Bill of Rights for Patients with a Primary Immunodeficiency Disease

To many, the first ten amendments of the United States Constitution - otherwise known as the Bill of Rights - is a document that outlines the fundamental rights and privileges of all Americans.

That premise, when applied to patients with primary immunodeficiencies, would offer members of the IDF community a collection of provisions to ensure those patients of the ‘inalienable’ healthcare rights they warrant.

The Bill of Rights for Patients with a Primary Immunodeficiency Disease is a statement of the privileges to which patients are entitled. It conveys the positive rights patients deserve and should expect; including what healthcare professionals need to consider when providing care to patients, thereby providing information, offering fair treatment, and granting them autonomy over medical decisions. This Bill of Rights was created by the IDF Nurse Advisory Committee and endorsed by the IDF Medical Advisory Committee.

Kim Duff, RN, BSN, and chair of the IDF Nurse Advisory Committee (NAC) commented, “We were having a NAC quarterly meeting and the discussion turned to the importance of patients knowing what treatment they were receiving—the product brand name and lot number of IVIG at every infusion. So many patients have no idea and it is so important to ensure both safety and consistency. Not all IVIG products are the same! Soon we were discussing other issues patients should be aware of and there was a consensus by our nursing group to develop a Bill of Rights for Patients with PIDD.”

The main sections of the Bill include information regarding:

- Medical Information
- Choice of HealthCare Provider
- Involvement in Healthcare Decisions
- Fair Treatment and Non-discrimination
- Privacy and Protection
- Grievances

The NAC members embraced the project. These knowledgeable, caring nursing professionals with years of experience working with patients with primary immunodeficiencies collaborated by submitting their ideas for the statement. They stressed the key role patients play in staying healthy, by laying out the rights and responsibilities for patients.

IDF encourages you to take an active role in getting the treatment and care you need and deserve. The Bill of Rights for Patients with a Primary Immunodeficiency Disease can provide you with not only a list of your rights as a patient, but also with the confidence and knowledge you may need to successfully be your own advocate. The entire document can be seen on page 3, is available at www.primaryimmune.org, or can be obtained by contacting IDF at 800.296.4433.
Save the Date!

IDF Retreats - For Persons Living with PIDD & Their Families

June 25-27
Doral Arrowwood Conference Center
Rye Brook, New York

August 13-15
Hotel Kabuki
San Francisco, California

Registration will begin in March 2010. For updates and more information, visit the IDF Website at www.primaryimmune.org

New Addition to the Boyle Family!

The Immune Deficiency Foundation is proud to announce the birth of John Stephen Boyle on Thursday, October 22, 2009. The first grandchild of Marcia Boyle, the President & Founder of IDF, arrived at 9:34 am, weighing a healthy 6 pounds, 13.7 oz and 20 inches long. Parents, John G. and Tara Boyle are doing well and could not be happier.

Marcia, the beaming grandmother, pictured here, gushed, “Little Johnny is just adorable, strawberry blond! Nothing prepared me for how amazing it feels to be a grandmother—this is one of the happiest days of my life. It is so exciting that my little XLA baby is now a father.”

NEW, REVISED!
IDF Diagnostic and Clinical Care Guidelines

Originally published in 2006, the Immune Deficiency Foundation Diagnostic and Clinical Care Guidelines for Primary Immunodeficiency Diseases has proved to be one of the Foundation’s most popular publications. Produced to enhance probability of earlier diagnosis, improve health outcomes and increase access to specialized health care and optimal treatment, the guidelines offers unsurpassed information not only for patients with primary immunodeficiency diseases, but also for patient families and treating physicians.

Since the guidelines were first made available, numerous changes have taken place throughout the field of medicine. Subcutaneous IgG administration is now more common; health insurance appeals require different input; and many other advancements in treatment and care have resulted in a need for revised and updated information.

The Foundation has answered that demand by releasing a second edition of the guidelines. As with the first edition, Dr. Rebecca Buckley has again lent her editing expertise, and her stellar effort—along with an array of contributing expert immunologists—has resulted in one of the most comprehensive publications available to the IDF community.

