The third weekend of February was a weekend for thirty teens and young adults—to escape to a place to meet other teens who also live with primary immunodeficiency diseases (PIDD). Patients ranging in ages from 13 to 22, arrived in Houston, Texas for the pilot of this first IDF Teen and Young Adult Program.

IDF has long had an interest in developing age-appropriate programs and resources for teens and young adults. The period of transition from adolescence to adulthood is a difficult time, period. However, those affected by primary immunodeficiency diseases have an even more complicated time. It is challenging to maintain consistency in healthcare during a time when teens begin to take more responsibility for managing their disease and treatment as parents gradually are letting go of total control.

Dating and peer relationships, as well as relating to their parents, are huge issues for teens. The academic stressors of trying to do well in school or get into college can be demanding. Future concerns about choosing a career and maintaining good health insurance after leaving their parents’ policies can weigh heavily on many young adults’ minds. Dealing with all this, while coping with a chronic illness obviously requires extra attention. Teens and young adults need additional resources and assistance.

To help fill this void, IDF created the IDF Teen and Young Adult Program. The Teen ESCAPE Weekend served as the kickoff for this program! This included the first meeting of the IDF Teen & Young Adult Council, a group of future leaders in the primary immunodeficiency patient community. Many of the members will serve as peer contact volunteers to other teens and young adults and assist in the development of educational programs and leadership opportunities.

“It was so awesome to talk to people our own age who knew what we were going through.

(Continued on page 3)
Celebrating Our Community!

The Immune Deficiency Foundation 2009 National Conference

Are you ready? Have you packed your giant mouse ears? Have you had time to THINK ZEBRA!? No? Then what are you waiting for? Register NOW for the largest gathering of our extraordinary IDF community, June 18 – 20, 2009, at Disney’s Contemporary Resort in Florida.

Jumpstart your National Conference weekend with the Welcome Reception, a great opportunity for attendees, especially first-timers, to meet with their peers, speakers, industry representatives, IDF volunteers and staff. We often hear, that the first time a person with PIDD meets another like patient is at an IDF national conference. If this is your first conference, prepare for a wonderful experience! If this is your fifth conference, get ready for the best one yet!

During the conference, members of the IDF community will come face-to-face with world-renown immunologists who will share their expertise on medical matters. Life management sessions will offer suggestions and solutions to improve everyday life and attendees will have the chance to get some of their own questions answered.

The Youth Program has been expanded to meet the needs of all ages. There are four sections, each with age-appropriate learning and fun activities. Starting with Childcare for six months to five years, Kids Club for those ages’ six to nine, Tween Scene for those in-between ten to twelve year-olds and the Teen ESCAPE for thirteen to eighteen. There are adventures that include trips to Disney Quest and the Magic Kingdom, plus plenty of team building activities and our very own “Silly Olympics.”

Healthcare professionals can jump on the “Medical Track,” and attend the Friday afternoon medical education program jointly organized by USF Health and IDF. This program is presented by leading professionals in immunology and offers 4.5 AMA PRA Category 1 Credits for physicians and 4.5 contact hours for nurses.

While we’re all aware of the importance of networking, peer support and education, IDF knows the value of having fun!

On Friday night, conference attendees will celebrate their “Zebra-ness” with food, beverages, entertainment and a fantastic silent auction all while decked-out in their own black and white.

THINK ZEBRA! is a spin on a phrase most doctors learn in the early days of medical school: “When you hear hoof beats, think horses, not zebras.” However, as nearly all primary immunodeficiency patients are aware, physicians sometimes need to look for zebras. Given our community includes the ‘zebras’ of the medical world, we are inviting all of our attendees to don their stripes and celebrate zebras!

On Saturday, conference attendees will venture to Epcot for an evening of fun, food and fireworks – the premier nighttime spectacular, Illuminations: Reflections for the Earth will immediately follow a scrumptious dessert reception.

IDF has secured special rates for hotel rooms, transportation to the off-site events and is offering an all-inclusive, economically priced registration fee. So, register today and join us at Disney for the IDF 2009 National Conference. All you need to register can be found at www.primaryimmune.org.
I’ve tried to explain my condition to people at college, but they don’t understand.”

