Health Insurance: What You Need to Know before the End of the Year

As the end of 2016 approaches, there are certain questions you need to ask yourself about your health insurance. Regardless of how you and your family obtain your health insurance, it is ultimately your responsibility to understand your plan. It is up to you to choose the plan that is right for you and your family’s healthcare needs.

Understanding your plan can have a huge impact on both your health and your finances.

What should I consider during open enrollment when my employer is offering new plans?

Individuals affected by primary immunodeficiency diseases (PI) need to make educated decisions about their coverage options. Do a thorough plan comparison to determine what plan best fits your needs. Things to look at include:

- What is my premium?
- What is my out-of-pocket maximum?
- What are my deductibles?
- Is deductible included in the out-of-pocket maximum or is it in addition to the maximum?
- How is immunoglobulin (Ig) covered?
- Do I have a coinsurance or a flat co-pay?
- Do I have options for site of care?
- Are my doctors in the plan’s network?
- Are there out-of-network benefits?

You may need to contact the insurance carrier or get assistance from your benefits or human resources department in obtaining the answers to these questions. Once you have these questions answered, you can make an informed choice.

What do I do if I’ve met my annual deductible for 2016?

If you have met your annual deductible for 2016, this is a time to consider scheduling any medical treatments you still need. When a new calendar year begins, out-of-pocket limits and deductibles reset. This may be a good time to consider what treatments or services you could schedule before the end of the year that would be covered under your plan. If you have questions about determining if you’ve met your deductible, contact your insurance carrier, or, if you get health insurance through your employer, talk with your benefits or human resources department for assistance.

What if I’m eligible for Medicare?

Similar to choosing a plan from your employer, you need to do a thorough evaluation of the choices to determine the plan that works best for you. There are many options when it comes to Medicare coverage. Ask yourself the same questions as noted previously when you choose a plan.

Why I Walk:

“I wanted to get the word out and make a difference.”

Lois Crudden shares her story of IDF Walk for Primary Immunodeficiency on page 2.
Health Insurance: What You Need to Know before the End of the Year

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If you receive Ig therapy, check out how your treatment will be covered. Ig therapy, whether intravenous (IVIG) or subcutaneous (SCIG), will be covered under the traditional Medicare Part B medical benefit. This is only covered at 80%, requiring patients to obtain a supplemental/medigap plan to cover the remaining amount. Another option is a Medicare Advantage plan (Part C). These plans are sold as an “all in one policy” and act more like a private insurance. According to Medicare regulations, the managed care plans must provide enrollees with all Part A and Part B benefits. However, Medicare Advantage plans are not required to provide enrollees the same access to providers that is provided under original Medicare.

The cost for your treatment is dependent upon the plan design. You could have a flat $20 copay, or you could be responsible for a percentage of the cost (co-insurance). Over the past few years, patients with Medicare Advantage plans have reported to IDF that most have a 20 to 30% co-insurance for treatment. Unfortunately, most of these patients picked the Medicare Advantage plan thinking it acted the same as traditional Medicare Part B and a secondary plan. Don’t forget that if you choose an advantage plan, you are not eligible to obtain a secondary policy. Make sure you know the coverage before enrolling.

Since Medicare plans vary from state to state and even by counties within a state, you need to research what plans you are eligible for. You can contact your State Health Insurance Assistance Program (SHIP) to find trained counselors who can tell you the plans you are eligible for and assist you in finding the answers to your questions regarding coverage. To find your state’s SHIP program contact information, go to http://bit.ly/SHIPprograms.

What will happen to my Flexible Spending Account funds?

If you’ve been utilizing a Flexible Spending Account (FSA) or Health Savings Account (HSA), you will want to check on your FSA. An FSA is an account offered and administered by employers that allow employees to set aside pre-tax dollars out of their paycheck to pay for the employee’s share of insurance premiums or medical expenses not covered by the employer’s health plan. Typically, benefits or cash must be used within the given benefit year or the employee loses the money. In the past few years a new rule was created where employers can allow you to carry over up to $550 of your FSA balance from one year to the next. So the end of the year is a perfect time to check your account and check with your benefits or human resources department to see if their plan allows this rollover.