The second edition includes recommendations, strategies and essential information to assist physicians in making educated decisions about appropriate healthcare for primary immunodeficiencies, as well as provide patients with the resources to deal more effectively with their physicians and with insurance providers.

The development and revision of the IDF Diagnostic and Clinical Care Guidelines was funded by an unrestricted educational grant from Talecris Biotherapeutics. This publication, like all IDF materials, is available at no charge to individuals. To get your copy, please visit the IDF Website at www.primaryimmune.org to download or order your copy, or contact IDF at 800-296-4433.
At the IDF 2009 National Conference in Orlando, over 30 different video testimonials were recorded for our Reel Stories Channel, a patient-generated video community designed to encourage and empower fellow patients and their loved ones. The videos, which cover a wide array of issues and topics pertaining to PIDD, are available for viewing at http://my.primaryimmune.org/reelstories. If you would like to share your experiences with PIDD, we encourage you to record a video and upload it to the IDF Reel Stories page. Simply visit http://my.primaryimmune.org/reelstories, click the “Browse” button to find the video you want to submit and then click the “Upload” button to attach the file. Once the file has completed uploading, click the “Submit” button to finish.

The maximum file size allowed is 500 MB, and allowed extensions are: avi, mov, mpeg, mpg, flv, mp4, qt, wmv and divx. If you are having trouble or need assistance uploading a file, contact IDF at 800-296-4433 or contact Adam Freestone at afreestone@primaryimmune.org.

Reel Stories is sponsored by CSL Behring.

Medical Information
You have the right to be fully informed about your diagnosis, the treatment options for your disease and the prognosis, in terms that you can understand.

Choice of Healthcare Provider
You have the right to choose medical personnel who can deliver quality healthcare for your disease state. You have the right to request second opinions or consultations if you so choose without consequence.

Involvement in Healthcare Decisions
You have the right to be fully informed regarding what is involved with your treatment options, procedures, and potential complications, in a way that you can understand.
You have the right to participate fully in any decisions regarding your treatment and/or procedures.
You have the right to be informed of specific drug information such as IVIg/SCIg brand, dose, lot number, rate of infusion, expiration date as well as any special properties about each medication.
You have the right to choose a treatment that best suits your medical needs, regardless of insurance policies.
You have the right to refuse any drug, treatment or procedure.

Fair Treatment and Non-discrimination
You have the right to be respectfully treated and cared for from your doctors, health plan and any other healthcare providers regardless of race, sex, nationality, religion, sexual preference, or ability/source of payment.
You have the right to be given the option of the Family and Medical Leave Act, based on the size of your employer, to address chronic absence from work due to a clinical condition.
Children in school are entitled to protection of their rights under Section 504 of the Rehabilitation Act of 1973.
You have the right to request to have an insurance case manager assigned to your medical case.

Privacy and Protection
You have the right to speak privately with your healthcare providers.
You have the right to confidentiality about your healthcare information.
You have the right to know what is in your medical record and have a copy of your own medical record.
You have the right to ask your doctor to change your record if it is not correct, relevant or complete.

Grievances
You have the right to petition and request review of any complaint you have against your health plan, doctor, hospital or other healthcare personnel.

Created by the Immune Deficiency Foundation Nurse Advisory Committee 2009
Comprised of a prominent group of physicians and scientists, the Primary Immunodeficiency Treatment Consortium (PIDTC) supports the mission of IDF through the development of science-based standards for diagnosis and care for individuals with primary immunodeficiency diseases and their complications.

This passionate group of specialists promotes key research issues in an effort to increase understanding of the pathogenesis and potential cure of these primary immunodeficiency diseases.

MAC members not only advance the diagnosis, treatment and/or immunologic understanding of these diseases, but also represent IDF at scientific and policy events, participate in the Consulting Immunologist and Visiting Professor Programs, and graciously lend their time and expertise to IDF program development and special projects.

The Immune Deficiency Foundation offers our appreciation and admiration for these extraordinary individuals, and salutes the vital contributions made to our patient community.