During the weekend activities, teen curriculum topics were introduced and educational sessions about PIDD were held. This was a trial run for some of the sessions for the IDF 2009 National Conference coming up this June in Lake Buena Vista, Florida. Participants were asked to react to the subject matter of the sessions as well as the content for the upcoming IDF Teen and Young Adult Website. Their feedback is essential to making the program successful and our attendees offered great ideas and insight.

A vital part of the weekend was starting the process of developing a support network for teens. Getting acquainted did not seem to be a problem as the teens and young adults enthusiastically dove into activities together. They did not have to be asked twice!

A scavenger hunt and an evening at Dave and Buster’s proved to be favorites for all.

As is often the case, there was not enough time. Some of the main topics included: college, academic and social stressors, dating and peer relationships, parents, coping with PIDD, transitioning to self-management, education about the disorder and treatment, health insurance options, and inheritance and future planning. Some of these topics were explored, while others were just touched.

This is just a beginning! The next step is the IDF 2009 National Conference June 18–20, 2009. We encourage all teens, ages 13 through 18, to sign up for the Teen ESCAPE program.

“This weekend was great. I enjoyed everything and cannot wait for Florida.”

— Participant of IDF Teen ESCAPE

A generous appreciation goes to Baxter Healthcare for sponsoring the IDF Teen ESCAPE and the IDF Teen and Young Adult Program with an unrestricted educational grant.
It is Time to Earn Your Stripes!
The Immune Deficiency Foundation is delighted to announce THINK ZEBRA!, IDF’s campaign to raise funds and promote awareness of primary immunodeficiency diseases.

“When you hear hoof beats, think zebras, not horses.”

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!” Let’s teach the world about “zebras” while raising funds to help promote awareness of primary immunodeficiency diseases. Money raised will help fund patient and physician education and awareness.

Every individual or family that registers for the National Conference in June will automatically receive a THINK ZEBRA! packet with everything they need to get started. Details can also be found at www.primaryimmune.org/zebra

If you are not attending the National Conference, you are still eligible to participate and earn prizes through THINK ZEBRA! To request a packet, please contact Susan Amoroso at samoroso@primaryimmune.org or 800.296.4433.

If you have any questions about THINK ZEBRA!, please contact Allison Mayberry, Director of Development, at amayberry@primaryimmune.org or 443.632.2555.

Thank you for your efforts on behalf of the Immune Deficiency Foundation. And remember to THINK ZEBRA!

Ten-year-old Emily Pell from Williamson, Michigan decided to do her part to help raise funds for IDF and set a goal of $100. She started a book club and even presented information about primary immunodeficiencies to a class of nursing students who chipped in and helped Emily reach her goal! Building on her success, Emily plans to continue her fundraising and increase her goal by $50 each year.

Congratulations Emily!
Before the November presidential election, the Gallup organization took a final poll as to the main concerns of voters as they prepared to cast their ballots. Healthcare consistently ranked just below the economy as one of the biggest issues the country is facing.

A recent ABC News survey found that 20% of baby boomers worry that they won’t be able to afford medical care in the coming year, and 42% of all Americans with chronic conditions report skipping care, drug doses, or doctor’s appointments due to cost.

It often seems that one cannot pick up a newspaper or turn on a television without hearing about the problems with our healthcare system. From the high cost of coverage, to the ineffectiveness of Medicare, to the denying of claims by insurance companies, Americans are struggling with premiums, deductibles and co-pays – that is, if they have any coverage at all.

With an understanding that your chances of encountering a problem with healthcare coverage is at an all-time high (20 percent of the people polled by ABC noted “issues” with their coverage), it is very important to be your own advocate at all times.

While the tips below won’t guarantee you’ll avoid clashes with your health insurance company, they will help you become better organized if such a situation should arise.

You can start organizing today by making this article the first component in your brand new insurance file.

**UNDERSTAND YOUR INSURANCE POLICY AND BENEFITS**

- **Obtain a copy of your policy.** Depending on your type of insurance plan, you may request a copy of your Summary Plan Description (SPD) from your Human Resources Department, if you have an employer sponsored group policy. If you have an individual policy, contact the insurance company directly. In some cases, you may access the plan document directly from the insurance company’s Website.

- **Familiarize yourself with all facets of your coverage:** deductibles, doctor office visits, outpatient hospitalization, inpatient hospitalization, emergency room services (if not admitted to inpatient), home healthcare services, prescription drug coverage, Out of Pocket Maximum (the maximum amount that you pay before the insurance pays at 100%), and Lifetime Maximum (the total amount the insurance company will pay out).