An HSA is a medical savings account available to individuals enrolled in a high-deductible health plan that meets certain federal rules for out-of-pocket costs. The funds contributed to an account are not subject to federal income tax at the time of deposit. HSAs are employer-established benefit plans that reimburse employees for specified medical expenses as they are incurred, and the employee contributes funds to the account through a salary reduction agreement and is able to withdraw the funds set aside to pay for medical bills. Funds roll over year to year if you don’t spend them.

What if I have more questions?

IDF is here for you! The IDF Health Insurance Toolkit can provide you with information and resources, including comparison worksheets, to help you understand health insurance plans and make the best possible choice in your selection. Download your toolkit at the IDF Patient Insurance Center today: www.primaryimmune.org/patient-insurance-center.

If you have further questions, contact IDF: 800-296-4433 or www.primaryimmune.org/ask-idf.

Why I Walk: “I wanted to get the word out and make a difference.”

By Lois Crudden

My name is Lois Crudden. I received a diagnosis of Common Variable Immune Deficiency (CVID) in 2005 after being sick since a very young age. I was always in the hospital receiving test after test, but each one came back negative. As the years went on, I began having more serious problems and ended up with several chronic diseases until I was eventually diagnosed with a primary immunodeficiency (PI) and began immunoglobulin treatment.

After many years of fighting the struggles of PI, I was introduced to IDF and attended the IDF Retreat in Boston in June 2016, where I learned that I am not the only person going through this and there is just not enough information about PI in the public. There is such a need to get the word out about these diseases.

Because of this need, I joined IDF Walk for Primary Immunodeficiency. At first, it was very difficult for me to raise money for the walk because of the lack of knowledge of PI within my network. I continued my fight to raise money for the walk because I felt
“Priceless” Experiences: IDF Retreats 2016
Boston and Salt Lake City

This summer, nearly 500 people from 36 states and Canada attended the IDF Retreats held in Boston, MA, June 17-19, and Salt Lake City, UT, August 19-21. These weekend getaways gave individuals and families living with primary immunodeficiency diseases (PI) the unique opportunity to learn the latest in diagnosis and treatment, all while connecting with others.

One attendee said, “Thank you so much for everything! These retreats are priceless—we always learn so much and love helping others now.”

From children to adults, IDF Retreats provided sessions for all ages. Healthcare and life management experts volunteered their time and knowledge to provide the most current and authoritative information, encouraging questions throughout their presentations. While the adults listened to the presenters, youth participated in educational and fun activities.

Perhaps one of the favorite aspects of the Retreats were the opportunities to meet and talk with others from the PI community. The Networking Groups for parents, patients and partners may have started the conversation, but discussions about living with PI and shared experiences continued throughout the weekends. These retreats created rare experiences for people of all ages to meet others with whom they can relate.

IDF National Conferences and IDF Retreats are held in alternating years. The IDF 2017 National Conference will be held June 15-17, 2017, and the next IDF Retreats will be held in 2018, dates and sites to be announced.

Thank You to the Presenters at the IDF Retreats 2016!

