013” and a bottle of champagne to celebrate the momentous achievement.

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The Affordable Care Act
How It Affects People with Primary Immunodeficiency Diseases

The constitutionality of the new healthcare law, or the Affordable Care Act (ACA), is now settled by the highest court in the land, but considerable questions still remain about what this means for patients with primary immunodeficiency diseases. Some of this will be dependent on the implementation of such provisions as the establishment of health insurance exchanges and the essential health benefits. However, this does have some very tangible outcomes right now:

- Adult children up to age 26 can remain on their parents’ health insurance policies.
- Children up to age 19 cannot be denied coverage because of a pre-existing condition.
- An insurance company cannot take your coverage away from you should you become sick.
- Insurers are prohibited from imposing lifetime dollar limits on insurance coverage.
- The Medicare Part D (prescription program) “donut hole” will begin closing.
- Preventive screenings and wellness programs will continue with no co-payments.

Also, beginning in 2014:

- No one can be denied coverage because of pre-existing conditions.
- A woman will not have to pay higher premiums than a man just because of her gender.
- There will be annual limits on the amount of money a person or family must pay out-of-their pocket.
- There will be new premium subsidies available for families who meet certain income requirements.
- Uniform appeal procedures and summary of benefits documents will be in all plans.
- Insurers will be prohibited from the use of annual dollar limits on insurance coverage.

IDF will continue to monitor the implementation of the ACA, particularly as states begin setting up insurance exchanges and establishing their essential health benefit benchmark plans. It is important that you stay informed of how these, and other provisions of the ACA, will impact you.

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Stay updated about the ACA!

Please check the Healthcare Reform section of the IDF Advocacy Center for more information:

To stay updated, sign up to receive e-mails from IDF:
http://primaryimmune.org/patients-and-families/ask-idf/get-connected
IDF Presents: Battle of the Bands!

Are you a fan of In Tune with Your Immune System, IDF’s popular teen-friendly video comparing the human immune system to a rock band? It now has a comic book version: IDF Presents: Battle of the Bands! Visit www.idfcommonground.org to download the comic book or contact IDF to order your own copy: 800-296-4433 or info@primaryimmune.org.

Teen Program Brochure

Learn more about the programs offered for teens living with primary immunodeficiency diseases in the new IDF Teen Program brochure. The Teen Program provides education and peer support, builds leadership skills and encourages teens with primary immunodeficiency diseases to live life to the fullest. Visit www.primaryimmune.org to download the brochure, or contact IDF to order additional copies: 800-296-4433 or info@primaryimmune.org.

Both publications were made possible by charitable donations from Baxter Healthcare Corporation, CSL Behring and Grifols.

IDF Becomes Member of National Health Council

IDF is now a member of the National Health Council (NHC), which is made up of more than 100 national health-related organizations and businesses. We are proud to join the nation’s leading patient advocacy organizations to provide a united voice for people with chronic diseases and disabilities and their family caregivers. As a member, IDF will be able to work with other patient organizations and healthcare industry partners to help raise awareness of rare and chronic diseases. For more information, visit www.nationalhealthcouncil.org.

IDF NAC Publishes Nursing Guidelines

“Nursing Guidelines for Administration of Immunoglobulin Replacement Therapy,” developed by the IDF Nurse Advisory Committee (NAC), was published in the January/February 2013 issue of The Journal of Infusion Nursing (Indexed in MEDLINE, CINAHL Plus, PubMed). The article is a comprehensive review and standards for administration of immunoglobulin replacement therapy, written by members of the NAC, including Mary Elizabeth M. Younger, PhD, CRNP; Loris Aro, RN; William Blouin, MSN, ARNP, CPNP; Carla Duff, MSN, CPNP, CCRP; Kristin B. Epland, MSN, FNP; Elyse Murphy, BSN, RN; and Debra Sedlak, CPNP.

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Spring 2013
Finding Renewed Strength

Brian Rath Recounts Liver Transplant

As I lay in my hospital bed late that night, I thought of my family. Earlier that evening, my wife had had the dreaded discussion with our two kids; that dad may not be coming home — ever. In the dark, I added up in my head what I would be leaving behind and prayed it would be enough for my family to move on without me. And I thought about the last thing I would say to my family and friends, if given the chance.

By November 2011, I had been battling the effects of my Hyper IgM Syndrome for all of my 39 years. Although I had more than my share of serious infections and illnesses, I was always strong enough to fight through each. This time, however, waiting for a new liver, my strength was gone. I had been fighting my whole life, I was the sickest I had ever been, and I was exhausted. I had nothing left. It was the longest night of my life.

Amazingly, as the morning’s first light filtered into my room, I received the call for which we had been longing; a new liver was found. Thanks to the skill of an amazing group of doctors and nurses, the prayers and support of my friends and family, and one incredibly generous decision by the parents of a beautiful 15 year old girl who died far too young, I awoke the following day with a new liver, 54 staples in my abdomen, strange tubes sticking out of me, and a new chance. Where I was no longer able to fight, others did for me. I was not struggling alone.

If my life were a movie (starring Bradley Cooper or that Indian guy from Big Bang Theory), I would have turned my life completely around, devoted myself to saving the world and, maybe even, bought the Cratchits the biggest Christmas turkey in the shop window. Real life is not so dramatic, however, and I may not be out saving the world, but I have found renewed strength. I still may get exhausted and I still feel my body’s limitations daily, but now, with the support of those around me, I am prepared to fight again.

In November 2012, my wife and kids threw a party to celebrate my new liver’s one year anniversary and my 40th birthday and to thank all of those who helped us throughout our ordeal. The three of them met with Carlo’s Bakery (of TLC’s Cake Boss) and designed a cake that celebrated all of the things that are important in my life (and, yes, that is a liver in the center). Like my second chance at life, it tastes as good as it looks.

Brian Rath is a former IDF Board of Trustees Member and mentor to the IDF Teen Program. In addition to living with Hyper IgM Syndrome, he was diagnosed with Hepatitis C in 1992 and developed liver disease. On July 25, 2011 he was placed on the national list for a liver transplant and underwent the transplant November 14, 2011. IDF wishes Brian all the best and looks forward to having him back as an active volunteer.
IDF Board Member
Carol Ann Demaret Honors
Dr. William Shearer

On February 9, Carol Ann Demaret, member of the IDF Board of Trustees and mother of David Vetter, who was diagnosed with Severe Combined Immune Deficiency and known around the world as the “boy in the bubble,” helped honor Dr. William Shearer, David’s physician. On behalf of IDF, she presented Dr. Shearer with an award for his dedicated career serving the primary immunodeficiency community at the symposium celebrating his 75th birthday and his work at Texas Children’s Hospital and Baylor College of Medicine. Carol Ann said, “As David’s mother and as a trustee of IDF, I was very proud to honor Dr. Shearer and listen to his peers speak so highly of him.”

In Memory Of:
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- Daniel Boje
- Clifton and Carrie Low Bowen
- Kristin Buyer
- Bud Calkins
- Lisa Codispoti
- Sonja Senn Doughty
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If so, there is a unique way of supporting IDF that you should know about. Recently passed legislation has extended a popular charitable giving option that allows you to take money from your IRA so you can make tax-free charitable gifts to organizations like IDF. If you are 70 ½ or older, you can distribute up to $100,000 from your IRA tax-free. This option is available through the end of 2014, so the clock is ticking.

For more information, please contact your tax advisor or financial planner to see if this is an option for you. Please contact IDF with questions: **800-296-4433**.
2013 National Conference

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The Immune Deficiency Foundation publishes IDF Advocate three times a year. To obtain a free subscription, please contact:

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