- **Register with your insurance company’s online member services** (if available). You can keep an eye on claims that are submitted and paid, how much has been contributed to your deductible, and many other benefits.
  - Know the exclusions and limitations in your policy.
  - Know your insurer’s Appeals and Grievance policy.

**Keep your own insurance file.**

If a problem should arise, it is best to be organized and have everything in one place. You may be able to solve the problem in the early stages. Following is a checklist of items that should be maintained and documented:

- Copy of your insurance policy and benefits (as discussed above).
- Paperwork from your doctor and insurance company.
- Copies of claims paid, received from your insurance company, private insurers call these EOBs (Explanation of Benefits).
- Insurance approved services, for those that require prior authorization.
- Medications that you are taking, dosage, and frequency, in addition to your infusion log.
- Copies of all medical tests and reports: blood work (including the pre-immunoglobulin full clinical work-up), CT Scans, MRIs, etc.
- List of all your doctors and their phone numbers.
- Pertinent letters from doctors.
- Detailed notes of your interactions with everyone: document the date, person’s name with whom you spoke, and what was addressed and discussed.
- Take notes at doctor’s appointments.
- Routinely confirm that your doctor’s participate with your insurance company. It is best to go to the insurer’s Website, and print off the doctor’s contact information ensuring the URL and date is included.

**If you find yourself with an insurance problem:**

1. Do not PANIC. It is important to first diagnosis the problem.
2. Grab your medical file and your insurance card, so you have everything in front of you. Remember to document your calls.
3. Your demeanor is very important when solving problems. Keep to the facts. Stay away from telling stories. Keep focused on solving your insurance problem. If you have to make a phone call, the person on the other end of the phone is more apt in helping someone who is polite and can answer their questions. Do not be condescending. Do not place blame on the person on the other end of the phone. They are not the one that caused the problem. Keep in mind that you are calling them to help you.
You are correct to question the health claims that many companies use when marketing “immune enhancing” products. What many do not realize is that these products – when and if they are regulated – fall under the regulations for foods and not the more stringent regulations for drugs. In October 1994, the Dietary Supplement Health and Education Act (DSHEA) was signed into law. Before this time, dietary supplements were subject to the same regulatory requirements as were other foods. This new law created a new regulatory framework for the safety and labeling of dietary supplements.

Under DSHEA, a firm is itself responsible for determining that the dietary supplements it manufactures or distributes are safe and that any representations or claims made about them are substantiated by adequate evidence to show that they are not false or misleading. A firm does not have to provide FDA with the evidence it relies on to prove safety or effectiveness before or after it markets its products. Therefore, a dietary supplement does not need approval from FDA before it is marketed.

Currently, there are no FDA regulations that establish a minimum standard of practice for manufacturing dietary supplements. The manufacturer is responsible for establishing its own manufacturing practice guidelines to ensure that the dietary supplements it produces are safe and contain the ingredients listed on the label.

The advertising claims for many of these products are totally without scientific merit and yet they continue to be able to make these claims with impunity. This practice is quite inexcusable – yet tolerated because many people believe in the value of these supplements, megavitamins, etc. FDA only has authority to step in if such a product is demonstrated to actually be harmful – as has been the case recently with several “weight loss” supplements that were causing serious health problems. In this case, the FDA was able to step in and have the products removed from the market.

I have reviewed some of the oral IgG products marketed on the Internet and if you read the fine print, they are produced using bovine and/or sheep IgG – not human IgG. There is no evidence presented on efficacy of these products in actually preventing or treating infections and it is very unlikely that any efficacy could be demonstrated. The idea that IgG isolated from cows raised in a barnyard and exposed to a very different universe of microorganisms than that seen by humans is itself a major limitation of this approach - even if the IgG survived its trip thru the GI tract. Normal Bovine IgG simply may not contain antibodies against “bugs” that commonly cause human disease.

There is probably little likelihood that these IgG products will be harmful (except to the wallet) since these proteins will be largely degraded in the intestinal tract just as they would be if you ate beef or lamb containing IgG in the blood and tissues. Similarly, there is little to suggest that individuals ingesting these products would experience the kind of side effects that patients are prone to develop following administration of human IgG intravenously. The mechanism causing the side effects with IV administration are more related to the physical structure and aggregation of the IgG molecules when shot immediately into the blood stream than with the fact that it is IgG – and oral IgG does not gain immediate access to the blood stream.

