Grateful Families Give Back to IDF
Sharing Their Stories of Finding Hope and Supporting the Foundation

Annual giving helps sustain the valuable programs and services that the Immune Deficiency Foundation provides to patients and families living with primary immunodeficiency diseases. As the end of another year approaches, donors reflect on why they choose to give to IDF.

Shelley and Jim Romeo
Shelley and Jim Romeo make an annual gift to IDF. Their four-year-old son, Cole, was diagnosed with X-Linked Agammaglobulinemia (XLA) in 2009.

After contracting bacterial meningitis, our son was diagnosed with XLA when he was just 21 months old. We felt very alone, and we were looking for a resource to turn to that would help us prepare our son, and ourselves, for the road ahead.

IDF provided us with a wealth of resources including parents, patients, doctors and other professionals who we turned to to help us navigate our future. IDF steered us in the right direction when we began in-home IVIG treatments for Cole.

Cole is doing GREAT! He does not appear to have any lasting impact from his bout of meningitis. And since he began receiving IVIG treatments, he rarely gets sick, even with attending full day preschool!

Chris Lingen and Ken Reinowski
Chris Lingen and Ken Reinowski contribute annually to IDF, and their gift is matched by Chris's employer, Hillshire Brands. Chris was diagnosed with Common Variable Immune Deficiency (CVID) six years ago. She tells her story.

When I was first diagnosed with CVID, it was a scary time, and I had a lot of questions. I discovered the IDF website and found a lot of helpful information and resources. IDF has been a wonderful support system for my husband and me. I have had a lot of great experiences with IDF including participating in Advocacy Day on Capitol Hill and speaking to a group of employees at my local plasma center.

I want to give back and make sure others who are diagnosed with a primary immunodeficiency disease have the same great resources available to them. Working for a company that believes in supporting the causes of their employees is something that I am very thankful for. I would encourage others to consider supporting IDF with an annual contribution.

continued on page 2
Ways to Give

✓ Donate Online
To make a one-time donation, visit:
https://primaryimmune.org/give.

✓ Mail Your Gift
Use the enclosed envelope and mail your check, made payable to the Immune Deficiency Foundation, to IDF, 40 West Chesapeake Avenue, Suite 308, Towson, MD 21204.

✓ Monthly Giving
IDF can automatically charge your credit card for a designated amount each month. On our giving page, simply select “I would like to make a recurring monthly donation” and specify the amount: https://primaryimmune.org/give.

✓ Tribute Gift
A donation to IDF is a thoughtful way to honor someone whose life has been impacted by a primary immunodeficiency disease. Gifts can be made to recognize milestones in a patient’s life or to express the sense of loss when someone loses their battle with this disease. Once your gift is received, IDF will notify the honoree or family acknowledging your gift. The names of those honored or memorialized by gifts will be published in the IDF Advocate. Complete the online donation form and designate your honoree or memorial:
https://primaryimmune.org/give.

✓ Matching Gifts
Some companies will match the gifts of employees. Please contact your employer’s human resources department to ask if they participate and request the form to accompany your gift.

✓ Workplace Giving
Your donation can be automatically deducted from your paycheck when you designate the Immune Deficiency Foundation as your selected charity with the United Way or the Combined Federal Campaign (CFC). IDF’s National CFC number is 10313.

✓ Gifts of Stocks and Bonds
Gifts may be made in the form of appreciated securities, which may provide a tax advantage.

✓ Gifts through Bequest, Life Insurance, or other forms of Estate Planning
Individuals may wish to make a difference by including the Immune Deficiency Foundation in their estate planning.

For more information, call 800.296.4433 or e-mail idf@primaryimmune.org.

Grateful Families Give Back to IDF
continued from page 1

Pinky and Sid Martin
Each year, Pinky and Sid Martin make a gift to IDF in memory of their daughter, Kristin, who passed away in 2004 at the age of 36. Kristin was diagnosed with CVID. In addition to her parents, IDF receives annual gifts in memory of Kristin from other family members and friends.

We choose to make an annual gift to IDF because it was an important part of our daughter’s life. Kristin found IDF on her own when she was in her early 30’s. Through IDF she found people who understood the risks and hardships that were a part of her life. She lived in a world where most people were healthy, it can make you feel isolated at times. Kristin went to an IDF Conference and came home talking about how much it meant to her. People there understood what it was like to live with a chronic illness.

We are very thankful to others who donate to IDF in memory of Kristin. If she were here, she too would thank everyone and then educate them about IDF and what it does for others. Kristin was such an advocate. She was a young woman who did not want her illness to get in her way of living. To have our daughter remembered – and remembered in this way – is wonderful and so very appropriate.

IDF is an advocate for so many. We can’t say enough about the importance of this organization to people who suffer from these diseases.

IDF is grateful to all those who contribute annually – each with their own stories, donating for their own reasons. If IDF has touched your life in some way, consider making an annual gift. There is no gift too large or too small, and there are many ways to give.