Daniel Ambruso, MD
Children’s Hospital Colorado

John F. Bohnsack, MD
University of Utah Health Care

Francisco Bonilla, MD, PhD
Boston Children’s Hospital

Karin Chen, MD
University of Utah Health Care

Colleen H. Dansereau, MSN, RN, CPHN
Dana-Farber Boston Children’s Cancer and Blood Disorders Center

Kristin Epland, FNP-C
Midwest Immunology Clinic

Adi Gundlapalli, MD, PhD
University of Utah Health Care

Terry Harville, MD, PhD
University of Arkansas for Medical Sciences

Anna Kovalszki, MD
Beth Israel Medical Center

Peter Mannon, MD, MPH
University of Alabama, Birmingham

Ralph Palmer, MA
Professional Counselor

Jennifer Puck, MD
University of California – San Francisco

Jolan Walter, MD, PhD
Massachusetts General Hospital

Linda Schneider, BSN, RN, CPN, IgCN
The Children’s Hospital of Philadelphia

Jodi Taub, LCSW, LLC
Private Practice

IDF Retreats were supported by charitable donations from CSL Behring, Grifols, Shire, Horizon Pharma, IgG America | ASD Healthcare | US Bioservices, and Sigma-Tau Pharmaceuticals.

The Special CGD Session was sponsored by Horizon Pharma.

The Young Adult Session was sponsored by CSL Behring.

The SCID Session for Young Adults & Older Teens was sponsored by Sigma-Tau Pharmaceuticals.

Thank you to Lois for sharing your inspirational story and your efforts to help future generations!

As of November 1, Lois has helped raise $3,160 for IDF. Way to go!

www.walkforPI.org
Dealing with Fatigue: What You Can Do

People with primary immunodeficiency diseases (PI) can experience fatigue, which is the feeling of tiredness, lack of energy and/or general weariness that does not seem to go away. Although some degree of fatigue may be common among people with PI and other chronic illnesses, it’s important to never assume that fatigue “goes with the disease” and that there is nothing that can be done about it.

First, you should try to figure out why you are fatigued. Obviously, when you don’t feel well or have an active infection, you are tired. It is a normal body response. But if you don’t have an infection and are tired, then other causes of fatigue need to be considered. You should consult your healthcare provider, as there may be another medical reason for your fatigue. For example, your provider might want to check to see if you are anemic. Anemia is a decreased number of red blood cells or a decreased amount of hemoglobin. This can lead to a reduced amount of oxygen able to be carried by the blood to the tissues and organs, which need oxygen to function. Your healthcare provider can determine if you are anemic and what the specific cause of your anemia is. Treatment options may be relatively simple. If your anemia is caused by a lack of iron, adding a daily iron supplement might be the recommended treatment.

Depression can also be a source of fatigue. The relatively high incidence of depression in people with chronic illness is well documented in scientific literature. Your clinician can help to determine if you are depressed and suggest ways of treating it.

Another source of fatigue can be stress. The importance of a healthy lifestyle which includes a balanced diet, adequate rest and exercise cannot be underestimated as a stress reducer. You should attempt to identify your stressors and seek ways to eliminate them or reduce their effect on you.

5 Tips for Fighting Fatigue

Here are some overall tips on how to improve your energy levels and combat fatigue. As always, consult your healthcare provider to determine what is best for you.

• Adjust Your Diet
Try to eat smaller meals spread out through your day to boost metabolism, blood sugar and keep energy up. Also, avoid overeating as this, in itself, can cause fatigue and can drain your energy. Just think how tired everyone is after Thanksgiving dinner! A healthy diet can provide the nutrients essential for normal growth and development, body repair and maintenance. Your primary healthcare provider is an excellent resource for direction and advice regarding a healthy diet.

• Get Some Sleep
Setting a pattern for your sleeping habits can improve the quality of your sleep, especially if you are getting to bed early enough. Most scientists recommend a consistent number of hours of sleep per night, and consistent bed times and waking times, as well. Try to go to sleep and wake up at roughly the same time each day, even on weekends or when you are on vacation.

• Get Moving
Studies have shown that physical activity, such as exercise or yoga, can jump start your energy levels. Each morning, try to fight off the early morning fatigue by doing some type of exercise and getting your body warmed up. Physical activity should be a part of everyone’s life whether they are immunocompetent or immunodeficient. Not only is physical exercise good for the body, it is good for the mind, as well. Your primary healthcare provider can recommend an exercise program for you.

