This past summer marked the 40th anniversary of the first manned mission to the moon. It also saw the Immune Deficiency Foundation (IDF) become one of the first patient organizations in America to pioneer the use of social media technologies for the benefit of our patients and families.

To paraphrase Neil Armstrong’s immortal words as he set foot on the lunar surface, IDF’s social media initiative might seem like a small step when compared to, say, Facebook, but it represents a giant leap forward when it comes to our patient community.

By creating a living, breathing online community, where patients and families can share their experiences, hopes and challenges of living with primary immunodeficiency disease (PIDD), we can capture and build upon the power and camaraderie generated at our National Conference and other events on an ongoing, real-time basis.

Our social media initiative - which we are calling IDF 2.0! - will enable our patient community to advance to a new level of sophistication and effectiveness. It also reflects our ongoing commitment to enable you to benefit from the social media revolution occurring in the digital universe.

As a small but passionate and engaged community, it is critical that we stay connected to one another and continue to share our opinions, insights, experiences, and perspectives. By utilizing social media technologies and tools, we have even more opportunities to do just this! Many in our community are already using social media venues such as Facebook, Twitter and YouTube. While such destinations have their place, it is easy to feel lost in the forest of millions of other users.

Now, however, IDF is making it possible to derive all of the benefits of social media within a community exclusively comprised of others like you. Specifically, our IDF 2.0 initiative encompasses the following social media endeavors: *IDF Friends, IDF Common Ground, IDF Arcade, IDF Reel Stories, and IDF Advocacy Channel.*

(Continued on page 2)
IDF Friends

**www.idffriends.org**

**IDF Friends** is the anchor of our IDF 2.0! initiative. Think of it as a custom-built social network created exclusively for the use and benefit of patients with PIDD and their loved ones. IDF Friends helps patients of any age find and connect with members of the PIDD community with common traits, interests, and causes. This online community enables its members to do a number of things including:

- Identifying, “friending” and engaging with other patients with whom you may have one or more traits in common (such as the type of PIDD disorder, type of treatment, similar life experience, similar geographic location, similar interests in music, reading, etc.)
- The ability to form “user group” communities (e.g., SCID User Group, Newly Diagnosed Parents User Group, Parents in Ohio User Group, etc.)
- The ability to participate in ongoing “threaded” discussions on a variety of issues and concerns
- The opportunity to share your story in words, pictures and video form
- The ability to search by a variety of field categories, including: Location, Type of Disorder, Type of Treatment, Status (i.e., parent, patient, caregiver, partner, etc.)

**IDF Friends** is jointly sponsored by unrestricted, educational grants from Talecris Biotherapeutics, Baxter, CSL Behring, IgG America and ASD Healthcare.

IDF Common Ground

**www.idfcommonground.org**

**IDF Common Ground** was developed and created just for teens and young adults with PIDD. Here, they can connect to their peers and share their experiences, concerns, and passions where they know their voice will be heard. It has all the capabilities of **IDF Friends**, but with a younger slant. It is an online community for teens, that no matter where they are located, they can get together with other teens and young adults who understand what it is like to live with PIDD. **IDF Common Ground** is sponsored by Baxter who also supports the IDF Teen and Young Adult program.

As you check out **IDF Friends** and **IDF Common Ground**, keep in mind that they represent the first steps in a website that will grow ever richer and more dynamic as time goes on. As you, your peers, and loved ones contribute to their development with your own content – be it in the form of photos, videos, or simply through your shared participation and ideas – our whole community will benefit!
IDF Advocacy Channel

The **IDF Advocacy Channel** uses social media to communicate the powerful message of our patients and their stories to impact policy decisions. The **IDF Advocacy Channel** is an online video channel available on the Advocacy section of our Website or through **IDF Friends**. The channel consists of patient-generated videos explaining how current legislative or regulatory policies and actions are personally affecting patients or their families. Currently, five volunteers from throughout the U.S. have worked with IDF to produce powerful testimonials. The IDF Advocacy Channel is sponsored by CSL Behring.

www.primaryimmune.org/advocacy_center/advocacy_center.asp

IDF Friends Discussion Forum

The **IDF Discussion Forum** has always been one of the most popular sections on IDF’s Website. Soon this old forum will be closed down, past postings will be archived and new forum activity will all take place on **IDF Friends**. The new Discussion Forum on **IDF Friends** has much more to offer, and we think members will be pleased with the new system.

