

# IDF ADVOCATE

THE NATIONAL NEWSLETTER OF THE IMMUNE DEFICIENCY FOUNDATION

## MANAGING MULTIPLE **MEDICAL PROBLEMS**



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The national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

# Letter from IDF President & CEO John G. Boyle

## Sometimes You Want to Fight

As we grow up, most of our parents tell us that fighting has never solved anything. Well... not my parents. For nearly my entire life, my parents have been fighting for people living with primary immunodeficiency (PI), founding IDF in 1980. Unlike many in our community, I have never remembered a point in my life without this. I was diagnosed with X-linked Agammaglobulinemia (XLA) at six months old.

My family and I have fought most of those fights for the PI community ourselves. I've always been surrounded by people who are grappling with PI, day in and day out. The years go on, **but the fight remains the same.**

Many of you who were at the IDF 2019 National Conference in National Harbor, MD will have heard these words before. I spoke about this during the opening session there, but it is worth repeating. This fight, it's ours. And we have to be there for one another, picking each other back up, standing behind our fellow zebras, and always advocating for those who are fighting alongside of us.

Unfortunately, I can't tell you that these fights will ever stop. But, I can tell you that as long as you are willing to fight for yourself and your loved ones living with PI, we'll be there to back you up. IDF has been fighting for those with PI for 40 years. And we're now at a turning point.

We have to raise awareness of what PI is for those who have never heard of it, or are misusing and misrepresenting us in the media. We have to bring understanding to our own community, including our family and friends. We have to push for better diagnosis and treatments. We must accelerate research and make our voices and experiences heard. We must fight.

Some rare disease communities have come together so completely that they have the critical mass that's needed to truly affect change. They fill clinical trials, they get folks to swarm their legislators, they do things that we're not yet able to do.

We have yet to hit that point of critical mass, but we CAN. There are 250,000 of us in the U.S. alone. That's one in 1,200 people. And we need each and every last one of you to take part, to affect change.

At the end of the day, so many things come down to having the numbers on your side. That's true of research: the more people who are available to participate, the faster it'll go. It's also true of fights. When there's a legislative fight, an insurance fight, or anything else – we need overwhelming force. We need to invite them in. Call on your friends on Facebook, reach out to someone you met at your doctor's office, leave materials at your immunologists. If you do, you'll not only be helping them. You'll be helping us build that critical mass. Once our community is together – once we have more of those 250,000 people – the research will accelerate, the fights will be easier to win.



We'll do all that we can at IDF, but we need you to back us up. We need you to be ready to fight.

A handwritten signature of John G. Boyle in black ink.

**John G. Boyle**  
IDF President & CEO

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See You on Social Media  
**@IDFcommunity**

# FIND ONLINE

*Your Requests, Our Answers*



[www.primaryimmune.org/find-online](http://www.primaryimmune.org/find-online)

## Where can I find the latest information about the immunoglobulin product shortage?

Since January 2019, IDF has been providing updates on the immunoglobulin (Ig) product shortage. As we've seen, this shortage has caused some turbulence in the lives of those living with PI who rely on lifesaving treatments derived from Ig. To hear the latest news about this issue, visit: [www.primaryimmune.org/shortage](http://www.primaryimmune.org/shortage).

## I missed my insurance Open Enrollment this year, but I want to be ready for next year. What resources can I use?

Health insurance is one of the most crucial things for those who are living with PI, and determining which plan is appropriate and will work best for you and your needs can be a difficult process. Be ready to tackle Open Enrollment next year: [www.primaryimmune.org/chooseaplan](http://www.primaryimmune.org/chooseaplan).

## I'm ready to make a difference, but I'm not sure how I'll best benefit the PI community. How can I help?

Whether you volunteer for an hour or make a commitment over many months, your time is greatly appreciated and can affect change. There are many opportunities to get involved and serve the PI community, and you can find them at: [www.primaryimmune.org/volunteer](http://www.primaryimmune.org/volunteer).

## I recently found your organization, but I'm still searching for a diagnosis. Where can I find advice?

Welcome to the PI community! There are various ways to diagnose the more than 350 types of primary immunodeficiency disease. You can find those, as well as specific diagnosis information for many types of PI, here: [www.primaryimmune.org/aboutPI](http://www.primaryimmune.org/aboutPI).