Therefore, the answer to your question is a resounding NO! There is no “edible IgG” on the market that will deliver the replacement therapy needed to treat primary immunodeficiency disease. Stay on your physician’s recommended treatment plan of Ig replacement.

R. Michael Blaese, MD
IDF Medical Director
Since 1992, The National Institutes of Health (NIH) have sponsored the development of a national registry of patients with primary immunodeficiencies. In 2004, this effort was greatly expanded through the United States Immunodeficiency Network (USIDNet), which is administered by IDF.

The efforts to develop the infrastructure have taken place over the last decade and a number of studies critically important for the care of patients have been published. Significant new data, which has altered the care of patients with chronic granulomatous disease, Hyper IgM, X-linked agammaglobulinemia and DiGeorge syndrome, have come from the registry.

Over the past five years, the registry has migrated to an electronic format and now has the capacity to perform yearly updates to enable tracking of patients’ health over time. As part of the migration to the electronic format, there is now a major initiative to recruit patients and to update data in the registry on previously enrolled patients.

**YOU CAN HELP!**

Population prevalence of diagnosed primary immunodeficiency disease in the United States is estimated at approximately 1 in 1,200 people, which means approximately 250,000 people in the U.S. are diagnosed with one of these diseases. Thousands more go undetected. To be able to derive long-term outcome data, we will need to recruit more patients to the registry. Please consider contributing your information to the registry. It will help so many other patients and it may just help you!

**If you are interested, you can do several things:**

**Talk to your physician about being a part of the registry**

- There are surveys for you to fill out on how you feel you are doing
- There is a form requesting certain medical information for your physician to fill out

We also want to hear from you concerning any questions you have about your disease.

Some of these questions could form the basis for research studies. This registry serves both patients and physicians and it is important that it provide meaningful answers to your questions.

**Patients, for more information or to obtain the forms, call (866) 939-7568 or email: Contact@USIDNET.org.**

**Physicians, if you would like to enroll your patients or want more information about the USIDNet Registry, call (866) 939-7568 or email: Contact@USIDNET.org.**

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**USIDNET Registry Collaboration with IDF**

Dr. John Bohnsack, Pediatric Immunologist at University of Utah, presents to patients and family members at the IDF educational meeting in Salt Lake City, UT in October. Thank you Bernadette McNally for organizing this successful event!
IDF and the Alpha-1 Association have teamed up in Minnesota to support legislative efforts that will ensure access to plasma protein therapies, including immunoglobulin replacement therapies. Senator Kathy Sheran has introduced this legislation (bill number SF 339) in the Minnesota Senate and Representative Kim Norton has introduced a companion bill (HF 410) in the Minnesota House of Representatives.

Both bills require the Minnesota State Board of Pharmacy to develop rules for the provision of pharmacy services based on the standards established by patient group medical advisory committees and professional societies. Further, the proposed bills require health plans to provide patients with the therapy that is the most medically appropriate.

Marcia Boyle, IDF President and Founder said, “Without these proposed standards of care, patients suffering from these rare and chronic diseases are at risk of being deprived of their needed lifesaving treatments. That is unacceptable as it will result in not only severe debilitation and possibly death for these patients, but will also increase health care costs for all Minnesotans.”

In early March, patients from both IDF and Alpha-1 flocked to the Minnesota Capitol to support both bills. More than 30 meetings were held with key members of the House and Senate to ask for their support and request that the Health Committees in both the House and Senate hold hearings on the bills - a key step toward passage.

Prior to passage, both bills may be required to go before the Commerce committees in each chamber. The reason for this is that the bills not only establish health policy, they also place requirements on private health insurers. The Senate and House Commerce committees have jurisdiction over health insurance companies and plans. Thus, the second committee will also review the bill before it could go to the floors of the Senate and House. Hopefully, both committees will send the bills to their respective floors for votes.

IDF will continue to organize visits with legislators and letter writing campaigns. Such campaigns are essential to secure public health policies that ensure all patients with primary immunodeficiency diseases can receive the care they need, at an affordable price.