Dr. Cowan is joined by Luigi Notarangelo, M.D., who serves as Co-Principal Investigator, and Jennifer M. Puck, M.D., Donald B. Kohn, M.D. on the PIDTC Steering Committee. Institutions that will participate include Cardinal Glennon, Cincinnati Children’s Hospital, Children’s Hospital Boston, Children’s Hospital Los Angeles, Children’s Hospital Memorial Chicago, Children’s Hospital of Philadelphia, Children’s Hospital Seattle, Duke Memorial Center, Memorial Sloan Kettering Cancer Center, NIH-NIAID, St. Jude’s Hospital, Texas Children’s Hospital, UCSF Children’s Hospital, University of Minnesota, and Pediatric BMT Consortium (PBMTC).

Research will focus on studying severe combined immunodeficiency (SCID), Wiskott-Aldrich Syndrome (WAS) and chronic granulomatous disease (CGD) – the three PIDDs that can be cured with hematopoietic cell transplantation (HCT), enzyme replacement or gene therapy. The objectives of the research will include characterizing the long term outcomes and late effects in children with SCID, WAS and CGD who undergo HCT. Additionally, the project will incorporate the design and implementation of prospective clinical trials that improve care for children with PIDD and allow for training to be provided to physician scientists in the understanding and treatment of PIDD. The research will determine critical questions concerning HCT for these disorders and aid in the development of prospective future clinical trials.

The PIDTC’s pilot project will be a study focusing on newborn screening for SCID in Navajo Indians to evaluate early diagnosis. With this initial project, the group is expecting to develop a prospective clinical trial of HCT for newborns diagnosed with SCID.

Other components of the grant work will include the development of a PIDTC Website that will explain the objectives of the consortium, provide research and clinical information and will list links to ongoing projects. The Website will also give information about center locations in each geographic area, as well as provide education, support and advocacy to families with affected children and the general public.

For more information about the PIDTC program or the Clinical Trials, please contact Elizabeth Dunn, Clinical Research Coordinator for the PIDTC at dunne@peds.ucsf.edu.

**Primary Immune Deficiency Treatment Consortium**

Congratulations are in order for the Primary Immune Deficiency Treatment Consortium (PIDTC). The group was recently awarded a U54 grant supported through the National Institutes of Health. The PIDTC brings together translational scientists, transplant physicians and immunologists with a strong commitment and expertise in the diagnosis and management of primary immunodeficiency diseases (PIDD) to consider different treatment methods and provide improved results to future patients.

“The Primary Immune Treatment Consortium will be counting on the support of the Immune Deficiency Foundation community,” said Morton J. Cowan, M.D., the consortium’s Principal Investigator. “Through the cooperation of patients participating in our studies, we can achieve our goal of disseminating our findings about the diagnosis and treatment of PIDD to clinicians, scientists, patients and parents. We are excited to be collaborating with IDF to further understand these diseases.”

Dr. Cowan is joined by Luigi Notarangelo, M.D., who serves as Co-Principal Investigator, and Jennifer M. Puck, M.D., Donald B. Kohn, M.D. on the PIDTC Steering Committee. Institutions that will participate include Cardinal Glennon, Cincinnati Children’s Hospital, Children’s Hospital Boston, Children’s Hospital Los Angeles, Children’s Hospital Memorial Chicago, Children’s Hospital of Philadelphia, Children’s Hospital Seattle, Duke Memorial Center, Memorial Sloan Kettering Cancer Center, NIH-NIAID, St. Jude’s Hospital, Texas Children’s Hospital, UCSF Children’s Hospital, University of Minnesota, and Pediatric BMT Consortium (PBMTC).

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For more information about the PIDTC program or the Clinical Trials, please contact Elizabeth Dunn, Clinical Research Coordinator for the PIDTC at dunne@peds.ucsf.edu.
Plasma Users Coalition Created

A United Front for Rare Diseases in Health Care Reform

Rare disease patients face chronic, life threatening diseases that inevitably bring with them some of this country’s highest treatment costs. As a result, these individuals and their families can sometimes be forced into personal bankruptcy and poverty. With thoughtful and reasonable healthcare reform, Congress can ensure this will never happen, ever again.