It is very similar to the old forum, but now offers members more privacy. All of the messages posted on the old discussion forum could be read by anyone, even if they were not a member or even logged-in. On the new **IDF Friends** forum, the topics are viewable, but the posted responses can only be seen by logged-in members.

Additionally, there are added features, such as a new red light/green light indicator that clearly shows when a member is on or off line. New posts are marked so members can keep track of activity since their last visits. Members have the ability to insert photos or images and attach files. There is even spell check!

For Discussion Forum members who may be reluctant to set up an **IDF Friends** account because they aren’t interested in the “social networking” aspect of the site, such as adding friends, uploading pictures and videos, etc., they don’t have to do any of that. Members can simply set up an account with the minimum information required, and then only use the discussion forum.

http://my.primaryimmune.org/forum

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**IDF Arcade**

**IDF Arcade** combines education and entertainment to teach young children about their disease through interactive games. The games, which include Whack-A-Germ, Phagocyte Force- The Power to Devour and Jigsaw Puzzler, are based on the popular characters from “Our Immune System” booklet. Participants have a great time joining in the adventures of the characters while learning healthy living tips and information about their immune systems. IgG America and ASD Healthcare support these enjoyable games.

http://my.primaryimmune.org/games

**IDF Reel Stories**

The **IDF Reel Stories** Channel is an anthology of patient-to-patient testimonials designed to encourage and empower fellow patients and their loved ones. In addition to general stories of hope and inspiration, the video stories cover a wide array of issues and topics, including the experiences of newly diagnosed patients, parents and caregivers, and patients with particular PIDD disorders. Tune in to find a story like yours or better yet, add your own! **Reel Stories** is sponsored by CSL Behring.

http://my.primaryimmune.org/reelstories

It is our hope (and our belief) that IDF 2.0! will enable everyone — from the newly diagnosed to longtime patients to parents of children with PIDD — to redefine what it means to be a true patient community.
Innovative education sessions, a bustling exhibit hall and exciting special events were again the signs of success as the Immune Deficiency Foundation presented its wildly successful 2009 National Conference in June at the Disney Contemporary Resort in Lake Buena Vista, Florida. Following in the spirit of this year’s theme, the IDF family “Celebrated Our Community” with the largest contingent of attendees in the history of the biennial event.

From the opening night Welcome Reception on Thursday evening, sponsored by CSL Behring, it was clear that participants were in for an extraordinary time. Volunteer Bill Hindin was our pianist and Sami Jenkins, a member of our Teen Council, serenaded the crowd with a song. It was the perfect time to reconnect with old friends, meet first time conference participants, and kick-off the conference.

The packed program agenda featured breakfast symposiums focusing on critical public policy issues and new IDF survey findings, panel discussions and comprehensive sessions on healthcare and life management. There were expanded specific disease sessions where attendees learned the latest information about their disorders from world-renowned clinical immunologists and even had time to share experiences with other patients and family members.

In addition, the professional medical program - led by notable immunologists and sponsored by the University of South Florida and supported by an unrestricted educational grant from Biotest Pharmaceutical Corporation - was attended by healthcare professionals who earned Continuing Medical Education (CME) credits.

Perhaps one of the most magical moments came during the Opening Session, sponsored by Talecris Biotherapeutics, when Mickey Mouse helped John G. Boyle to not only introduce his mother, Marcia Boyle, the president and founder of IDF, but to unveil IDF 2.0! This interactive platform for the primary immunodeficiency community offers many opportunities for people to connect online and share experiences and perspectives. In particular, IDF Friends, the anchor of IDF 2.0!, was introduced as the social networking place and all members of the IDF community were encouraged to join.