IDF 2013 National Conference
Registration Begins in February

Mark your calendars for IDF’s signature event! The IDF 2013 National Conference will be held June 27-29 at the Hilton Baltimore, which overlooks Oriole Park at Camden Yards and is steps away from the popular Inner Harbor.

To kick off the weekend, IDF Advocacy Day will be held on the Thursday before the conference, allowing all attendees to participate, potentially bringing the largest group of patients and family members affected by primary immunodeficiency diseases to gather on Capitol Hill at one time.

The IDF 2013 National Conference will include engaging educational sessions from medical and life management experts as well as opportunities to connect with others and have fun. Attendees will enjoy the wonderful IDF Zebra Gala on Friday evening, and Saturday’s Family Fun Night will be held at one of the country’s top aquariums, the National Aquarium in Baltimore.

Registration will begin in February. Stay tuned for more information!
“Thank you for a wonderful weekend! It was life changing!”

IDF Retreats 2012 – Milwaukee and Houston

More than 400 people from 33 states and Canada attended the IDF Retreats this summer, held June 22-24 in Milwaukee, Wisconsin and September 7-9 in Houston, Texas. Approximately half of the patients and family members who attended were first time attendees, affirming that we are reaching more and more people and those who we have met before continue to attend and benefit from our events. The IDF Retreats give our community the unique opportunity to connect with other patients and family members who live with primary immunodeficiency diseases. One Milwaukee participant commented, “Very well organized. Again, a wonderful IDF experience!”

Positive responses like this result from the valuable programs at the retreats developed for both adults and youth. Expert immunologists and experienced professionals volunteered their time and knowledge to provide the most current and authoritative information on medical and life management issues.

While the adults listened to the presenters, we provided educational and fun youth activities. From the youngest learning how to really wash their hands to tweens and teens being challenged with their “survivor skills,” everyone got involved. The best part of each activity was young people meeting and bonding with their peers.

And, like the participant who had a “wonderful IDF experience,” the comments we received were overwhelmingly positive:

“I feel so empowered and not alone. I am so thankful to have connections and help when I need it.”

“This event has been fantastic!! I have learned so much. I came here believing I was dying and now I have hope!”

“Loved content of retreat. Real ability to connect to so many patients. Amazing turnout. IDF is changing lives for patients each day - Thank you!”

Thank You to Our Presenters!

Maggi Dodds, BSN, MSN, CPNP
Kristin Epland, FNP-C
James Gern, MD
Vlasta Hakes
Celine Hanson, MD
Gavin Lindberg
Donna Marie Meszaros, PhD
Stephen Miles, MD

Jordan Orange, MD, PhD
Jason Raasch, MD
Jack Routes, MD
John Seymour, PhD, LMFT
Elizabeth Stoltz
Lynne Szott, RN, CCM
James Verbsky, MD
Richard Wasserman, MD, PhD

The IDF Retreats are generously supported by Baxter Healthcare Corporation, CSL Behring, Grifols, IgG America/ASD Healthcare/US Bioservices, Octapharma and Sigma-Tau Pharmaceuticals.
IDF fields hundreds of questions each month from patients and families living with primary immunodeficiency diseases, and many of those questions deal with health insurance. We know health insurance is an important and often times complicated issue for patients. We also know the choices of policymakers directly affect those issues. With this in mind, we redesigned sections of our website to help you easily find the information you need to ensure you have access to quality care!

Patient Insurance Center
The majority of patients living with primary immunodeficiency diseases rely on some form of insurance to assist with expenses – whether that is private insurance, Medicare, Medicaid, or some other form of government insurance program – but dealing with health insurance and understanding the maze of issues involved can be overwhelming. IDF understands and has created the Patient Insurance Center to provide information regarding insurance issues, as well as other possible sources of assistance, for you and your family. Take advantage of these resources:

- **Health Insurance Toolkit**: This document includes information and worksheets that will help you make the best possible choice in selecting a private health insurance plan.
- **FAQ - Health Insurance Frequently Asked Questions**: Get answers to general insurance questions to help you better understand your options and policy.
- **Health Insurance Denial**: How to Appeal – We compiled tips to help you explain the importance of Ig therapy and overcome denials. You can view sample letters and tailor them to your own medical history.

Visit the Patient Insurance Center for these resources and more: [http://primaryimmune.org/patients-and-families/patient-insurance-center](http://primaryimmune.org/patients-and-families/patient-insurance-center).

**IDF Advocacy Center**
Members of the primary immunodeficiency patient community have unique needs with which most policymakers are not familiar. We maintain a full-scale advocacy program focused on national and state healthcare issues, and the IDF Advocacy Center is where you can learn more and get involved.

- Stay updated about Healthcare Reform, Medicare Patient IVIG Access Act, SCID Newborn Screening and more public policy issues.
- Have your voice heard through Action Alerts.
- Contact your elected officials.
- Follow the Policy Matters Blog.
- Tune in to the IDF Advocacy Channel featuring videos that communicate the powerful stories of patients.
- Participate in Training Webinars to learn how to advocate in your state.

Check out the new Advocacy Center today: [http://primaryimmune.org/idf-advocacy-center](http://primaryimmune.org/idf-advocacy-center).