The Plasma Users Coalition (PUC) was fashioned in the belief that our healthcare system must provide affordable, quality coverage for all Americans. As the healthcare reform debate intensifies, we have concerns regarding continued access to the specialized, expensive care and therapies for individuals with rare diseases.

IDF was instrumental in organizing and providing leadership to the PUC, a group of national patient organizations that represent patients whose lives depend on plasma-derived and recombinant therapies. Members of the PUC are the Immune Deficiency Foundation, the Alpha-1 Association/Foundation, the Committee of Ten Thousand, GBS/CIDP Foundation International, Hemophilia Federation of America, Jeffrey Modell Foundation, National Hemophilia Foundation, Platelet Disorder Support Association and Patient Services Incorporated.

The PUC has identified six principles that are the top priorities for inclusion in healthcare reform:

- **Private Insurance Market Reforms** - While we applaud the annual caps on out-of-pocket costs, we are concerned that they are not adequate for the rare disease community. High out-of-pocket costs and co-pays disproportionately impact individuals with rare diseases whose therapies can be extraordinarily expensive and life-long.
- **Affordability** - Securing reasonably priced insurance and covering the uninsured is an important component of healthcare reform. In addition, healthcare reform legislation must also limit deductibles and co-payments.
- **Access to Specialists** - Individuals with rare diseases require services and care from members of the medical profession who have specialized knowledge of the diagnosis, treatment and management of their disorders.
- **Access to Therapies** - Individuals with rare diseases must have access to the full range of medically necessary treatments appropriate for their condition. Decisions regarding which treatments are most suitable must be reserved for the physician in consultation with the individual patient.
- **Comparative Effectiveness Research** - The Coalition supports comparative effectiveness research that identifies treatments and services for rare diseases based on comparative clinical effectiveness, rather than cost effectiveness, studies.
- **General Recognition of Rare Diseases** - Payers and providers of health services must recognize the unique and on-going needs of the rare disease community.

For more detailed information, visit http://www.primaryimmune.org/advocacy_center/advocacy_center.asp.

IDF Nurse Advisory Committee

A decade has passed since the Immune Deficiency Foundation first established the Nurses Advisory Committee (NAC). Founded with the intent of improving the quality of healthcare and education provided by nurses for patients with primary immunodeficiency diseases, the NAC has been immeasurably successful in its endeavors.

In addition to increasing awareness of primary immunodeficiency diseases, the NAC has been instrumental in expanding both educational and peer support opportunities for individuals and families. Thanks to an unrestricted grant from CSL Behring, the NAC has been an operative force in IDF educational programs throughout the country.

For ten successful years, the NAC has also been invaluable in their collaboration on IDF publications such as the *IDF Guide for Nurses on Immune Globulin Therapy for Primary Immunodeficiency Diseases* and the *Bill of Rights for Patients with Primary Immunodeficiency Diseases*.

Not only does IDF appreciate our partnership with the NAC, but we also take great pride in recognizing the dedication of these exceptional individuals. From a nursing perspective, the NAC commitment to the IDF mission is unequalled, and we look forward to that determined spirit for decades to come.

**Kim Duff, RN, BSN, Chair**
Rainbow Babies & Children’s Hospital

**Loris Aro, RN**
St Michael’s Hospital

**Amy Bellin, RN, CPNP-PC**
Children’s Hospitals & Clinics of Minnesota

**William Blouin, MSN, ARNP, CPN**
Miami Children’s Hospital

**Maggi Dodds, RN, MS, CPNP**
Texas Children’s Hospital

**Carla Duff, RN, BSN, CCRP**
University of South Florida

**Kristin Epland, FNP-C, Vice - Chair**
Midwest Immunology Clinic

**Vanessa Howard, BSN, MSN, FNP**
St Jude Children’s Research Hospital

**Terry Raburn, RN, BSN, ACRN**
Texas Children’s Hospital

**Jeanette Scott, BSN, RN**
Santa Clara Valley Medical Center

**Debra Sedlak, CPNP**
Duke University Medical Center

**Beth Younger, CPNP, PhD**
Johns Hopkins Hospital
Few aspects of the now raging healthcare debate draw as much attention as a denied claim that plays out in the public arena.