Visitors to the site can view the “Reel Story” channel, a Website-based anthology of patient generated videos about their experiences living with primary immunodeficiencies. Many conference attendees taped their stories at “Studio IDF” and told of their experiences of being diagnosed and passed on helpful hints and encouragement. The “studio,” sponsored by CSL Behring, produced some wonderful stories of hope for “Reel Stories.”

Much like the host site of Orlando, the 2009 National Conference placed the spotlight on our youngest attendees with a mixture of fun and age appropriate instruction and information. Children from six months to 17 were able to enjoy the 2009 National Conference, thanks to Baxter sponsoring the Youth Program.

Teens were able to “escape” to their own two-day conference where participants not only benefitted from information and educational opportunities, but also found time for a scavenger hunt through the Magic Kingdom and a Retro Party where guests enjoyed dinner, dancing and even a game of flag football. The new interactive Website for teens and young adults, IDF Common Ground, was also introduced at this time.

While the teens were hanging out with Chip ’n’ Dale, the Tweens (ages 10 -12) and the Kids Club (ages 6 - 9) were competing in separate “Silly ’Lympics” competitions, visiting the interactive
Conference

John and Tara Boyle unveil IDF’s new Web initiatives with Mickey Mouse

Luigi Notarangelo, MD, receives the Boyle Scientific Achievement Award from Marcia Boyle and Rebecca Buckley, MD

IDF 2009 National Conference Award Recipients

Boyle Scientific Achievement Award
Luigi Notarangelo, MD

Blue Jeans for Healthy Genes Awards
BioLife Plasma Services
Biomat USA
CSL Plasma

Volunteer Awards
Grassroots Advocacy
Jenny Gardner

Patient Advocacy
Roger Kobayashi, MD

Fundraising
Stephanie Bush and Michelle Fox

Peer Support
Kathi Beiswenger

Outstanding Achievement
Anne Marder Bishop

With Goofy’s help, Steve Fietek, IDF Board of Trustees Member, and his wife Sonja Vohnout, IDF Volunteer, announce the location of the IDF 2011 National Conference in Phoenix, Arizona

Bill Hindin, IDF Volunteer, and Sami Jenkins, IDF Teen Council Member, provide entertainment at the Welcome Reception
IDF Families Earn Their Stripes

In conjunction with the National Conference in June, IDF created THINK ZEBRA! to raise money and promote awareness of primary immunodeficiency diseases. Over 100 families enthusiastically contacted friends and relatives to educate them about PIDDs, and raise money for IDF. Black and white rubber bracelets featuring the IDF Website were created, and volunteers sold thousands of them. Over 500 donors made contributions through THINK ZEBRA!, and the gifts keep coming!

The fundraising and awareness campaign culminated in a zebra-themed extravaganza on Friday, June 19, at the 2009 National Conference sponsored by Talecris Biotherapeutics. Hundreds of attendees embraced the theme and sported zebra-striped clothes, shoes, and accessories.

A highlight of the evening was IDF’s first-ever Silent Auction. The Auction featured a stunning array of over 140 items, and bidding was, at times, frenzied. Some lucky winners walked away with exciting items like baseballs autographed by Derek Jeter or Cal Ripken, Jr. Other party-goers were thrilled to pick up original artwork, long weekends at the beach, or new iPods.

Thanks to a generous financial matching incentive provided by CSL Behring, all auction donations were doubled. By the end of the evening, over $80,000 had been raised for IDF. Our amazing community embraced this new program with an enthusiasm that surprised and delighted everyone.

And the success of THINK ZEBRA! continues! More gifts arrive weekly and discussions are underway for the expansion of this innovative program. And plans are already forming for another Silent Auction at the 2011 IDF National Conference in Phoenix! You may even find a zebra in your mailbox this fall.

So remember, Think Zebra!

In medical school, many doctors learn the saying, “when you hear hoof beats, think horses, not zebras.” Most physicians 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 immunodeficiencies are the zebras of the medical world. So, IDF says “Think ZEBRA!”
The IDF School Guide: A Valuable Resource for Parents, Students and Educational Professionals

IDF is proud to offer the new edition of the IDF School Guide, Information about Students with Primary Immunodeficiency Diseases, a resource that can help parents plan for the upcoming school year. For some children, making the transition from summer to school requires more than having the coolest backpack or popular new tennis shoes. When parents have particular concerns about a child with a primary immunodeficiency disease attending school, advance preparation can help alleviate some of the worry.