**Ask IDF**
If you want to know more about health insurance, public policy or have other general questions about living with primary immunodeficiency, you can always ask IDF!

- Call 800.296.4433 (Monday-Friday 9 a.m.-5 p.m. EST).
- E-mail idf@primaryimmune.org.

We are here to help you and your family!

**New Website Features Help Ensure Access to Quality Care**

Through federal and state advocacy efforts, IDF works on behalf of patients living with primary immunodeficiency diseases to ensure their access to high quality treatment. These efforts were highlighted in a July 2012 article in the Journal of Clinical Immunology, titled “Local and National Advocacy Support.”

The article demonstrates that policy decisions by third-party payors restrict delivery of appropriate immunoglobulin (Ig) treatment for patients with primary immunodeficiency diseases. Effective action to reverse these policies requires coordinated efforts by patients, physicians and advocacy groups at both the local and national levels.

According to the article abstract, “Some of the strongest advocacy to date is from patient organizations, such as the Immune Deficiency Foundation (IDF), which strive to educate stakeholders on key issues that determine patient access to appropriate IgG treatment. These issues include the ability to choose the appropriate site of care based on a patient’s experience and circumstance and greater awareness of product choice. Advocacy by physicians on these issues at the local level is needed, as are national efforts by organizations such as the American Academy of Allergy, Asthma & Immunology and their regional societies.”

Authors include Marcia Boyle, Immune Deficiency Foundation; Ralph S. Shapiro, MD, Midwest Immunology Clinic and University of Minnesota; and Elena E. Perez, MD, PhD, All Children’s Hospital and University of South Florida. To read the full article, go to [http://primaryimmune.org/2012/10 journal-of-clinical-immunology-article-stresses-the-importance-of-local-and-national-advocacy-support](http://primaryimmune.org/2012/10 journal-of-clinical-immunology-article-stresses-the-importance-of-local-and-national-advocacy-support).
Over the past year, the IDF Nurse Advisory Committee (NAC) launched a number of innovative projects that will help improve the quality of healthcare and education provided by nurses for patients with primary immunodeficiency diseases here in the U.S. and internationally. The work of the NAC is quite amazing, from developing new materials to publishing and presenting their work.

“The efforts of this committee will ultimately increase the awareness of primary immunodeficiency diseases and assure safe administration of the therapies available,” explains Kristin Epland, FNP-C, Nurse Practitioner at Midwest Immunology Clinic in Plymouth, MN, who has served as the Chair of the NAC for two years, “We have been very active in the last year taking on some pretty big projects.”

Some of the big projects include:

IDF Online Continuing Education Course for Nurses (English): Primary Immunodeficiency Diseases and Immunoglobulin Therapy
A free, 5-hour, U.S. accredited course for nurses, written and recorded by the NAC, provides an update on primary immunodeficiency diseases, immunoglobulin (Ig) therapies and the nurse’s role with these therapies. http://primaryimmune.org/healthcare-professionals/continuing-education-course-for-nurses

IDF Video Series for Nurses (French, German, Spanish): Primary Immunodeficiency Diseases and Immunoglobulin Therapy
A free, non-credit video series, based on the IDF Online Continuing Education Course for Nurses, is translated in French, German and Spanish. To date, this project has been one of the widest reaching education programs for nurses sponsored by IDF. http://primaryimmune.org/idf-video-series-for-nurses

Poster Abstract Presentations
IDF Online Continuing Education Course for Nurses presented at the annual meetings of:
- American College of Allergy, Asthma & Immunology
- Infusion Nursing Society
- International Nursing Group for Immunology

Development of Standards of Care presented at the annual meetings of:
- American Academy of Allergy, Asthma and Immunology
- International Nursing Group for Immunology
- Immunoglobulin Nursing Society

Nursing Guidelines for Administration of Immunoglobulin Replacement Therapy
A comprehensive review of standards for administration of Ig therapy, developed by members of the NAC, will be published in the January/February 2013 issue of The Journal of Infusion Nursing (Indexed in MEDLINE, CINAHL Plus, PubMed). This document is the first of its kind to offer infusion nurses solid guidelines on the standard of care in Ig administration.

IDF Guide for Nurses
The IDF Guide for Nurses Immunoglobulin Therapy for Primary Immunodeficiency Diseases –3rd Edition includes general information about primary immunodeficiency diseases, delivery of Ig replacement therapy, product selection and characteristics, troubleshooting subcutaneous immunoglobulin therapy (SCIG) and more. The sleek design and pocket size make it easy to use for busy nurses. To order or download, go to http://primaryimmune.org/about-primary-immunodeficiency-diseases/idf-publications

IDF 2012 Retreats and Patient Education Meetings
NAC members played vital roles presenting and leading sessions at both adult and youth sessions.

The Committee will continue its work to expand the competency of all healthcare providers who care for patients with primary immunodeficiency diseases. Kristin says, “I have been honored to chair this committee and look forward to more exciting patient and healthcare provider educational opportunities coming up.”