## I didn't attend the IDF 2019 National Conference, but I want to attend in 2021! Where will it be?

The IDF 2021 National Conference location was announced as Dallas, TX and will be held June 24-26, 2021. In the meantime, if you want to attend an event with IDF before 2021, take a look at our Calendar of Events for more opportunities to meet up with the PI community before then: [www.primaryimmune.org/events](http://www.primaryimmune.org/events).

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# Managing Multiple Medical Problems

By: Andrew Pugliese, MD



Primary immunodeficiency diseases (PI) can be difficult for many, but it also may only be one of several diseases that they are trying to manage simultaneously. Over the past decade, people dealing with multiple chronic conditions (MCC) has escalated dramatically. MCC is defined as two or greater chronic conditions simultaneously occurring. This has become a public health problem which offers significant medical challenges to our healthcare system.

The most common reason for this dynamic change to MCC being more prevalent is due to an increase in life expectancy, which contributed greatly to our aging population. Several examples include a decrease in childhood fatalities because of better infant care through the use of vaccines and cancer screening, such as mammograms, colonoscopies, and PSA testing in adults. Other contributing factors include cholesterol screening, management of hypertension, smoking cessation, and diabetes screening.

By definition, a chronic illness is a condition that lasts more than one year. In my practice, a significant majority of my patients with an underlying PI have other related or unrelated chronic conditions that make managing their underlying PI more difficult. See figure 1.1 for a list of other chronic conditions.

Unfortunately, many that have MCC may suffer from suboptimal care according to an article published in Public Health Reports 2011 titled *Managing Chronic Medical Problems: A Strategic Framework in Health Outcomes and Quality of Life*. As stated in the article, healthcare systems have been dependent on outdated medical models. In these medical models, each medical condition is handled separately in a linear fashion with no regard for how these other chronic conditions may impact other chronic conditions the patient has or vice versa. This leads to many frustrated patients. Despite getting treatment they still cannot achieve the quality of life they expect.

As stated in the article, this is a significant problem affecting at least one in four Americans alive today, and it's estimated that at least two-thirds of older adults suffer from MCC. Problems that result from MCC are directly related to the number of conditions that individuals are dealing with. Complications include "increased mortality, poor functional status, unnecessary hospitalization, adverse drug events and conflicting medical advice."

Recently, several of my patients who had biopsy-proven autoimmune diseases had their findings dismissed by other specialists because serologies for their particular disease state were negative.

Another area of concern is the designs of clinical trials today, especially when it comes to the use of new medications. In many of these clinical trials, exclusion criteria may leave out certain patients from the study pool because of an underlying condition

## Chronic Conditions Associated with PI

These are examples of secondary chronic conditions that have been found in my patients with a diagnosis of PI.

Chronic Bronchitis Obliterans

Asthma

Chronic Rhinosinusitis

Allergic Fungal Sinusitis

Gastro-Esophageal Reflux Disease (GERD)

Scleroderma

Inflammatory Bowel Disease (IBD)

Celiac Disease

Diabetes Mellitus

Diabetes Insipidus

Hypothyroidism

Hashimoto's Thyroiditis

Adrenal Insufficiency

Psoriatic Arthritis

Psoriasis

Sjogren's

Lupus

Rheumatoid Arthritis

HIV/AIDS

Mast Cell Dysfunction

Paroxysmal Orthostatic Tachycardia Syndrome (POTS)

Gammanopathies including Multiple Myeloma

Fatty Liver Disease

Alpha 1 antitrypsin Deficiency

Obstructive Sleep Apnea (OSA)

Hypertension

Multiple Sclerosis

or disease. What happens in these instances is that the study population is small compared to what is being seen in the general population. This may give an incomplete picture of how effective a certain treatment regimen may be in the general population.

For example, several years ago our practice was involved in a clinical trial for a new treatment for *C. difficile*, the pathogen involved with antibiotic-associated diarrhea and colitis. Several patients had developed *C. difficile* but were excluded from the study because the patient had an underlying PI. The question now becomes just how effective is this medication in those with PI and will insurance companies understand if there is treatment failure initially.