First published in 2005 and titled A Guide for School Personnel, Primary Immune Deficiency Diseases, the manual was developed in response to parents wanting information to help their children succeed in academic settings. It included key medical points about primary immunodeficiency diseases and associated special needs, legal rights of children with chronic disease and resource referrals. This second edition, renamed the IDF School Guide, Information about Students with Primary Immunodeficiency Diseases, adds updated and expanded information on all these topics, as well as a glossary of medical and educational terms that should be helpful to school personnel and parents alike.

Given primary immunodeficiency diseases affect each person differently (and with varying degrees of severity) the information in the IDF School Guide should be used to fit each student’s individual needs. Used in conjunction with information on a student’s specific diagnosis, personal medical history and current treatment, this guide will be a valuable reference throughout the school year. The IDF School Guide, like all IDF publications, is free of charge and can be printed from the publications page at www.primaryimmune.org, or obtained by contacting IDF at 800-296-4433 or idf@primaryimmune.org.

Parents might want to get several copies to keep one at home, and to give others to the student’s teachers and school nurse.

The Eric Marder Scholarship Program Awards More Than $30,000

The Immune Deficiency Foundation is honored to award scholarships to undergraduate students living with primary immunodeficiency diseases who plan on completing their secondary education. In 2009, IDF awarded 35 scholarships totalling $31,500.

The Eric Marder Scholarship Program of the Immune Deficiency Foundation is open to patients with a primary immunodeficiency as classified by the World Health Organization and is intended for undergraduate students attending or entering college or a technical training school.

The program is made possible by donations to a scholarship fund to honor Eric Marder, a vibrant young man whose life was cut short at the age of 28 by complications of Common Variable Immune Deficiency. This scholarship program not only honors Eric’s memory, it also helps students who have primary immunodeficiency diseases attend college and pursue their dreams.

Online applications will be accepted beginning January 2, 2010. The Scholarship deadline is March 31, 2010.

Anyone wishing to make a contribution to the IDF Eric Marder Scholarship Program can do so by donating online at www.primaryimmune.org or by mailing their contribution to: IDF Eric Marder Scholarship Program, 40 W. Chesapeake Avenue, Suite 308, Towson, MD 21204.
Primary immunodeficiency diseases (PIDD) are a group of extremely rare diseases and therefore, to ensure recognition, access to specialists and therapies as well as continued research and awareness, it needs all the advocates it can get! However, being an advocate, fighting for a cause about which one feels passionately, can be intimidating. No matter how passionately one feels, the majority of people are more comfortable “behind the scenes.” Nevertheless, you can choose your comfort level and how far you want to go in the cause. You can choose to be what is known as an “armchair advocate!” As the name implies, an armchair advocate can fight for a cause from the comfort of their home.

One thing everyone can do is send a ready-made letter through the IDF Action Alert. Provide your name and address, click “send” and the letter will go to your Congressperson. To take it to the next level, forward the Action Alert link to everyone you know and ask them to take two minutes to do the same. An IDF advocate from Nevada stated it clearly: “I’ve already emailed one hundred of my closest friends…”

Phone calls are an excellent way to be counted! It is, very honestly, easier than you think. So, if you’re ready to take the leap, write down what you want to say before you make that call. Simply tell the person you speak with your name, where you are from and that you want the person in charge to vote for (or against) a piece of legislation or change their policy.

It really is that simple! As another advocate from Florida shared, “This was my first time calling and I have to admit that by the third call, I felt pretty confident and comfortable with it.”

If you enjoy putting pen to paper (or fingers to keyboard!), a personalized letter is a wonderful tool. Remember to state at the very beginning and at the end the reason you are writing, and to not make the letter too long! On the other hand, submitting an Op Ed piece to your local newspaper can provide you the opportunity to share your story and really spread the word, encouraging people in your community to get involved as well.

It is very important to remember that an advocate is respectful and professional at all times. You will get better results approaching a policymaker this way than you would otherwise.