While such high-profile occurrences provoke the loudest outcries, it’s the millions of denied claims that seem random, feel arbitrary and are certainly more commonplace than the media discussion of, say, pre-existing conditions.

According to a report by the California Nurses Association (CNA), the state’s largest health insurers rejected approximately one-fifth of all medical claims made over the last seven years.

In a September press release, entitled “California’s Real Death Panels”, the CNA maintains that California’s six largest HMOs rejected more than 45 million claims – 22 percent of all claims – for care from 2002 through June of this year. The rejection rates in just the first six months of 2009 ranged from a high of nearly 40 percent (PacifiCare) to a low of 6.5 percent (Aetna).

“It is, as Georgetown University Health Policy professor Karen Pollitz describes, ‘one of the dark corners of the black box that is private health insurance.’”

Don DeMoro, a policy director for the CNA, told the Huffington Post that he received a phone call from the managed care department after its press release came out.

“They said, ‘you couldn’t have gotten this data from us. We don’t collect it ourselves,’” DeMoro said. “‘The data is there,’ I told them, ‘but it’s hard to find.’ I walked them through the steps and waited while they clicked through their own website. Once they saw that the data was there, they politely said, ‘Thank you’ and hung up.’”

DeMoro’s declaration, however, as well as the overall report citing the high percentage of denials, has come under scrutiny from both the insurers and state officials.

Lynne Randolph, spokesperson for the California Department of Managed Health Care, insists the CNA misrepresented the results of their findings, arguing that the number of ‘claims denied’ not only include actual rejections, but also duplicate claims and claims that were eventually appealed and accepted.

The insurance companies also maintain the legitimacy of some denials, but also say that others were denied for ‘technical reasons.’ The California Association of Health Plans, the trade group for the state’s health insurers, agrees.

“We question the credibility of this report,” said Nicole Evans, spokeswoman for the trade association.

Insurance companies point to a number of factors that may result in denied claims, including a filing with the wrong insurer, receiving services from an out-of-network provider or seeking experimental procedures not covered.

IDF receives numerous calls from individuals regarding insurance claim denials. Reasons for rejection range from simple coding issues, incorrect Dates of Services (DOS), and duplicate claim submissions to not-so-simple denials such as, “not considered medically necessary.”

If you have received an Explanation of Benefits (EOB) from your insurance company, read the document carefully to determine the reason for the denial. Your insurer may simply be requesting more information about your claim. If so, gather the necessary information and resubmit. If the EOB is not asking for additional information, then you should contact the insurer and provider and ask why the claim was denied. Be sure to note the name of the person with whom you spoke, as this information is important for future communications.

If the EOB states the claim was denied because treatment is not considered medically necessary, it could be a result of incorrect (or misinterpreted) insurance company guidelines.
Additionally, the initial clinical work-up may not have been completed prior to the start of immunoglobulin (IG) therapy. In some cases, a second opinion by a clinical immunologist may be needed.

Unfortunately, some insurance companies deny IG therapy for primary immunodeficiency until the insurer understands the rationale behind this expensive, life sustaining therapy. That justification may have to be established through a consultation between the prescribing physician and the medical director from the insurance company.

For help on how to appeal a claim, please visit: http://www.primaryimmune.org/patients_families/insure_howtoappeal.asp.

Tim Labas, assistant deputy director in the California Office of Health Plan Oversight, estimated that the actual denial rate across the board in California is probably somewhere between 10 and 20 percent. “That might still seem high,” he said. “But there are legitimate reasons why claims are denied.”

If the two sides in the California ‘data debate’ can agree on one thing, it is that the responsibility for a complete library of documentation, as well as an understanding of what coverage your policy offers, falls squarely on the consumer – which in this instance is a patient who may be facing a chronic, debilitating or life-threatening disease.

Most importantly, an individual who has been denied an insurance claim must be proactive in contacting the provider with any (and all) questions about the rejection.

In 2000, the Kaiser Family Foundation published a national survey that found more than 50 percent of respondents had experienced some type of issue with their health insurance. Of those, only 2 percent had issued a formal complaint. Nearly 90 percent of participants could not name the agency that regulates health insurance in their state.