The IDF NAC and many of its initiatives, including the IDF Online Continuing Education Course for Nurses, the IDF Video Series for Nurses in French, German, and Spanish and the IDF Guide for Nurses are sponsored by CSL Behring.

For more information about the NAC, visit http://primaryimmune.org/about/nurse-advisory-committee.
Flu Information 2012 - 2013 Season

By R. Michael Blaese, MD

Influenza, commonly known as the “flu,” is a contagious viral disease that typically occurs in the winter months and causes cough, fever, sore throat, headache, chills, muscle aches and fatigue. In 2009 a new strain of influenza known as swine flu or H1N1-A influenza appeared, raising concerns that it might represent a much more serious illness than typical seasonal influenza. However, for the most part, the H1N1-A flu virus appears to cause an illness similar to that caused by the typical seasonal influenza virus. The H1N1-A virus has caused some deaths, just as does seasonal influenza. Pregnant women as well as some children under the age of six have been reported to experience more serious infections than average. There is no information to suggest that patients with primary immunodeficiency diseases have a higher relative risk from H1N1 than from earlier influenza strains. It is expected that this H1N1-A strain of influenza will continue to circulate throughout the population this flu season.

The influenza vaccine for the 2012-2013 season will once again guard against the pandemic A (H1N1) virus from 2009. Except for that repeat, the new formulation of the trivalent seasonal flu vaccine, just approved by the FDA, differs slightly from last season’s formulation. The agency selected two new virus strains that replace cousins of theirs in the previous mix. The three viral strains that comprise the vaccine for the upcoming influenza season are:

1. A/California/7/2009 (H1N1)-like virus (the pandemic virus that surfaced in 2009).

The formulation follows last season’s pattern of 1 “B” strain and 2 “A” strains, with one in the A (H1N1) camp and the other in the A (H3N2) camp. Not making it into the 2012-2013 formulation is a novel version of a swine influenza virus called A (H3N2)v that has sickened more than 150 individuals across the country since July 2011. Most of them caught it directly or indirectly from pigs at county fairs and farms. The CDC is closely monitoring this novel swine influenza virus, which contains a gene from the pandemic A (H1N1) virus, to see if it begins to spread easily among humans. Just in case, the agency plans to test a special vaccine against the virus before year’s end.

Influenza (caused by both the H1N1-A and seasonal viruses) is transmitted from person to person by airborne droplets formed during coughing and sneezing. These droplets are inhaled or land on mucus membranes (lining of the nose or inside of the mouth) or the conjunctiva (the thin membrane that covers the surface of the eye). Influenza virus also can be transmitted orally. Good hygiene and frequent hand washing are important to prevent transmission. For most people, the flu lasts only a few days, but some people get much, much sicker. Influenza can lead to pneumonia and is of particular concern in people with pre-existing heart and/or lung conditions.

The most effective way to avoid an infection with influenza is to receive the influenza vaccine annually.

Prevention

Common sense hygiene practices are critical in helping to limit the spread of the virus. The CDC recommends that patients refrain from returning to work or school until 24 hours after body temperature has returned to normal without fever-reducing medication. It is also recommended that all people cough into their elbows or sleeves, and wash their hands frequently.

The most effective way to avoid an infection with influenza is to receive the influenza vaccine annually. The CDC has recently updated its guidelines and now recommends that everyone over the age of six months be given the influenza vaccine every year. Influenza vaccines are safe and effective, and, contrary to a common misconception, they do not cause the flu. Because the influenza virus characteristically changes or mutates from year to year, each year it is necessary to prepare a new vaccine for protection from the new flu strains that are present that year. For this reason it is essential that everyone get immunized against the seasonal flu every year because last year’s vaccine may not be protective against this year’s virus strains. Currently there are two different types of seasonal flu vaccine available in the US – the inactivated or killed flu vaccine (the flu shot) and a live attenuated influenza vaccine (nasal spray). Both are highly effective in preventing influenza in normal individuals.

In 2009 a swine flu virus mutated to allow that virus to cause disease in humans and, therefore, a new vaccine to protect against this mutant virus needed to be prepared. Because swine flu appeared after the seasonal flu vaccine for that year had already begun to be manufactured, a separate vaccine needed to be prepared for the H1N1-A virus. This year the H1N1-A virus has been incorporated into the regular seasonal flu vaccine so that only one vaccine is needed for this flu season.

The Flu-Shot

The most commonly used vaccine, often called the “flu shot,” is a killed virus vaccine that can be given to individuals ranging from six months to senior citizens. This inactivated vaccine can be used by everyone, even by individuals who are allergic to eggs. Because the vaccine virus is grown in eggs, there was concern in the past that egg-allergic individuals might be at risk if they received the vaccine. However, recent studies have shown that individuals allergic to eggs do not have a higher chance of a reaction to the vaccine than non-allergic individuals and therefore the previous recommendation that egg-allergic individuals not receive the killed virus vaccine has now been withdrawn.