Never doubt that your voice makes a difference. One person alone can move mountains. One person joining thousands can change the world.

Act Now!
The Medicare Patient IVIG Access Act has been a top focus of IDF’s advocacy work in 2009. The Senate version of this bill, S. 701 as well as the House version, H.R. 2002, both include language that will fix the reimbursement issues for IVIG created by the Medicare Modernization Act of 2005. While you may not be on Medicare, these bills still directly affect you as private insurance companies base their policies on Medicare policies. The language from these bills should be included in any health care reform legislation that is considered.

Should Congress choose to postpone the topic of health care reform, the PIDD community still needs the Medicare Patient IVIG Access Acts to pass! Be an advocate for the PIDD community right now! Visit the IDF Advocacy Center Webpage, click on the Action Alert button and send letters to your Members of Congress! Your action is needed to get this message heard on Capitol Hill!

Be Proactive!
For the latest up-to-date activities, please visit the new, updated IDF Advocacy Center at http://www.primaryimmune.org/advocacy_center/advocacy_center.asp.

What You Can Find:
- IDF Advocacy Priorities – important public and private policy issues on which IDF is working
- IDF Advocacy Toolkit – tips and tools on letter writing and other media options to help you build your skills as an advocate
- IDF Advocacy Channel – watch patients tell their own personal stories
- IDF Advocacy Blog – read about IDF’s latest advocacy work and share your comments
- IDF Action Alert – send ready-made letters to Members of Congress on the latest public policy issues
- IDF Hot Issues – current issues needing immediate attention

Join IDF Friends Social Network and link to the Advocacy Forum
Disney Quest theme park and being Lion Kings at their own Jungle Safari parties. They also learned a few things during educational sessions such as “Our Immune System,” “Clean Hands, Healthy Kids” and “Introducing Genetics.”

While the sessions were the focal point of the day, the IDF community saved its serious celebrating for the evening.

On Friday, guests celebrated zebras with a special evening of dinner, music and a silent auction, and the salute to the black-and-white-striped equine was not without cause. The THINK ZEBRA! Celebration, sponsored by Talecris Biotherapeutics, was inspired by a phrase most doctors learn while still in medical school: “When you hear hoofbeats, think horses, not zebras.” The horse analogy teaches physicians to focus on the most likely possibilities when making a diagnosis. The IDF community, certainly the zebras of the medical world, encourages healthcare professionals to start thinking zebra.

The Conference used the international venue of Epcot to close this year’s festivities. After a scrumptious dessert reception, the largest gathering of the IDF community to date enjoyed the rousing fireworks spectacular, Illuminations: Reflections for the Earth, thanks to the support of Baxter.

The Immune Deficiency Foundation 2009 National Conference had it all, and thanks to everyone involved, it was a Celebration of Our Community the attendees would not soon forget. And, looking ahead, it is time to start making plans now to join the IDF family in 2011 at the JW Marriott Desert Ridge Resort in Phoenix, Arizona to celebrate IDF’s 30th Anniversary!