In California, state officials said that a large jump in claims denials raises a red flag for that insurance company. If such a rise is noted, the state says it has the authority to request more specific information from the provider in question.

The California Office of Health Plan Oversight, however, cannot cite a single example of when it made such a request.

Apparently, there remains very little interest in illuminating those dark – and oft times dangerous – corners of the private healthcare system.

And for a patient with a primary immunodeficiency disease, the complex, chronic and expensive condition demands an honest and open glimpse into the business practices of their insurer.

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**Be Proactive!**

- Keep copies of every blood test (especially the lab work done prior to immunoglobulin therapy), CT Scans, prescriptions, infections, surgeries, hospitalizations, etc.
- If you are not already in possession of such documentation, call your providers and request the information.
- Be sure to document the name of every person you speak with regarding your health insurance problems.

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**I’ve Been Denied, Now What?**

- If your provider told you that your claim has been denied, request a copy of it.
- Read the EOB carefully to determine the reason for the denial.
- Call your provider to see if they have already started working on resolving the issue.
- Call your Case Manager (if one has been assigned to you) and ask for their assistance.
Emmy-Winner
Jordan Lee

J. Doug Gill

Billy Corgan is both a rock star and a Cubs fan. The leader of the Smashing Pumpkins, along with ten other die-hard followers of Chicago’s “Lovable Losers” baseball team, share stories of a century’s worth of woe and heartbreak in an Emmy-Award winning documentary entitled, “No Love Lost.”

Jordan Lee, on the other hand, is not a Cubs fan. Nor is the 24-year-old Seattle resident a world-renowned musician, but the talented graphic designer can lay claim to his very own rock star moment: accepting the Emmy for being part of the team responsible for the production of “No Love Lost”.

“We were thrilled just to be nominated,” Lee says, “and went to New York because we thought attending the ceremony would be fun. Given our category and our competition, we weren’t really expecting to win.”

Jordan was responsible for the Website design – a homage to the iconic Wrigley Field scoreboard surrounding the videos that featured the die-hard Cubs’ fans lamentable tales of World Series failure.

“No Love Lost” was up against industry stalwarts such as Topps Baseball, NFL.com and the network that was broadcasting the Sports Emmys, ESPN.

“When they called our name it was like, ‘wow,’” Jordan laughs, “We couldn’t believe we had beaten the odds... and the ‘big boys.’”

For Jordan Lee, however, beating the odds is a scenario with which he is all-too-familiar.

Jordan has spent his entire life living with X-linked Agamaglobulinemia (XLA). XLA is an inherited immunodeficiency disease in which patients lack the ability to produce antibodies – the proteins that make up the gamma globulin or immunoglobulin fraction of blood plasma.

“I was pretty much diagnosed before birth,” Lee tells me. “My grandmother was determined to be the carrier. She had five kids – one died not long after his first birthday.”

Knowing the risk of having a brother, maternal cousin or maternal uncle with XLA, Jordan’s parents pursued every medical avenue available while preparing for his arrival.

“I benefited from a great support network,” he shares. “My mom and dad made sure I had the best of everything – the best treatments, the best doctors... I can’t define how huge that is.”

Jokingly, I teased Jordan about his exceptional graphic design talents, and wondered aloud if his primary immunodeficiency resulted in his spending his childhood indoors in front of a computer and away from the health threats posed from the public at large.

“You’re asking if my disease led to being a computer geek,” he laughs, “and the answer is no. Growing up, I led a perfectly normal life. I played baseball, football, basketball – I couldn’t have been more active. Although, I do remember that some days after school my classmates would be running off to play without me... no time for playing when you’re getting your three-hour shots.”

While Jordan’s mates were playing without him, the future Emmy-winner wasn’t facing his treatments alone. His younger brother – the two were born a year apart – was also diagnosed with XLA, and Lee says that having a sibling with the same primary immunodeficiency allowed the boys to “deal with it together.”

“And the treatments became as much a part of my life as brushing my teeth,” Lee adds. “It’s just one of those things – the way the chips fall.”

For Jordan, being educated as a patient was his first step in overcoming the stigma often faced by children that are seen as ‘different.’