This traditional vaccine requires an injection and may cause local swelling and tenderness at the injection site. For children receiving the flu shot for the first time, two injections spaced about one month apart are required. These should preferably be given in September and October before the influenza season begins. In subsequent years, only a single vaccine dose is required. Children who only received a single dose of vaccine in the first year often do not develop protective immunity and therefore two doses should be given to the child in the second year.

FluMist

The other vaccine is a live attenuated influenza virus (LAIV) vaccine that is administered by droplets given into the nose (FluMist). FluMist...
is the name given to the intranasal seasonal influenza virus vaccine. Attenuation means that the virus has been weakened so that it does not cause illness in normal healthy people. FluMist is approved for individuals ranging from 2 to 49 years old. Administration does not require any injections. However, since it is a live virus vaccine, it has some theoretical risk for patients with defective immunity. It is the general recommendation that patients with T-cell disorders, such as SCID and DiGeorge Syndrome, and B-cell disorders with hypogammaglobulinemia/ agammaglobulinemia, such as X-linked agammaglobulinemia and CVID, not be given this form of influenza vaccine (FluMist).

The Immune Deficiency Foundation has reviewed this issue carefully with the FDA and the manufacturer of FluMist and hopes that additional studies will be conducted to help clarify the actual level of risk to our patient population. There seems little reason to expect that FluMist poses an increased risk for patients with CGD or complement disorders. Patients with HIV infection and immunodeficiency have been given this live agent vaccine without problem, but there have been no studies of patients with primary immunodeficiency diseases.

As with any live virus vaccine, concern has been raised about the possible spread of the vaccine virus from an immunized person to a close contact such as a family member with primary immunodeficiency disease. Studies looking for spread in nursery schools where only some children received the FluMist found the level of spread to non-immunized classmates was very low. This observation gives us some reassurance that the risk of the spread of this agent from a FluMist immunized child or adult to a family member with primary immunodeficiency should also be low. Furthermore we are not aware of a single instance of a patient with primary immunodeficiency disease developing influenza as a result of contact with a FluMist immunized individual, despite several million doses of this vaccine being used each year for the past several years. As a general recommendation only patients with the most severe forms of primary immunodeficiency diseases (babies with untreated SCID) should avoid contact with individuals recently immunized with FluMist.

The CDC Advisory Committee on Immunization Practices (ACIP) issued the following recommendation concerning FluMist (LAIV) use in individuals in close contact with patients with impaired immune systems:

“The flu shot is preferred for people (including health care workers and family members) in close contact with anyone who has a severely weakened immune system (requiring care in a protected environment, such as a bone marrow transplant unit). People in close contact with those whose immune systems are less severely weakened (including those with HIV) may get LAIV.”

Primary Immunodeficiency Family Plan

Nevertheless, for families with a member who has a primary immunodeficiency, we recommend that all members of the family should be given the inactivated (killed) vaccine. The vaccines usually become available in August or September. Studies have shown that immunization can still be effective when given well into February or March in some years, so it is important to ask for the vaccine even if the New Year has passed.

Why do we recommend that everyone be immunized? First, some patients with a primary immunodeficiency may benefit from the vaccine. Even if they do not, there is little down side to receiving the inactivated vaccine. Family members who are able to respond to the vaccine will be protected (a good thing in its own right). Even if the patient with primary immunodeficiency does not respond to the immunization, he or she will benefit from having everyone else in the family protected from infection and not susceptible to bringing the virus home with them. We want to create a “protective cocoon” of immunized persons surrounding our patients so that they have less chance of being exposed. It would be a good strategy to encourage employers to provide influenza immunization programs at the place of work and schools to similarly encourage immunization of the student body to further extend this “cocoon.”

Currently, the Immune Deficiency Foundation understands that individuals with primary immunodeficiency have at least the same risk of contracting flu as does the rest of the population. The same type of anti-viral medicine, i.e., Tamiflu or Relenza, which is effective for people with normal immune systems, would be effective for patients with primary immunodeficiency diseases who get influenza. Note that Ig replacement therapy may not protect against new strains of the influenza virus since the Ig contained in the currently available lots of IVIG or SCIG was obtained from donors several months ago, probably before the newer strains of influenza had circulated thru the donor population to result in antibody formation.

Influenza can be diagnosed rapidly by a test done in physician offices. If the test is positive, it is recommended that persons immediately begin anti-virus treatment. Speed is important in this situation since the antiviral medications are most effective if begun within 48 hours of the onset of the illness. It would be a good idea to discuss with your physician plans for dealing with influenza before you get sick so that you are prepared. If you do become ill, you should contact your doctor immediately about initiating treatment. However, it would be wise to contact your physician first, before going to their office, an urgent care facility or emergency room.

During the flu season, you may want to stay away from crowded public places, such as shopping malls, if you are concerned about exposure. Most people can get information from the national media and from their physicians on other ways to prevent exposure, as well as when to use additional precautionary measures.

What do I do if there is seasonal or swine flu in the schools or at my workplace?