• Give Yourself a Break
Take a few minutes during the middle of your day to unwind. Sometimes, a few deep breaths or a short walk is all it takes to de-stress. Some people find that their productivity and energy levels increase after they take a break. Others feel a sense of accomplishment if they have made a “To Do” list and can cross off the tasks they have completed.

• Power Down
Sleep time should be No Power Hours. Melatonin is one of the body chemicals that needs to rise in order for you to fall and stay asleep. Light can keep your melatonin levels from rising. Similarly, gaming or other electronic activities can “rev” you up rather than calm you down. Your sleep routine should always include a period of time to calm down and relax. Each night, turn off all electronics an hour before you go to bed; this may help you to get the restorative sleep your body needs.

The bottom line is to discuss your fatigue with your healthcare provider. Together see if you can determine what is causing it and make a plan for how to prevent it or reduce the effect that it has on your life.

Keep Your Health Info at Your Fingertips
Download the IDF ePHR App

Download the mobile app for IDF ePHR, the electronic personal health record specifically designed for the primary immunodeficiency community. Easily keep track of your health information from your computer, tablet or smartphone!

Visit the App Store or Google Play Store and search for “IDF ePHR.”
Questions? Contact us at info@idfeehr.org or 800-296-4433.

IDF ePHR is exclusively sponsored by CSL Behring.
Updated Flu Information for 2016-2017

Nasal Spray Influenza Vaccine NOT Recommended for the Upcoming Flu Season

For the 2016-2017 Flu Season, IDF has published recommendations for patients with primary immunodeficiency diseases and their families, including prevention, vaccination and creating a family plan.

Also, please note, this season, the Centers for Disease Control and Prevention’s Advisory Committee on Immunization Practices (ACIP) has recommended that the nasal spray influenza vaccine not be used.

To read IDF’s 2016-2017 Flu information, go to www.primaryimmune.org/flu.

IDF Young Adult Webinar Series

Videos Available Online

The years of your life when you’re determining who you are and who you want to be can be challenging, which is why having a community to support, guide and answer your questions can be crucial to growth and success.

With this in mind, the IDF Young Adult Webinar Series was developed to specifically meet the needs and interests of young adults (ages 18-30) living with primary immunodeficiency diseases (PI). In 2016 five live webinars were held. Presenters and participants alike asked and answered questions, discussed concerns, shared stories, and connected with people who are living with the unique challenges that young adults with PI face.

To date, IDF has posted these webinar recordings on the IDF website, and they are available for anyone to view. These webinars cross a wide range of topics for young adults, including:

- Managing Your Career as a Young Adult with PI
- Fitting Your Medical Care into a Busy Life
- Health Insurance – Get the Facts
- Family Planning and PI
- Balancing Your Health and Your Social Life

To learn more about this program or to listen to webinar recordings, go to: www.primaryimmune.org/young-adult/webinars.

This program is supported by a charitable donation from CSL Behring.
Many people living with primary immunodeficiency diseases (PI) receive immunoglobulin (Ig) therapy, created from plasma collected from plasma centers across the country. Because they will depend upon this therapy for the rest of their lives, members of the PI community have a special relationship with plasma donors—what we like to call a special “vein to vein” connection. For over a decade IDF has worked with plasma centers to link plasma donors, center staff and the communities that surround those centers to people living with PI through the IDF Plasma Partners Program.

At the core of the IDF Plasma Partner Program are the amazing volunteers that IDF arranges to visit participating plasma centers. These dedicated volunteers share their experiences about living with PI and receiving the lifesaving Ig therapy that is derived from donated plasma. Those centers, in turn, use those visits as an opportunity to conduct activities that increase awareness of PI and raise funds for IDF.

The IDF Plasma Partner Program gives plasma donors and center staff an opportunity to see the vital role they play in the lives of people affected by PI. At the same time, members of the PI community gain a better understanding of the importance of plasma donation and learn first-hand about the regulations in place to produce the safest, highest quality plasma for their life-saving therapies.