Over the past several years, the Department of Health and Human Services (HHS) has offered some modeling to improve integration of healthcare and patients dealing with multiple medical chronic conditions. Listed below is the framework that The HHS Interagency Workshop on Multiple Chronic Conditions has developed in dealing with patients with multiple medical problems. These include:

*"(1) foster healthcare and public health system changes to improve the health of individuals with MCC; (2) maximize the use of proven self-care management and other services by individuals with MCC; (3) provide better tools and information to healthcare, public health, and social services workers who deliver care to individuals with MCC; (4) facilitate research to fill the knowledge gaps about and intervention and systems to benefit individuals with MCC" (Parekh et al., 2011).*

As can be seen from this modeling, the challenges are lofty and will become greater as time goes on and we identify more individuals with chronic illnesses who will live longer. The challenges for the PI community, and organizations like IDF, will be to implement some of these changes to provide better guidance for patients and their providers who are living with PI and other chronic medical conditions that are making the management of their PI more difficult.

## About Dr. Andrew Pugliese, MD

I am a passionate blogger, author, speaker and 3X Board Certified MD in Infectious Disease, Internal & Sleep Medicine. I currently am an infectious disease physician in Atlanta, GA for Infectious Disease Consultants. I currently serve as President of Sinus Solutions LLC and I'm a pioneer in the non-surgical treatment of acute and chronic sinusitis. I write an informative medical blog ([www.theiddoc.com](http://www.theiddoc.com)) that focuses on underlying causes, detection and treatment of numerous infectious diseases.

## References:

Parekh, A. K., Goodman, R. A., Gordon, C., Koh, H. K., & HHS Interagency Workgroup on Multiple Chronic Conditions (2011). Managing multiple chronic conditions: a strategic framework for improving health outcomes and quality of life. *Public health reports (Washington, D.C. : 1974)*, 126(4), 460–471. doi:10.1177/003335491112600403

## Why You Should Understand Your Health Insurance



As 2020 draws near, there are certain questions you should be asking yourself about health insurance. Regardless of how you and your family obtain your health insurance, it's still ultimately up to you to understand your plan and how it will work in regards to living with a primary immunodeficiency disease (PI).

Understanding your health insurance plan can often have a large impact on your life, mostly on your health and your finances. Employers typically provide options that work for the large majority of their employees, but you might have special concerns related to your plan to ensure you can receive any potentially lifesaving treatments. If you receive Ig therapy, check out how your treatment will be covered. For example, Immunoglobulin (Ig) replacement 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 plan to cover the remaining amount.

Another thing to consider is scheduling any medical treatments at the end of the year. When the new calendar year begins, out-of-pocket limits and deductibles reset. Now may be a good time to consider what treatments or services you should schedule before the end of the year that will be covered under your plan. Questions about whether or not you've met your deductible can be addressed through your insurance carrier, or, if you get your insurance through your employer, talk with your benefits or human resources department for assistance.

### What if I have more questions?

IDF is here for you! We have information and resources to help you understand health insurance plans. To access these vital resources, visit: [www.primaryimmune.org/insurance](http://www.primaryimmune.org/insurance).

If you have further questions, contact us: 800-296-4433 or [www.primaryimmune.org/ask-idf](http://www.primaryimmune.org/ask-idf).



## SPRING INTO A NEW SEASON

### IDF Walk for PI 2020

Thank you to everyone who participated in IDF Walk for PI 2019! Because of each individual and team that registered, we were able to raise over \$365,000 in funds and raise awareness for all those who live with PI.

As we make our way into 2020, we are excited to announce that you won't need to wait until fall to dust off your walking shoes. That's right, we are launching a 2020 Spring Mini Walk Series! We'll be kicking off the 2020 Walks in New Orleans, Louisiana on February 1, 2020. By adding more walks, we're able to go to more locations and see more friends, families, and zebras than ever before!

Ready to spring into a new walk season? See if any walks are coming your way by visiting: [www.walkforpi.org](http://www.walkforpi.org).

And make sure you stay up-to-date on all things IDF Walk for PI 2020 by following us on social media!

 @Walkforpi
  @TZtheIDFZebra
  @TZtheIDF Zebra

**Registration for Spring 2020 is officially open!**

If you are interested in hosting your own Spring or Fall community walk, please email: [walk@primaryimmune.org](mailto:walk@primaryimmune.org).

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**WWW.WALKFORPI.ORG**



# IDF Donor Spotlight

## The Memory of Gloria Moeder

Gloria Moeder was born July 12, 1929 and grew up in the Shaker Heights suburb of Cleveland, Ohio before moving to La Crescenta, California. Descending from a German immigrant family, she valued hard work, had a deep spiritual faith, believed in caring for others, and did so without needing recognition or attention. Gloria had a long career with AT&T, traveled with friends and family, and made it a point to volunteer at local hospitals after her parents passed. Gloria passed away May 20, 2018.