There is no single recommendation that is applicable to every situation. Some medical advisors recommend that unless influenza is in their classroom children with primary immunodeficiency diseases should go to school. If there is a known direct contact with secretions from a flu-affected child or adult by the child with primary immunodeficiency, some medical advisors suggest that the child should go on Tamiflu once a day for 10 days. If the child with primary immunodeficiency disease develops symptoms of influenza, that child should go on Tamiflu twice a day for 10 days. Relenza could also be used as the anti-viral treatment. The same treatment recommendations should apply to adults with CVID. As stated earlier, only patients with the most severe forms of primary immunodeficiency diseases (babies with untreated SCID) need to strictly avoid contact with individuals recently immunized with FluMist. If you have any questions, please contact your specialist.

For more updated information on the flu, visit the CDC website: www.cdc.gov/flu/ or www.flu.gov
Before the Allen twins came to the National Institutes of Health (NIH) in 2011, severe eczema had dominated nearly every aspect of their lives. Their disease was more than the scaly rash most people are familiar with; it had progressed to the point where it was life-threatening. In addition health concerns, food purchases, employment decisions, sleep patterns, and the family budget were all affected by the twins’ condition.

“They were sick all the time,” said Crystal Allen, the twins’ mother. “They had MRSA a couple of times. When they came to NIH, they had blood poisoning from infections.”

Through a recommendation by their physician, the Allens met medical researchers, Joshua Milner, MD, and Kelly Stone, MD, at the NIH’s National Institute of Allergy and Infectious Diseases (NIAID). Drs. Milner and Stone study the immunology of allergic diseases, such as eczema, to find new ways of preventing and treating them. Dr. Milner is particularly interested in studying allergies in people with underlying primary immunodeficiency diseases (PIDD) such as Job’s syndrome.

“Eczema this severe is rare and often associated with an underlying immune deficiency disease,” said Dr. Milner. “What made the Allens’ case unusual was that the twins didn’t seem to have any evidence, such as an underlying disease”.

**Avoiding Harsh Medications and a Restrictive Diet**

Having suffered from severe eczema since they were infants, the Allen twins were taking numerous medications prior to coming to NIH. Tests had shown that the twins had high levels of immunoglobulin E (IgE), an antibody involved in triggering allergic reactions. To bring their IgE levels back to normal, doctors had prescribed the twins corticosteroids, strong antihistamines, and eventually cyclosporine, a powerful immune-suppressing drug commonly prescribed to transplant recipients. Nothing worked.

The twins also were on a restrictive and expensive diet that cut out certain foods thought to trigger eczema flare-ups. Unfortunately, the bland diet did not provide the nutrition the growing children needed and, more importantly, had little—if any—impact on improving their skin health.

Drs. Milner and Stone made some immediate changes in the twins’ treatment regimen soon after they checked into the NIH Clinical Center.

“One of the first things we did when they arrived was to take them off the various medications they were using,” said Dr. Milner. “Many of the drugs were very strong and not only were they not managing the eczema, we were concerned about the long-term impact they may have on the twins. The next thing we did was put them on a diet that was more nutritious and more interesting than what they had been used to, since foods rarely are the culprit when it comes to severe eczema.”

**Using Wet Wraps (and Training) to Soothe the Skin**

The next step was to introduce the Allens to an innovative treatment called wet wrap therapy. The key to this therapy is keeping the skin moist, which allows topical medicines to penetrate and soothe the scaly, weeping rashes associated with severe eczema.

After soaking in a lukewarm bath, the eczema patient receives an application of topical medicine and moisturizer on his or her skin. This skin treatment is followed by the wet wrap, which consists of wet gauze that covers the face, wet socks that cover the hands and feet, and wet long underwear or pajamas that cover the rest of the body. The person dresses in a layer of dry clothes and blankets to stay warm and remains covered for about two hours and, sometimes, overnight.

“We had recently visited National Jewish Health in Denver and were very impressed with how they were treating eczema with wet wrap therapy,” said Dr. Milner. “The treatment can greatly reduce eczema symptoms after only five days. Combining this intensive therapy with education on ongoing skin care has produced long-lasting results for our patients.”

Before and after photos of a pediatric eczema patient treated at the NIH Clinical Center using wet wrap therapy. Photo credit: National Institute of Allergy and Infectious Diseases.
Hope for
ma

Prior to coming to NIH, the twins’ eczema caused such intense nighttime itching that the twins only slept for short periods of time, leaving them and their parents chronically sleep-deprived. After two days of wet wrap treatment, the twins and their mother were sleeping through the night.

“The therapy is not a cure,” Dr. Milner added. “In most cases, patients will experience periodic flare-ups that need to be treated. This is why we devote a lot of time to training someone in the patient’s family on how to classify flare-ups and use the appropriate treatment. With a trained caregiver at home, the family can avoid certain medical expenses and structure the treatments to fit within the family routine.”

Advancing Eczema Research and Patient Care

NIAID’s eczema treatment protocol is part of a larger effort to better understand the causes of eczema and develop new strategies to prevent and treat the disease. The twins have been home for about a year. They still come to NIH for follow-up visits, but their eczema remains under control. Before their first treatment at NIH, the twins’ skin rashes were so pronounced that the school nurse could not manage their daily bouts of itching. Classmates and other parents worried that the eczema was contagious. As a result, the twins were home-schooled and had few friends outside the family. Now, they are back in school and are involved in many social and sporting activities that the twins and their parents never dreamed would be possible.