“I never felt I was different,” Jordan confides. “I found out early-on that most people are simply unaware of primary immunodeficiency diseases... everyone automatically assumed it meant HIV.”

“So I found that being able to explain my disease helped bridge that gap,” he continues. “And at the same time, my explaining was also helping to either provide or raise awareness about primary immune deficiency.”

One doesn’t have to look far to find the character trait that most defines the 24-year-old designer, a level of maturity that belies his young age is what anchors Jordan Lee.

Whether he’s discussing his work, his Emmy or his XLA, Lee’s answers are measured, thoughtful and possess a degree of humility rarely found in his peer group - especially those who have met with any measurable success.

Through the course of our conversation he reminded me three times that “No Love Lost” was a team effort.

“Make sure you write that eight people worked on that project,” he chides.

Lee, an entrepreneur with his own graphic design business (jordanwlee.com), remains grounded almost in spite of his recent award-winning venture.

“I absolutely love what I do and I’m really proud of that project,” he explains, “But I approached ‘No Love Lost’ as I would any of my clients. Each and every project is just as notable and just as important to me as the last.”

Lee, mindful of his teamwork accomplishment in regard to “No Love Lost,” wanted to be sure I noted the many medical professionals that have played such a huge role in his support network.

And while he thanks them all and notes they are a “credit to his current health,” there is one man in particular that rates a higher level of affection: Dr. Hans Ochs.

“Dr. Ochs has been a huge part of my life,” Lee confides. “I can’t remember him ever not being a part of it... I feel fortunate to have had him as my doctor. Dr. Ochs does amazing work for primary immune patients,” Lee explains. “And in his tireless efforts to help diagnose, treat and further understand XLA, he has sent samples of my blood all over the world. I’m proud to be helping him in his quest.”

For Jordan Lee, life with XLA, is a misnomer. To this Emmy-winning designer, it is simply life, and he intends on enjoying it to the fullest.

“I just love to have an impact on people,” he adds. “And I’m determined not to let anything hold me back.”
SCID, Angels for Life Foundation hosted its first annual Charity Golf Tournament on March 28, 2009 in Lakeland, FL at The Club at Eaglebrooke with 40 golfers participating. Kicked off with a shotgun start, the teams of four participated in a best ball “scramble” style competition. Great food was served, followed by an awards reception, however the highlight was when IDF Board Member John Smith and his wife Heather, IDF volunteer, took the opportunity to tell their personal story.

“SCID, Angels for Life Foundation was founded in 2008 to honor my two sons, Brandon and Taylor Dahley, who were both born with SCID. While Brandon lost his battle with SCID in 1993, we benefited from the knowledge learned in Brandon’s short life. Taylor is now a teenager with a bright future,” Heather explained. “My husband John and I started this Foundation in order to raise awareness of SCID in the hope that someday families will not have to endure the loss of a child from this devastating disease.”

For many in attendance this was their first opportunity to learn about SCID and PIDD. The proceeds, $12,000, were presented to the IDF SCID Initiative.

Planning is already underway for next year’s event so mark your calendars for Saturday, March 2010. For more information on participation or sponsorship opportunities contact Heather at Heather@SCIDangelsforlife.com.

SCID, Angels for Life was also the recipient of pledges for Tim Schwarz’s “Stop SCID for Kids” run in the Chicago Marathon on October 11. Julie and Tim Schwarz are the parents of four-year-old Caz, who was diagnosed with SCID as an infant and they wanted to find a way to help other families affected by SCID. Despite having never run a marathon before, Tim trained hard and finished the 26.2-mile run in 4 hours and 22 minutes. His amazing efforts garnered pledges in excess of $7,000 with more still coming in. Tim’s effort exemplifies what one individual can do to make a difference.