Sisters Lynn Haass and Debbie Rivard, Gloria's relatives, remember her fondly, and enjoyed talking to and visiting her whenever they were in the Los Angeles area. "Gloria would tell me stories of her mother and my great-grandmother, who were sisters," says Lynn Haass. "When she reached her 80's, she asked my family if we would settle her estate once she left this Earth."

Gloria was familiar with Debbie's story and that of her two sons, Justin and Tyler. Justin and Tyler were diagnosed with Chronic Granulomatous Disease (CGD) and have dealt with many difficult situations due to their diagnoses. Both have been a part of studies at the National Institutes of Health (NIH) since they were seven and four years old, respectively.

CGD is a genetic (inherited) disease in which the body's cells that eat certain invaders (also called phagocytes) do not make hydrogen peroxide and other chemicals needed to kill certain bacteria and molds. As a result of this defect, individuals with CGD get more infections, and they also get too many immune cells forming "knots" called granulomas, hence the name of the disease. To learn more about CGD, visit:

[www.livingwithCGD.org](http://www.livingwithCGD.org).



*Debbie Rivard, Gloria Moeder and Lynn Haass*

"When we talked to Gloria about her wishes, she said she would like to donate something that would help Justin and Tyler and the CGD community," says Haass. Debbie then spoke to the healthcare professionals she knew at the NIH to see what would be the best use for the money to help CGD. They recommended IDF. "Debbie and her family were familiar with IDF as they had attended an IDF event in Atlanta before. We were pleased to be able to pass along Gloria's funds."

Gloria's estate has since donated \$40,000 to IDF in Gloria's memory and in honor of Justin and Tyler.

"The most important thing about this gift is that it comes from Gloria Moeder, a single woman who worked hard, saved, and wanted to help out family members who struggled with CGD all of their lives."

Like Gloria, you can make a difference to the lives of those living with PI. To make a donation to IDF, please visit: [www.primaryimmune.org/donate](http://www.primaryimmune.org/donate).

## Where You Can Find Your Fellow Zebras

In 2019, IDF held the 10th IDF National Conference in National Harbor, MD. From June 20-22, more than 1,300 zebras from around the country met to learn from experts in their field, make new connections, and catch up with old friends. We were thrilled to see zebras who represented 46 different states and 9 countries, and more than 570 first time conference attendees.

Interested in joining us at an IDF event? Well, you're in luck! 2020 will be an exciting year for IDF as we hold two IDF Regional Conferences, two IDF Teen Escapes, multiple IDF Walk for PI events in cities all over the U.S., and an inaugural event that will focus on forms of PI that are not antibody deficiencies. Interested in learning more? Make sure you're subscribed to "IDF Events" in your IDF My Account for updates and check out our Calendar of Events: [www.primaryimmune.org/events](http://www.primaryimmune.org/events).

**IDF 2020 REGIONAL CONFERENCES**

**SAVE THE DATES**

**Nashville, TN**  
July 10 - 12, 2020  
The Franklin Marriott

**Phoenix, AZ**  
July 31 - August 2, 2020  
Sheraton Grande at Wild Horse Pass

Registration details will be available in early 2020.

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# Community Immunity

## Protecting Those Who Can't Protect Themselves

We all know the saying “it takes a village to raise a child,” but in the world of primary immunodeficiency diseases (PI), it takes a herd. Herd immunity, or community immunity, is the resistance to the spread of contagious diseases that happens when a significant portion of the population (or herd) provides a measure of protection for individuals who have not developed immunity or are lacking an immune system, like those with PI.

Over the last few years, outbreaks in certain diseases have been prominent and growing. Diseases that were all but eradicated are suddenly popping up all over the country in pockets of the population who take community immunity for granted or don't believe in vaccinations. In 2019, the Centers for Disease Control and Prevention reported that measles cases in the U.S. have surged to a 25-year high. The vast majority of these cases originated in close-knit communities that have low rates of vaccinations.

This outbreak shows us that while the virus is eliminated in the U.S. it can still be brought into the country from travelers. However, the virus usually comes into a highly vaccinated population, where outbreaks either don't happen at all or are incredibly small and contained. This is the importance of community immunity.