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Please keep a lookout for Legislative Updates on IDF’s Website: www.primaryimmune.org.
In 2005, as a part of the Medicare Modernization Act (MMA), a new formula to calculate reimbursement for Part B drugs was instituted. This new reimbursement method was an effort to use taxpayer money more wisely, and ensure that Medicare was not paying too much for many drugs. While this change was implemented with the best of intentions and this new reimbursement formula has been sufficient for the majority of drugs, it has been inadequate to cover the cost of complex and costly intravenous immunoglobulin (IVIG). To further complicate the issue, the current Medicare benefit for primary immunodeficiency diseases does not reimburse for the specialized nursing and supplies necessary for infusion in the home. This is obviously a serious problem for patients with primary immunodeficiency diseases (PIDD) whose ideal site of care is their home.

**Why is it so challenging for Medicare beneficiaries with primary immunodeficiency diseases?**

This only affects older patients and those on disability, right?

Wrong. IDF has received reports of patients with PIDD of all ages experiencing changes in reimbursement. Private health insurers often follow Medicare’s lead. As a result, some privately insured patients are having their treatments questioned or postponed. It is important to remember that in a small and unique patient group like ours, this is everyone’s fight.

How can this be fixed?

IDF believes that the best way to fix these problems is to work with Congress. We are supporting the Medicare IVIG Patient Access Act, introduced into the Senate recently and soon to be in the House of Representatives in the spring 2009. This legislation would require additional reimbursement from Medicare for IVIG infused in the physician’s office and hospital outpatient department, and it would require Medicare to reimburse for items and services needed for IVIG infused in the home.

After the Medicare IVIG Patient Access Acts were introduced, the bills are then referred to the committees with jurisdiction over the matter. For Medicare legislation, those committees are the Finance Committee in the Senate, and both the Committee on Ways & Means and the Committee on Energy & Commerce in the House.

Since this is a unique issue affecting a small patient community, it is extremely unlikely that there would be a direct hearing or vote on the bill. Instead, the best strategy is to work to include the bill in a bigger legislative vehicle, and this year, that would be the large Medicare package that is expected before the end of the year.

**What can I do to help?**

In today’s world, your senators and representative are swamped with a variety of concerns. They need to hear from people in their states and districts about what is important to them. The most important thing you can do is contact your Members of Congress and ask that they sign on to cosponsor these bills.

IDF relies heavily on the voices from our patient community who make this possible. You can expect to see a new Action Alert on the IDF Website and in the e-newsletter, *Primary Immune Tribune*. Please help our efforts by contacting your representative and senators through the IDF Action Alert. Don’t forget to ask your friends, family and neighbors to also sign up at the IDF Action Alert-they can make a huge impact. If you prefer, pick up the phone and call your senators and representative in their local offices.

If you have any questions or ideas on what to say, contact Larry LaMotte at 443.632.2552 or llamotte@primaryimmune.org. We’re here to help! With all of us working together, we are confident that we can make our needs be heard.
**Phase III Trial Begins for GAMMAGARD LIQUID Plus rHuPH20 in Primary Immunodeficiency Patients**

Baxter International Inc. and Halozyme Therapeutics announced the start of a Phase III clinical trial of Baxter’s GAMMAGARD LIQUID [Immune Globulin Intravenous] 10% (IGIV), marketed as KIOVIG in the European Union, with Halozyme’s recombinant human hyaluronidase enzyme (rHuPH20, Enhance™ Technology) for the treatment of primary immunodeficiency (PID). The purpose of this clinical trial is to evaluate the safety and efficacy and gain regulatory approval for the treatment of PID using GAMMAGARD LIQUID and rHuPH20 via subcutaneous (under the skin) injection at a single site.

GAMMAGARD LIQUID is currently administered intravenously (IV). Subcutaneous (SC) administration of GAMMAGARD LIQUID with Enhance Technology is an investigational study and when approved could allow patients to receive a full monthly dose in a single injection site in their home setting.

This Phase III clinical study is a prospective, open-label, non-controlled design that will be conducted in 10-20 centers in the U.S. and Canada. The trial will evaluate the efficacy of GAMMAGARD LIQUID administered SC with rHuPH20 in the prevention of acute serious bacterial infections and will also assess pharmacokinetic parameters of SC and rHuPH20 compared to intravenous administration.