The Science Museum of Minnesota was the location of the IDF Family Conference Day in St. Paul, MN on Saturday, November 7, 2009. 170 adults living with PIDD, parents of children with this condition and medical personnel had the opportunity to hear medical presentations by Jason Raasch, MD and Tamara Pozos, MD, PhD. Meanwhile, kids, ages five and older, participated in interactive educational sessions, toured the museum and viewed the film Titanic. Kim Isenberg, CSL Behring and Larry LaMotte, IDF, presented a session about being the one to make a difference by working with policy makers. In addition to receiving information about living with PIDD, the conference provided the opportunity for individuals of all ages to get-together, share with each other and realize that they aren’t alone.
On Friday, October 2, 2009, a bell-ringing ceremony to celebrate Talecris Biotherapeutics launching an initial public offering of common shares was held at the NASDAQ market site in Times Square in NYC.
Making an Investment in IDF’s Future

“When I was first diagnosed with a primary immunodeficiency in 1974, there was no one who understood. Then I found IDF and I truly believe that I have lived long-term with this disease because of IDF. Now, I don’t feel alone. IDF really made a difference in my life and I wanted to continue to do something meaningful for the Foundation so I decided to make a planned gift to IDF.”

Frances Massa of New Jersey, one of IDF’s dedicated volunteers, doesn’t shy away from discussing plans for her final wishes.

“IDF has been so essential to me over the years, as I’ve learned to live with my primary immunodeficiency disease. After everything IDF has done for me, I felt it was critical to make an investment in the Foundation’s future. By naming IDF as a beneficiary in my will, I am making a statement,” adds Fran.

IDF is proud of what we do. And we hope to continue serving as a resource for patients and families with primary immunodeficiency for a very long time, which is why we are planning for our future.

You can be a part of our legacy and help ensure the future of IDF through a planned gift or bequest to IDF.

Most people leave property, money, or personal belongings behind when they die, even if they do not have a great deal of wealth. Even an individual with a small estate can arrange to leave a charitable bequest. This can be arranged in several different ways. You can set aside a specific dollar amount, leave a percentage of your estate, or leave any assets left over after your family has been provided for. Some donors choose to leave a paid life insurance policy or other financial investments, such as stocks, bonds, or CDs.

In addition to making a difference to IDF, bequests and estate gifts may provide significant tax benefits to you and your family. Consult a tax professional for details.

Frances is quick to encourage others to include IDF in their estate plans.

“It’s critical for patients to give to IDF. IDF is so important to thousands of patients just like me, and there are so few of us, that we must stick together in supporting IDF.”

For more information on including IDF in your estate plans, please contact Allison Mayberry, Director of Development, at amayberry@primaryimmune.org or at 443.632.2555. You can be a part of our future.

The Immune Deficiency Foundation says THINK ZEBRA! this holiday season!

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. Primary immunodeficiency patients are the zebras of the medical world. So IDF says THINK ZEBRA!

IDF makes a real difference to thousands of ZEBRAS, however, we cannot do it without you! Join the herd and make a generous gift today to assure IDF can continue to advocate for the needs of those who live with primary immunodeficiency diseases.

With IDF leading the pack, you are never alone!

Please visit our Website at www.primaryimmune.org or call 800.296.4433 to make your gift today!
Supporting IDF at the Highest Level

Because primary immunodeficiency diseases are chronic conditions, continuity in the core IDF programs is critical. Individuals living with primary immunodeficiency diseases - as well as their families - need to know that these services will be available. They need to know they can consistently count on IDF.

IDF Core Services includes our essential programs like direct patient services—patient advocacy, peer support, local patient meetings and volunteer activities. Medical programs like our Consulting Immunologist Program and the LeBien Visiting Professor Program, as well as medical meetings and exhibits are included. Vital advocacy efforts to help ensure access to quality healthcare and support research priorities also fall into this category.

To continue to offer these indispensable services, IDF relies on the generosity of several organizations for program funding. IDF Core Service Sponsors are dedicated partners that support IDF at the highest level.

2009 IDF Core Service Sponsors

- Baxter Healthcare
- CSL Behring
- Grifols
- IgG America / ASD Healthcare
- Octapharma
- Talecris Biotherapeutics

2009 Home Health Sponsor

BioRx

These sponsors make an enormous difference in the Foundation’s ability to plan and provide long-term resources on behalf of people with primary immunodeficiency diseases. IDF greatly appreciates these devoted sponsors and their commitment to our mission.

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