**Special Thanks to Our National Conference Presenters**

Katherine Antilla, MAEd  
Loris Aro, RN  
Steven Baxter  
Kathi Beiswenger  
Amy Bellin, RN, CPNP-PC  
Julie Birkofe  
Francisco Bonilla, MD, PhD  
John Boyle, PhD  
John G. Boyle  
Marcia Boyle, MS  
Tara Boyle  
Diane Buckberg  
Rebecca Buckley, MD  
Fabio Candotti, MD  
Javier Chinen, MD, PhD  
Lisa Codispoti  
Mort Cowan, MD  
Charlotte Cunningham-Rundles, MD, PhD  
Maggie Dodds, RN, MS, CPNP  
Carla Duff, RN, BSN, CCRP  
Kim Duff, RN, BSN  
Matt Fenske  
Rebecca Firlak  
Thomas Fleisher, MD  
Ramsay Fuleihan, MD  
Jennifer Gardner  
Sonja Gaston  
Patti Guetz  
Elizabeth Hart  
Terry Harville, MD, PhD  
Vivian Hernandez-Trujillo, MD  
Steven Holland, MD  
Dennis Jackman  
Kim Jones, RN  
Charles Kirkpatrick, MD  
Roger Kobayashi, MD  
Lisa Kobryniski, MD  
Donald Kohn, MD  
Serrie Krash, MS  
Larry LaMotte  
William Leach  
Howard Lederman, MD, PhD  
Heather Lehman, MD  
Harry Malech, MD  
M. Louise Markert, MD  
Marla Marshall  
Lloyd Mayer, MD  
Donna Marie Meszaros, PhD  
Frank Meuers  
Steven Miles, MD  
Lisa Miller  
Kelli Nash  
Allison Nichol  
Luigi Notarangelo, MD  
Mike Nunke  
Hans Ochs, MD  
Jordan Orange, MD, PhD  
Jennifer Pate, MD  
Jennifer Puck, MD  
Sue Ramthan  
Brian Rath  
Joseph Roberts, MD, PhD  
Jack Routes, MD  
Lawrence Rubin, PhD, LMHC  
Christopher Scalchunes, MPA  
Richard Schiff, MD  
Joan Schwarz  
Jeanette Scott, BSN, RN  
Debra Sedlak, CPNP  
John Seymour, PhD, LMFT  
Ralph Shapiro, MD  
E. Richard Steihm, MD  
Tarea Stout, MS, LPC  
Kathleen Sullivan, MD, PhD  
Lynne Szott, RN  
Jodi Taub, LCSW  
Troy Torgerson, MD, PhD  
Sharon Walton  
David Watters  
Kathleen Wolfe  
M. Elizabeth Younger, CPNP, PhD
CSL Limited and Talecris Biotherapeutics Terminate Their Merger Agreement

CSL Limited and Talecris Biotherapeutics, Inc. announced that they have mutually agreed to terminate their merger agreement, announced on August 12, 2008, under which CSL agreed to acquire Talecris for US$3.1 billion in cash.

Dr. Brian McNamee, CEO and Managing Director of CSL Limited, said, “We are disappointed that the U.S. Federal Trade Commission (FTC) resolved to block the transaction. Although we continue to believe in the many customer benefits and significant financial synergies that supported the transaction, CSL’s Board of Directors did not believe that entering into a protracted litigation process with the FTC, with its inherent risks, substantial costs, and lengthy distraction of CSL management and staff from planning and running our businesses would be in the best interests of our stakeholders.”

Excerpted from CSL News Release June 2009

Baxter International Cites Progress In Convenient Delivery Methods of Antibody Replacement Therapy

Baxter International Inc. announced data supporting further progress in efforts to make antibody therapy more convenient for patients with primary immunodeficiency (PID), including ways to give patients more options of where, how often and when they receive treatment. The data were presented in three posters at the 2009 American Academy of Allergy, Asthma & Immunology (AAAAI) Annual Meeting in Washington, D.C., on Saturday, March 14.

Current intravenous (IV) administration of immune globulins requires a healthcare professional to monitor infusions, taking up three to four hours, and current subcutaneous administration may require multiple injections and higher doses of immune globulins than IV. Data presented at AAAAI add to a growing body of evidence supporting Baxter’s work to develop a different delivery method of antibody replacement therapy applied under the skin using an enzyme that can help deliver and disperse the antibodies into the body at the appropriate dose. This is an investigational study that Baxter has undertaken to develop a subcutaneous mode of administration of Intravenous Immune Globulin (IVIG) therapy to patients.

Excerpted from Baxter International News Release March 2009

CSL Behring Requests Approval of Subcutaneous Human Immunoglobulin for Use as Replacement Therapy in Patients with Primary Immunodeficiencies

CSL Behring announced it has submitted a biologics license application (BLA) to the United States Food and Drug Administration (USFDA) requesting approval to market its 20 percent liquid formulation, Immune Globulin Subcutaneous (Human) (IgSc), in the United States for weekly replacement therapy in patients with primary immunodeficiencies.