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**CSL Behring Launches Voice2Voice™ Vivaglobin® Advocacy Program for New Patients and Caregivers**

CSL Behring, a worldwide leader in developing immunoglobulin therapies, announced the launch of Voice2Voice™, a consumer outreach program offering peer-to-peer support to primary immunodeficiency (PI) patients and caregivers. The program will offer assistance exclusively to new patients as they begin at-home use of Vivaglobin® (Immune Globulin Subcutaneous, Human), the first and only U.S. Food and Drug Administration-approved subcutaneous immunoglobulin (Ig) for treatment of patients with primary immunodeficiency.

Through Voice2Voice, a third party assigns new patients and caregivers their own personal advocate, a patient experienced in self-administering Vivaglobin, who will call them to help ease the transition to at-home self-administration.

The Assurance Program is designed to ensure that people who rely on Vivaglobin can continue to receive the product even if they experience a lapse in their third-party, private health insurance.


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**Grifols Celebrates Initial Construction of New IVIG Facility with Los Angeles Officials and Dignitaries**

On January 13, 2009, Grifols, a global healthcare company based in Barcelona, Spain, welcomed Los Angeles Mayor Antonio Villaraigosa, Cal State LA President James Rosser, Councilman Jose Huizar and other elected officials, patient representatives and dignitaries for the ceremonial dedication of its new IVIG facility. Grifols recently broke ground on a new 92,000 square foot, intravenous immune globulin (IVIG) production facility at its US headquarters in East Los Angeles. This new facility is the initial realization of its $600 million long-range investment plan announced in October 2007 to increase production for Grifols lifesaving therapies.

“Without the support of Mayor Villaraigosa and his business team, we would not have been able to make our vision a reality in Los Angeles. This is the first step in our long-range growth plans for Los Angeles and to meet increasing patient needs for lifesaving plasma therapies,” said Gregory Rich, President of Grifols, Inc.

“We commend Grifols’ increased commitment to the production of IVIG. Assuring continued access to this lifesaving medicine means countless people who live with primary immunodeficiencies, such as my son, can lead healthy and productive lives,” said Marcia Boyle, President and Founder of IDF.

Catching Up With IDF Volunteer Mary Dietz

— by J. Doug Gill

It’s all about the attitude. Just ask Mary Dietz, a forty-eight-year-old CVID patient who lives in Iowa. That is, if you can catch up with her.

My first contact with Mary was abruptly cut short.

“I’d love to talk to you,” she excitedly exclaimed, “but right now I’m riding on the back of a motorcycle.”

That “Born to be Wild” spirit was still evident when she returned my call.

“All things considered, I’ve been very fortunate,” Mary explained.

Having been diagnosed with CVID just four years ago, Mary spent the first four-plus decades of her life living with a condition of which she was unaware.

“When I was little – say three or four – I had plenty of ear infections and such. I also had tonsillitis. But once they removed my tonsils, I really never had any other health issues of that nature. But as I got older, and thought I was catching cold, the flu or whatever, it was easy for me – and for the doctors – to say: ‘It’s just an infection’.”

As a result - and save for periodic congestion, bronchial issues and septum surgery - Mary spent 40 years never questioning the possibility of other factors lurking behind her recurring illnesses.

“I always thought – and the doctors always thought – it was just allergies,” Mary said, referring to her state of perpetual congestion.

“One ENT – based on a white-colored coating in the back of [my] throat – even suggested I was allergic to milk or dairy products – which, as I pointed out, I’d been consuming for 40 years!”

Now, Mary talks of her 90-minute subcutaneous treatments – that she administers herself – with the same tone one would apply to the mundane nuances of everyday life. But, it hasn’t always been that way.

Mary has seen her share of unsympathetic bosses, disagreeable co-workers and even a husband who sometimes thought she was using her illness as a crutch.

“I give all the credit to my immunologist,” Mary says, “She took the time to really talk to me – to help me understand. If it hadn’t been for that doctor, I would have really been a mess.”

Messier, say, than that hair-do after being squished into a motorcycle helmet?

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Mary has seen her share of unsympathetic bosses, disagreeable co-workers and even a husband who sometimes thought she was using her illness as a crutch.

“Of course,” this motorcycle mama concludes, “Life is so much better once you get what you need!”

Get your motor runnin’. ’
SILENT AUCTION AT IDF 2009 NATIONAL CONFERENCE

Please donate to our silent auction!

To find out more about donating an item to our silent auction, please visit our Website at www.primaryimmune.org/zebra or contact Elizabeth Ferguson at eferguson@primaryimmune.org or at 443.632.2554.

THANK YOU!

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