Since 2005, inspired employees have helped to raise over $1 million for IDF. We applaud the continued commitment and look forward to a promising future for the efforts of the following plasma companies that have recently held fundraising and awareness raising events on behalf of IDF:

- BioLife Plasma Services
- Biotest Plasma Centers
- CSL Plasma
- Grifols

To learn more about the IDF Plasma Partners Program, go to: www.primaryimmune.org/idf-plasma-partners-program.

Spotlight on IDF Plasma Partner

Sonya Williams
Senior Manager, Corporate Communications and Community Relations, CSL Plasma

“I have had the privilege to work with IDF for over eight years. Part of this time has been spearheading our annual IDF fundraising campaign in which donors and employees participate. This spring, U.S. CSL Plasma donors and employees donated over $118,000 to IDF. Each location conducted their own fundraisers, which included bake sales, pie toss events, mini-carnivals, dunking booths and much more.

It has been an honor for me to meet and talk to many of the IDF patients and their families. Each person has their own, compelling story about how plasma-derived therapies has helped save or improve their lives. To hear what life was like before and after receiving a plasma-based therapy is life-changing. Each day that I come to work, I think about the patients and each unique story. It gives me personal and professional satisfaction knowing that I have made a difference in this world.”

Special thanks to Sonya and the entire team at CSL Plasma for their record-breaking fundraising and inspirational enthusiasm year after year! Pictured above, Sonya during one of the many center fundraisers CSL Plasma holds to raise money for IDF.
Don’t Miss the Largest Gathering of People Living with PI in the World!

The IDF 2017 National Conference promises to be another extraordinary event! Featuring valuable opportunities for members of the PI community to learn from world-renowned immunologists, attendees will learn about scientific advancements in the diagnosis and treatment of PI and gain the skills needed to manage their healthcare.

Individuals and families will benefit from the opportunity to meet others and enjoy the festivities of social events, as well as talk with the faculty and sponsors in the interactive exhibit hall. Save the date, and look for more details to come!

**Register Now!**

**IDF National Conference 2017**

Anaheim, CA / June 15-17, 2017

Registration begins February 2017

Your Support Changes Lives

Thousands of individuals and families living with primary immunodeficiency diseases (PI) count on the Immune Deficiency Foundation, and we in turn count on you. With your support, we are changing lives. In fact, we’ve already accomplished so much this year. Here are some examples:

- More than 160,000 IDF educational materials have already been distributed to members of the PI community.
- Nearly 7,500 patients and healthcare professionals have attended more than 105 IDF educational presentations in 56 cities in 28 states.
- IDF’s patient advocacy services have helped fulfill nearly 7,000 requests from patients and families seeking education, information and assistance. Locating a specialist is currently the number one need with almost 1,000 requests.
- IDF Peer Support volunteers have offered one-to-one encouragement to 220 individuals.
- Once again, IDF was awarded a 4-Star Rating from Charity Navigator, America’s largest independent charity evaluator. This top distinction is awarded for sound fiscal management practices and commitment to accountability and transparency.

Your support can help ensure the important work of IDF can continue. Will you make a donation to IDF this year, ensuring that many more will receive the resources they need and richly deserve?

Simply complete and return the enclosed envelope, or donate online at: [www.primaryimmune.org/appeal](http://www.primaryimmune.org/appeal).

Thank you for your generosity and commitment to changing lives!
IDF SCID Newborn Screening Campaign: 42 States Currently Screening for SCID, Covering 88% of All Births in the U.S.

The IDF SCID Newborn Screening Campaign works to establish newborn screening programs for Severe Combined Immune Deficiency (SCID), a primary immunodeficiency disease, in all 50 states. Affected infants lack T lymphocytes, the white blood cells that help resist infections due to a wide array of viruses, bacteria and fungi. Babies with SCID appear healthy at birth, but without early treatment, most often by bone marrow transplant from a healthy donor, these infants cannot survive.