The ready-to-use, high concentration subcutaneous immunoglobulin is stabilized with L-proline, a naturally occurring amino acid and can be stored at room temperature (up to 25°C [77°F]). If approved for marketing by the USFDA, it will represent another treatment option for patients on Ig therapy who want the freedom and convenience of safe, at-home self-administration of replacement therapy.

Excerpted from CSL News Release May 2009
WITH GRATITUDE
Honorary and Memorial Gifts – 3/6/09 to 8/10/09

Gifts In Honor Of
John G. Boyle
John & Connor Chauvin
Clayton Cowan
Jeremy & Gini Ennis
Christopher & Tyler Finethy
Mr. and Mrs. David Ginsburg’s birth of twin grandsons
Carson Hardee
Cullen David Hull
Matthew Jarbeau
Judith Kanef
Hallie Kendis’ Graduation from Medical School
Charley Key
Jaryd Leady
Tom Marbach
Ben Rashbaum
Scott Solberg
Dr. Robert Sugerman
John Wettstein
Mr. and Mrs. Harold Yamron’s 60th Wedding Anniversary

Gifts In Memory Of
Bud Calkins
Flora Constantino
Douglas Harlan
Alvin Kendis
Devin and Lauryn Kenny
Ada May Loewen
Tom Marbach
Eric Marder
Jonah Noel
David Novak
Diana Tish Obal
Helen A. Ouellette
Dominick Passalacqua, Jr.
Rachel Roy
Marvin Shapiro
Veronica Yaroch
Maxine Weissenfluh

These donations help IDF to 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 on our Web site, www.primaryimmune.org and click the “please donate today” picture in the top right corner. You can also contact us in any of the following ways:

Phone: 800.296.4433 or 410.321.6647
E-mail: idf@primaryimmune.org
Mail: IDF, 40 W. Chesapeake Avenue, Suite 308 Towson, MD 21204

With Gratitude
Honorary and Memorial Gifts – 3/6/09 to 8/10/09

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VOLUNTEERS IN ACTION

Summer Style: The Maple Lawn Fashion Show

Mike Nunke, Marcia Boyle, Beth Younger, Clayton Cowan, Paula Burton and Marti Cowan

Summer Style: The Maple Lawn Fashion Show was held at Ranazul Restaurant in Fulton, Maryland on May 30th. The afternoon event featured a fashion show, raffle, and delicious foods and libations. Proceeds from the event, including a percent of all purchases at Hyatt & Co. and Simply Divine Boutique that day, benefited IDF, and Marcia Boyle had the opportunity to thank organizer Marti Cowan. Marti’s son Clayton has Chronic Granulomatous Disease and Marti worked tirelessly to ensure the success of this delightful afternoon.

Beer and Beef
Eleven-year-old Jaryd Leady was diagnosed with CVID in 2008. And just nine months later his family hosted a “Beef and Beer social” in Gibbstown, New Jersey to raise money for IDF. Jaryd’s mother, Marlene, found IDF to be of enormous assistance, guiding them to find area peer support, sending them packets of information, and connecting them with patient education meetings. The Leady family wanted to give back. And give back they did! Their event, held on March 6, 2009, raised over $8,000 for IDF!

Marlene Leady dancing with her son Jaryd at the Beef and Beer event

IDF Volunteer Joanna Tierno and her husband Chris promote awareness at “Back to the Beach” held June 20-21, 2009 on Staten Island, New York.
Visiting Professor Program Accepting Requests for 2010!

IDF is currently accepting Letters of Request for the IDF & USIDNet LeBien Visiting Professor Program for next year. The purpose of the program is to foster improved knowledge about the diagnosis and treatment of patients with primary immunodeficiency disease. It is available to teaching hospitals without an Immunology program in the United States. We hope that you will consider applying and believe your medical education program will benefit from having one of the leading clinical immunologists as your Visiting Professor.

If you are interested in participating in this exciting 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 of Program Services at dgill@primaryimmune.org by November 30, 2009, stating your desire to participate in the program. The letter should include a tentative list of teaching and clinical activities for the Visiting Professor and information on how your training program would benefit from a Visiting Professorship.

Please direct any question to IDF at 800.296.4433.

For an updated IDF Calendar of events, visit www.primaryimmune.org/idfcalendar.