Those who are living with PI understand the importance of vaccinations, but there may be some in your family or social circle who don't understand or think it's not important to get vaccinated because “they never get sick.” What they need to realize is... it's not about them. Community immunity is crucial for our population because it uniquely protects the most vulnerable members of our communities, including infants, pregnant women, the elderly, those undergoing chemotherapy/radiation, and those who are living with PI or other chronic, rare conditions that prevent them from becoming vaccinated themselves.

But what can we do? How do we educate others about the importance of community immunity?

### Make it Personal

Telling your story can make a surprisingly large impact. Think of all the moving posts on social media that you've seen shared thousands of times. It's usually a post that someone wrote about their personal story that mattered to them, that was shared by their friend and family, and then by their friends and family, and so on.

### Start Small

Reach out to those close to you, or even just start with your immediate family, and have them get vaccinated. Explain the benefits for you and others who are vulnerable, speak about how important community immunity is. As someone who spends time with you, they are a large part of your protection.

### Go Big

In March, IDF President & CEO John G. Boyle testified before the Senate HELP Committee about what is driving preventable disease outbreaks. The loss of community immunity as a result of the current decline in vaccine usage is a threat to us all—especially the PI community. As he said that day, “We need to band together to dispel myths, combat misinformation campaigns, and help ensure that measles and other vaccine-preventable diseases are once again put in their place—in history books, not in our communities.”

If given the opportunity, you too can speak at state-level hearings about vaccinations. Sharing your story puts a face to our cause.

## Vaccinations and Those Living with PI

Among some of the greatest medical advances in the past two centuries is the development of effective vaccines. While they have great effect on the population at large, vaccines can be problematic for those who are living with PI. Since some types of PI interfere with the body's ability to make antibodies in response to vaccination, many would ask if it makes any sense or does any good for those living with PI to get vaccinated.

Not all people with PI have problems with vaccines. Those with phagocytic cell disorders, such as Chronic Granulomatous Disease (CGD) or with Complement Deficiencies, benefit from immunizations. However, people with T and B cell deficiencies, like Common Variable Immunodeficiency (CVID) and Severe Combined Immunodeficiency (SCID) are unable to develop protective immunity following vaccination, so the vaccines would not do them any good. Live vaccines could actually cause them harm. For those with antibody deficiencies who receive immunoglobulin (Ig) replacement therapy, Ig provides these people with the antibodies that their own bodies cannot make, protecting them from vaccine preventable diseases.

For a person with PI, vaccines are an important weapon in the arsenal to prevent infection and stay healthy. People with PI, their parents, and family members should consult their immunologist and primary care providers to determine the need for vaccination.

For more information about the importance of community immunity and vaccinations for those living with PI, visit:

[www.primaryimmune.org/immunizations](http://www.primaryimmune.org/immunizations).



*IDF President & CEO John G. Boyle getting his flu shot at the IDF office in Towson, MD.*



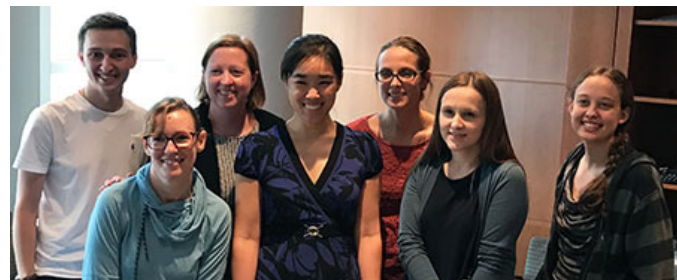
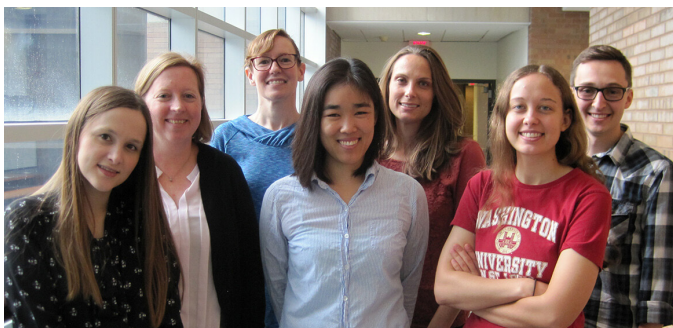
# The Importance of Research

In May 2018, IDF awarded a 12-month research grant to Megan Cooper, MD, PhD of the St. Louis Children's Hospital and Washington University School of Medicine. This research grant has led to the identification of a new primary immunodeficiency disease which is currently being referred to as TLR8-associated disease. Dr. Cooper and her team are currently investigating how this disease comes about and why patients with this genetic change have immunodeficiency.