“It saved their life. Before they couldn’t do anything,” said Crystal Allen. “Our life has completely changed.”

After helping families like the Allens regain control over severe eczema, Drs. Milner and Stone are focusing on finding the underlying cause of why the Allens’ eczema is so severe, and turning their attention to people with known or suspected PIDD who also suffer from eczema.

“Eczema is associated with several PIDDs, and it can have effects on the patient’s quality of life as great or greater than the underlying PIDD,” said Dr. Milner. “We think that studying eczema in conjunction with these rare diseases may provide insights into the causes of eczema and other allergic conditions.”

For more information, visit: [http://www.niaid.nih.gov/topics/allergicDiseases/Pages/eczema.aspx](http://www.niaid.nih.gov/topics/allergicDiseases/Pages/eczema.aspx).

Make the Most of Your Appointment with the IDF eHealthRecord

Time with your healthcare provider is valuable, and planning for the visit can improve the experience and lead to better care for you. You can prepare for your visit by using the IDF eHealthRecord and following these suggestions:

**Use the IDF eHealthRecord on a regular basis.**
Keep track of your medications, infections, infusions, etc. with the IDF eHealthRecord. It can help you track your healthcare, and you can print reports to share at your visit. When your provider asks you - “How have you been?” – you will have an accurate and complete response.

**Prepare questions.**
Write a list of questions about your symptoms, medications, treatment – any topic concerning your health before your visit. Log into the eHealthRecord and review the information you have tracked. Preparing questions in advance will help you remember what you want to discuss, and it will help the visit move along smoothly.

**Minimize stress.**
Make the most of your time with your doctor by minimizing stress the day of the visit. Preparing with the eHealthRecord will help. Get any necessary insurance authorizations ahead of time. Silence your cell phone while you are in the provider office. If you are a parent, bring books, toys and/or snacks to keep your children calm. Minimizing stress will help you and your doctor concentrate on the visit.

**Ask for written instructions.**
Request written instructions concerning your medicines and treatments before you leave. This helps you avoid mistakes as well as gives you written instructions to be scanned and saved into your eHealthRecord account. In the event that you have a question or concern after your visit, make sure you know the best way to communicate with your provider.

Take advantage of the IDF eHealthRecord to make the most of the important time with your provider.

[www.IDFeHealthRecord.org](http://www.IDFeHealthRecord.org)
The IDF & USIDNET Visiting Professor Program

A Valued Experience for East Tennessee State University

IDF Medical Advisory Committee Member Kathleen Sullivan, MD, PhD, Chief, Division of Allergy and Immunology at the Children’s Hospital of Philadelphia, traveled to East Tennessee State University (ETSU) Quillen College of Medicine to serve as a Visiting Professor, September 4-6.

Her visit was a part of the IDF & USIDNET LeBien Visiting Professor Program through which teaching hospitals may present a leading clinical immunologist to lead Grand Rounds and present at other educational activities. According to David Kalwinsky, MD, FAAP, Professor and Chair of Pediatrics at ETSU, participating in the program was “a valued experience for our department.”

Upon meeting the faculty and residents, Dr. Sullivan said, “It is clear that the immune deficient patients get very high quality care and the physicians work hard to ensure that they have the best insights available.”

Dr. Sullivan’s expertise “provided a boost to our didactic coverage of pediatric immunology for our residents and students,” explains Dr. Kalwinsky.

Two Days in the Life of a Visiting Professor

During her brief visit, Dr. Sullivan’s packed schedule had multiple opportunities to help residents better understand primary immunodeficiency diseases. She shares her thoughts on each experience.

Wednesday, September 5
9:00 a.m. - Niswonger Children’s Hospital Case Presentation: Five-Year-Old with Frequent Pneumonias, Leukocytosis and Low IgG
10:00 – 11:00 a.m. - Discussion of above case with pediatric residents
“Dr. Williams, a resident, presented a very puzzling case. We went over the case as a group and talked about how primary immune deficiencies present in childhood and the appropriate tests to send when an immune deficiency is suspected.”

11:45 a.m. – 1:15 p.m. Pediatric Grand Rounds: DiGeorge syndrome
“I gave grand rounds on chromosome 22q11.2 deletion syndrome. Members of the audience asked very sophisticated questions and were interested in the natural history of the disorder. This talk was broadcast to other centers and a number of medical students attended.”

10:00 – 11:00 a.m. - Niswonger Children’s Hospital Case Presentation: Five-Year-Old with Frequent Pneumonias, Leukocytosis and Low IgG

12:30 – 3:00 p.m. Minigroup teaching with pediatric residents
“The afternoon ended with a two hour interactive discussion of presentations of primary immune deficiencies with the medical students and residents. The residents were impressively well informed and made astute clinical decisions on hypothetical cases. They also asked practical (and difficult!) questions. I always enjoy teaching residents, and this group was among the best I have interacted with.”