We are now in the home stretch to get every state to fully implement newborn screening for SCID. There are eight states not currently screening for SCID: five are in the process of implementing screening and three do not have concrete plans:

- North Carolina has begun their pilot study and plans on full implementation in 2017.
- Nevada, Kansas, Missouri and Alabama have plans to begin their pilots in 2017.
- Arizona, Indiana and Louisiana are not screening or implementing actual plans to screen.

IDF is focusing its efforts on getting Arizona and Indiana to screen all babies for SCID. To advance efforts in Arizona, IDF presented at an Arizona SCID Awareness Week event sponsored by the Arizona Department of Health on October 20, 2016. IDF also had productive meetings with the Governor’s office and health department. Drs. Rebecca Buckley and Jennifer Puck of the IDF Medical Advisory Committee also presented at the events. Only infants born on the Arizona Navajo Nation Reservation are currently being screened. We are also collaborating with the March of Dimes in Arizona to address the barriers to implementation.

In Indiana, we are working with the Indiana State Medical Association and March of Dimes to urge the Governor to use his authority to implement screening. Families impacted by SCID are telling their stories to make the case that screening saves lives and saves the state millions in healthcare costs. The IDF community in Indiana and Arizona will be called upon to support these efforts by responding to IDF Action Alerts to contact key decision makers.

Louisiana received a grant from the CDC; however, there are major financial problems as well as recovery from the recent devastating floods that are the primary focus of the state. IDF and volunteers are still working to help the state move forward.

To stay updated, follow the IDF SCID Newborn Screening Blog: www.idfscidnewbornscreening.org.

The IDF SCID Newborn Screening Blog is sponsored in part by PerkinElmer and Sigma-Tau Pharmaceuticals, Inc.

Want Public Officials to Hear Your Voice? Sign Up for IDF Action Alerts

Be notified when your voice can make a difference! When there is a public policy issue affecting the PI community, we will send an IDF Action Alert directly to your inbox. All the background information, and a sample of what you need to say and do is all right there. Simply customize each alert with your name and contact information, and hit send.

To sign up, go to: www.primaryimmune.org/action-alerts.
1. What is newborn screening?
All babies born in the U.S. undergo newborn screening (NBS) in the first days of life. NBS consists of a panel of laboratory tests for a variety of genetic or metabolic disorders, and more recently some immunologic disorders, which without intervention may permanently impact newborns and their families. For example, there is a test for phenylketonuria (PKU) as well as tests for hemoglobin disorders (sickle cell disease), hormonal insufficiency (hypothyroidism) and Severe Combined Immunodeficiency (SCID) or other causes of a low lymphocyte count. The most common way NBS is performed is by heel stick to collect drops of blood onto a filter paper called a Guthrie card, which is then sent to the state Department of Health for processing and interpretation. Although NBS is mandatory, each state develops and manages its own program, and determines how many disorders are tested. Most states screen for a standard number of conditions, but some states may screen for more or less. Remember that any abnormal NBS result should be followed up with an examination and additional confirmatory testing by an experienced healthcare provider such as an immunologist in the case of a positive SCID screen.

2. Why is early diagnosis of SCID important?
SCID, a group of genetic diseases that are fatal in infancy if left untreated, has been characterized in the medical community as a pediatric emergency. However, if a baby with SCID receives a bone marrow transplant in the first 3.5 months of life, the survival rate can be as high as 94%. Early recognition and treatment of SCID, as well as the other disorders identified through NBS, can lead to a better outcome for the baby.