Dr. Cooper and her co-investigator Dr. Jeff Bednarski used the funding from IDF and from the St. Louis Children's Hospital to pursue research in Novel Genetic Variants in Pediatric Patients with Immune Dysregulation and will continue progress their work through 2019 and 2020.

This type of discovery shows us how important research grants are to the PI community. The 2019 IDF Research Grant Program, which supports well-defined research projects on PI and is made possible by a portion of the funds raised from IDF Walk for PI, will continue to provide opportunities for research and medical professionals.

**Applications for 2020 close February 21, 2020.**



IDF has a seed grant program to encourage and support patient-oriented research on PI. The intent of the grant is to support well-defined research projects that have a specified benefit for improving the treatment, health, disease management or diagnosis of people with PI. Consideration will also be given to studies that contribute to the body of medical knowledge in PI.

The program is open to applicants currently based in the U.S.\* and will consist of one-year grants. Award Value: \$25,000 - \$50,000 (a somewhat higher level of support is available for a few exceptional proposals).

*\*These grants are not open to Federal Government Agencies or Departments.*

Each research proposal is reviewed by IDF's Research Committee, which recommends funding for the highest scored proposals. The grant review process is based on the peer review system utilized by the National Institutes of Health (NIH). Scoring of grants is done individually by each member of the Research Committee and scores are added together to determine the final ranking of each proposal. Any reviewer with a conflict of interest is excused from voting on a specific proposal. The grant selection process is unbiased and independent; awards are based solely on scientific merit.

For more information on how to apply, visit:  
[www.primaryimmune.org/idf-research-grant-program](http://www.primaryimmune.org/idf-research-grant-program).  
Questions? Contact: [idfgrant@primaryimmune.org](mailto:idfgrant@primaryimmune.org).

*Photo credit: [http://research.peds.wustl.edu/labs/cooper\\_m](http://research.peds.wustl.edu/labs/cooper_m)*

**Four individuals were selected as recipients of the 2019 IDF Research Grant Program for their exceptional research proposals for improving the lives of those living with PI:**

**Rui Yang, MD, PhD** – The Rockefeller University, Inherited T-BET deficiency in Mendelian Susceptibility to Mycobacterial Disease. "Our ongoing research will result in a more in-depth understanding of an immunodeficiency caused by T-BET deficiency as well as the non-redundancy immunological role of T-BET."

**Shanmuganathan Chandrakasan, MD** – Emory University. PIDD in patients with persistent post-rituximab hypogammaglobulinemia. "Understanding the biology and genetic basis could help in ascertaining long-term prognosis, could aid in the initiation of targeted therapies and consideration for definitive treatment such as bone marrow transplant if a genetic defect is identified."

**Carolyn Baloh, MD** – Duke University. Clinical indicators for early bone loss in Common Variable Immunodeficiency. "This provides a first step toward the creation of guidelines for low bone density/osteoporosis in CVID."

**Stacey Lynn Clardy, MD, PhD** – University of Utah Department of Neurology. Neurologic Manifestations of Common Variable Immune Deficiency (CVID). "We propose to conduct a prospective epidemiologic study to ascertain the instance and prevalence of neurologic disease in CVID."

# Newborn Screening Saves Lives Reauthorization Act Awaiting Vote in the Senate



The Newborn Screening Saves Lives Reauthorization Act (H.R. 2507), a bill to eliminate preventable newborn deaths and severe disabilities through the increased use of comprehensive and standardized newborn screening tests, is awaiting consideration in the U.S. Senate, as of early December 2019.

This legislation reauthorizes critical federal activities that help states improve and expand their newborn screening programs, support newborn screening education for parents and providers, and ensure laboratory quality and surveillance. The bill renews funding for the programs of the Newborn Screening Saves Lives Act, which was originally introduced in the House by Reps. Congresswoman Lucille Roybal-Allard (CA-40) and Congressman Mike Simpson (ID-02), and was passed and signed into law in 2008. The Newborn Screening Saves Lives Act was last reauthorized in 2014. While the reauthorization that passed in

2014 expired on September 30 of this year, funding allocated for the Act remains available through the end of the year.