Thursday, September 6
9:30 – 11:30 a.m. Internal Medicine Rounds at Johnson City Medical Center (JCMC) with Balraj Singh, MD, Chief Resident of Internal Medicine
“Today was dedicated to internal medicine. I met with Dr. Singh who introduced me to the residents, and a case of Common Variable Immune Deficiency (CVID) was presented by a fourth year medical student … They picked a great case to present, and I think they left with a much better appreciation of the key disease features.”

12:30 – 3:00 p.m. Internal Medicine Lecture about systemic lupus erythematosus (SLE), followed by discussion
“In the afternoon, I gave internal medicine grand rounds and the resident group was very interactive. They had asked me to talk about SLE which is not an immune deficiency but is not infrequently associated with immune deficiencies. Once again, the residents impressed me with the sophistication of their questions.”
Visiting Professor Accepting Requests for 2013!

IDF is currently accepting Letters of Request for the IDF & USIDNET LeBien Visiting Professor Program for 2013. The purpose of this program is to increase knowledge about the diagnosis and treatment of patients with primary immunodeficiency diseases. It is available at no cost to teaching hospitals across the country.

For teaching hospitals interested in this program, please send a brief (one page) letter by January 18, 2013 stating your desire to participate in the program, how your training program would benefit from a visiting professorship, and a tentative list of teaching activities.

WITH GRATITUDE

Tribute Gifts – 4/15/12 - 10/1/12

In Memory Of:
Lila Albin
Allene C. Atwood
Barbara Boggetti
Bud Calkins
Lisa Codispoti
Erica Drapp
Joanne Finck
Harold “Bud” Finethy
Ruben Fletcher
Cameron Garcia
Dolores Y. Goldsmith
Ryan Gough
Joe Horn
Albert Johnson
Alvin M. Kendis
Thomas Marbach
Eric Marder
Kristin Martin
Ann Mozarki
Minnie Knuckles
Samantha Penn
Jacob Patriak
Rachel Roy
Richard Ryan
Kevin Scheper
Vincent Sherburne
Honey Wettstein
Rosemarie Willis

In Honor Of:
Chris Baer
Dan Bencher
John G. Boyle
Susan Branch
The Brock Family
Justin Cacucciolo

These donations help IDF 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 to http://primaryimmune.org/give or contact us:

Phone: 800.296.4433 or 410.321.6647
Monday - Friday, 9 a.m. - 5 p.m. (EST)
E-mail: idf@primaryimmune.org
Mail: IDF, 40 W. Chesapeake Ave., Suite 308 Town MD 21204

The Immune Deficiency Foundation welcomed Larry Stern, the former Chairman and CEO of Talecris, to the IDF office, June 20. IDF President & Founder Marcia Boyle recognized Larry for his dedication to IDF and patients with primary immunodeficiency diseases.

Daughter Donates Sweet Sixteen Gifts in Memory of Her Dad

Edith Sherburne of Saugerties, NY celebrated her Sweet Sixteen July 28 with a big backyard birthday bash, complete with fabulous food, games and fireworks. Many generous guests gave her monetary gifts. Like most teenagers Edith considered saving for a car or putting the money towards a new iPhone or computer.

Instead, Edith decided to honor her father, Vincent, who passed away in 2008. She donated her birthday money to the Immune Deficiency Foundation (IDF), specifically to help support IDF Teen Escapes.

Edith, a junior at Saugerties High School who plays trumpet and guitar, wanted to help another teenager. When she first heard about Teen Escape, IDF’s weekend program for teens living with primary immunodeficiency diseases, Edith knew that is where she wanted her birthday money to go.

Edith’s father, Vincent, was diagnosed with Common Variable Immune Deficiency (CVID). She remembers attending the IDF 2007 National Conference in St. Louis with her parents as a child. “It helped them both learn more about what my father was dealing with,” she explains. “I wanted to make this donation because I want someone my age to learn more about their disease.”

Her mother, Hazel, is proud of Edith’s kindness, “I am greatly blessed with kids who are such great human beings, and recognizing children who care about others encourages continued good works.”

Edith knows that her father would be proud of her, “He would be filled with happiness for me.”

Larry Stern Recognized for Dedication

The Immune Deficiency Foundation welcomed Larry Stern, the former Chairman and CEO of Talecris, to the IDF office, June 20. IDF President & Founder Marcia Boyle recognized Larry for his dedication to IDF and patients with primary immunodeficiency diseases.
ADA-SCID Patients:
Register with USIDNET!

If you have ADA deficiency or you know someone with ADA deficiency, please contact USIDNET (United States Immunodeficiency Network) to enroll in a natural history study: 800.296.4433 or contact@usidnet.org.

All patients with primary immunodeficiency diseases are encouraged to register with USIDNET. The more patients registered, the more possibilities exist for advancing research. It is simple, secure and cost free. Contact USIDNET today: 800.296.4433 or contact@usidnet.org.

For an Updated IDF Calendar of Events, Visit
www.primaryimmune.org/event-calendar.