3. What has newborn screening taught us about SCID?
In 2010, the U.S. Department of Health and Human Services recommended that all states include SCID screening in their NBS programs. SCID is a group of disorders caused by mutations in a number of different genes, all of which have very low or absent T cells, resulting in death unless immune reconstitution can be achieved by a bone marrow transplant or possibly gene therapy very early in life. Prior to newborn screening for SCID, the estimated annual incidence of SCID in the U.S. was approximately 1 in 100,000 live births, or a total of approximately 40 new cases annually. As more states screen for SCID, it is becoming clear that SCID incidence is higher than previously thought. In fact, in New York State, the incidence is 1 in 48,500 lives births. In 11 states routinely screening, the incidence was 1 in 58,000 in 3,030,083 infants. Screening for SCID is feasible, cost-effective, facilitates timely referral for confirmatory immunologic evaluation and therapeutic intervention if indicated, which greatly improves clinical outcomes. SCID screening is now being conducted or planned to begin in all but three states.

4. What other types of PI can be identified by SCID newborn screening?
The SCID NBS test measures circular pieces of DNA called TREC within newly developed T cells that have recently entered the bloodstream from the thymus gland. Therefore, any disorder characterized by low T cell numbers can have low TREC. For example, a PI such as DiGeorge Syndrome has been detected frequently in SCID NBS programs, whereas PIs that do not result in low T cells, such as X-linked agammaglobulinemia or Chronic Granulomatous Disease, are not detected. There are other diseases such as Ataxia-Telangiectasia and Down’s syndrome or Trisomy 21 that have also been detected by this test. Therefore, all infants with positive TREC screening should be evaluated by an immunologist before any treatment considerations are made, so as to make certain of the correct diagnosis.

Currently, no U.S. state screens for a PI other than SCID in routine NBS. However, researchers have shown that the technique used for SCID screening can also be adapted to PI characterized by low B cells. Similar to T cells, B cells also undergo maturational steps during their development resulting in the formation of B-cell kappa chain excision circles, or KREC that can be measured during NBS. Some European countries have started pilot programs to screen for PIs with low B cells at birth, and the results of such pilot programs have been promising. A current shortcoming is that PIs associated with decreased or absent antibody production but not low B cells, such as Common Variable Immunodeficiency, would be missed by such strategies. Being able to expand NBS to include other types of PIs without low T or B cells is an active area of research.

5. What does the future hold for newborn screening of other types of PI?
All primary immunodeficiency diseases, not just SCID, stand to benefit from early diagnosis. Continued advances in molecular technology may soon allow screening for other types of PI. Moreover, it is possible that future newborns will have extensive testing for known genetic mutations that cause PI or even eventually sequencing of their entire genome. Even predisposition to the more common multifactorial immune disorders with later onset may become possible through deep sequence analysis of DNA from newborns. However, since the mere presence of a mutation does not fully predict phenotype for these conditions, much more needs to be learned about the true predictive value of each proposed type of screening.

Want to learn more about the underlying biology for SCID newborn screening? Read these questions and more on the IDF SCID Newborn Screening Blog: www.idfscidnewbornscreening.org.
Each year leading companies in the healthcare industry provide support to the Immune Deficiency Foundation (IDF). Without such funding, IDF would be unable to provide our community with many of the services, resources and programs that contribute to the improved quality of life for the individuals and families of those living with primary immunodeficiency diseases.

IDF Core Service Sponsors are dedicated partners that support IDF at the highest level. They help fund direct services that offer peer support, help locate a specialist and offer information on dealing with health insurance issues. Local IDF patient meetings are offered throughout the country because of their generosity. They support medical and scientific programs like the IDF Consulting Immunologist Program and the IDF & USIDNET LeBien Visiting Professor Program, as well as IDF exhibits at medical meetings.

Funding from sponsors allows IDF to provide services and publications free of charge to our community.

Our sponsors understand the chronic nature of primary immunodeficiency. Because the diseases never go away, individuals and their families will continually rely on IDF, and the Foundation extends sincere appreciation to these companies for their continual support to make this possible.

**IDF Core Service Leaders**

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