IDF has been and will remain engaged on the effort to pass this vital legislation. On June 20, IDF was out on Capitol Hill advocating in support of the passage of the Newborn Screening Saves Lives Reauthorization Act of 2019 during Advocacy Day. If you were not able to participate in Advocacy Day this year, you can help support this effort by signing up for IDF Action Alerts at [www.primaryimmune.org/action-alerts](http://www.primaryimmune.org/action-alerts). You will be notified when you're needed to make your voice heard to legislators about this important legislation.

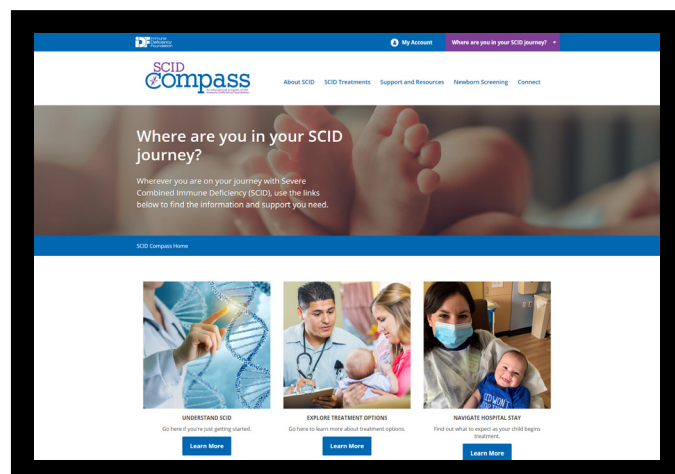
To read the most current updates on this important legislation, visit: [www.primaryimmune.org/NBSSLRact](http://www.primaryimmune.org/NBSSLRact).

## SCID Compass Update: Wrapping Up 2019

Since 2018, IDF has been partnering with the Association of Public Health Laboratories (APHL) and RTI International to develop a new program called SCID Compass. The two-year program, which is funded by the Health Resources and Services Administration (HRSA), aims to address many gaps in education, support, and long-term outcomes that exist for children with SCID across the United States and, specifically, rural and underserved populations. Thanks to universal newborn screening for SCID, many children have the opportunity to thrive due to earlier detection, diagnosis, and treatment.

The SCID Compass team recently launched a new website, [www.scidcompass.org](http://www.scidcompass.org). The purpose of the website is to educate and support parents of children who are newly diagnosed with SCID. This comprehensive site is a resource for all topics related to SCID. Users will find an overview of SCID and important points to know when first diagnosed, explanations of the causes of SCID, descriptions of the types of SCID, detailed steps involved in treatment, listings of support and resources, and guidance in caring for a child with SCID. A collaborative project between IDF, physicians, researchers and parents, [www.scidcompass.org](http://www.scidcompass.org) is designed to meet the needs of parents at every step in the SCID journey as they navigate a SCID diagnosis.

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# TZ's Corner

## Helping Your Fellow Zebras

Hey Friends, TZ here! There are many ways that you can help your fellow zebras, including volunteering for IDF. There are many exciting activities for volunteers; passionate and dedicated volunteers help us achieve our mission. Also, you're never too young or too old to become a volunteer! Join us: [www.primaryimmune.org/volunteer](http://www.primaryimmune.org/volunteer).



Color our pal, TZ the IDF Zebra, volunteering at school and spreading awareness, then post it on social media! Be sure to tag IDF and use **#THINKZEBRA!**

First Name: \_\_\_\_\_

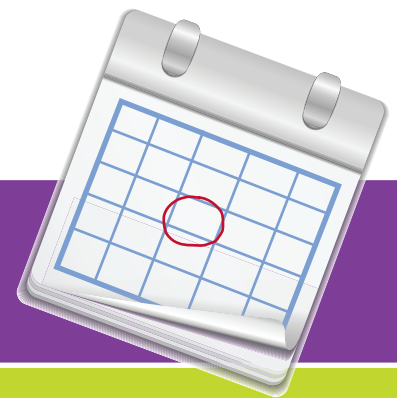
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**For an Updated IDF Calendar of Events, Visit**  
**[www.primaryimmune.org/events](http://www.primaryimmune.org/events).**



## IDF Patient & Family Handbook, Sixth Edition Download it Now!



IDF has now released the downloadable version of the sixth edition of the IDF Patient & Family Handbook for Primary Immunodeficiency Disease. To learn more about and download this important publication, visit:

**[www.primaryimmune.org/handbook](http://www.primaryimmune.org/handbook)**

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