Fostering a community empowered by advocacy, education, and research

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HRSA Awards $2.97 Million Grant Extension to Immune Deficiency Foundation (IDF) for SCID Compass, a Nationwide Screening and Education Program for Severe Combined Immunodeficiency (SCID)

Association of Public Health Laboratories (APHL), RTI International and the Primary Immune Deficiency Consortium (PIDTC) serve as collaborative partners with IDF to implement ongoing initiative targeting people with SCID in underserved areas

August 19, 2020 (Towson, MD) – The Immune Deficiency Foundation (IDF), a nonprofit advocating for people with primary immunodeficiencies (PI), is proud to announce that the U.S. Health Resources and Services Administration (HRSA) has provided a $2.97 million grant extension to fund screening and education programs for people with Severe Combined Immunodeficiency (SCID) through the SCID Compass program. SCID is a collection of genetic disorders that cause profound defects in the immune system, leaving infants highly susceptible to infection and almost always resulting in infant mortality if not treated within the first year of life.

The one-year grant is an extension of an original two-year $4 million grant awarded in 2018 to IDF by HRSA to improve outcomes for infants with SCID. The original grant led to the development of the SCID Compass program.

"I'm really happy we got the extension for year-3. It's truly a testament to the progress of the team and it will make such a difference in the lives of families dealing with such a challenging medical diagnosis," said Dr. John Routes, SCID Compass physician advisor.

SCID Compass aims to build upon the work done in the first two years of the grant to continue to address and increase awareness and knowledge about SCID; support state NBS programs; link families, especially those in rural and underserved areas, to clinical services; and better identify and develop long-term follow-up strategies. In addition, the grant supports IDF's goal of access and inclusion for all by addressing disparities in knowledge and barriers to services that portions of the underserved population may experience.

Highlights of accomplishments during the two-year grant cycle from 2018 to 2020 include:

- ensuring that all 53 newborn screen programs in the U.S. and associated territories offer universal screening for SCID which covers roughly 99.9 % of U.S. births
- establishing the SCID Compass program, a support and educational initiative for both parents and healthcare professionals
- launching a website, www.scidcompass.org, designed to act as a resource for families of children with SCID

- presenting on SCID and SCID Compass at conferences for parents and healthcare professionals
- collaborating with APHL and RTI to collect data related to SCID from parents and healthcare professionals
- establishing a telehealth support group for parents
- beginning work on a Spanish version of the SCID Compass website

Despite moving forward with earlier identification of babies with SCID, the SCID community continues to face a number of significant challenges including: disparities in knowledge and care for patients with SCID in rural and underserved communities; generally low awareness and knowledge about SCID and SCID newborn screening for all stakeholders; and lack of coordinated long-term follow-up strategies for SCID.

"Even with monumental advancements in testing and treatment of SCID, critical gaps still exist," states John G. Boyle, President & CEO of the Immune Deficiency Foundation. "We are grateful to HRSA for their continued confidence in our ability to use SCID Compass as a platform to maximize and leverage the collective resources of IDF, APHL, and RTI in order to have a transformational impact on improving the lives of people with SCID and enhance the knowledge base of testing and treatment for these diseases. We are honored to continue this work under the extended HRSA grant."

To implement SCID Compass over the past two years, IDF has partnered with the Association of Public Health Laboratories (APHL), the primary professional association responsible for supporting newborn screening programs, and RTI International, a non-profit institute which provides expertise in communication science, evaluation, and family/patient studies. In addition, IDF will partner with the Primary Immune Deficiency Treatment Consortium (PIDTC), a consortium of 43 treatment centers whose shared goal is to improve the outcome of patients with rare, life-threatening, inherited disorders of the immune system.

The partnership of key collaborators will continue to foster a family-centered approach designed to ensure that what is accomplished through the grant leads to sustained advancement of SCID - both during the newborn screening period, and in the long-term as the results of SCID newborn screening become apparent.

SCID Compass understands that family members are the ultimate consumer of services but also targets health care providers, public health professionals, and the public. The program's goal will be accomplished through a systematic approach to communication science, building on already identified family and clinician needs, to develop, evaluate, and disseminate a variety of educational resources using multiple communication modalities and strategies.

In partnering with PIDTC, SCID Compass will investigate the neurodevelopmental outcomes on patients through newborn screening, which will deliver profound insight into the long-term outcomes of patients diagnosed with SCID, and, finally, support the needs of the newborn screening programs as they work to enhance their materials, equipment and Laboratory Information Management Systems (LIMS) to support screening for years to come.

For more information on SCID Compass, visit www.scidcompass.org.

About the Immune Deficiency Foundation
The Immune Deficiency Foundation (IDF) improves the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency through fostering a community empowered by advocacy, education, and research. Primary immunodeficiencies (PI) are a group of more than 400 rare, chronic disorders in which part of the body's immune system is missing or functions improperly. There are approximately 250,000 people who are diagnosed with PI in the U.S., and thousands more go undetected. IDF provides accurate and timely information for individuals and families living with PI and offers valuable resources and support. To learn more about IDF, visit www.primaryimmune.org.

About APHL
The Association of Public Health Laboratories (APHL) works to build effective laboratory systems in the U.S. and globally. The association represents state and local governmental health labs that monitor and detect public health threats. The Newborn Screening and Genetics program of APHL strengthens the role of public health laboratories in newborn screening and genetic testing and designs strategies to address changes in the field. For more information, visit www.aphl.org.

About RTI
RTI International is an independent, nonprofit research institute dedicated to improving the human condition. Clients rely on RTI to answer questions that demand an objective and multidisciplinary approach—one that integrates expertise across the social and laboratory sciences, engineering, and international development. We believe in the promise of science, and we are inspired every day to deliver on that promise for the good of people, communities, and businesses around the world. For more information, visit www.rti.org.

About PIDTC
The Primary Immune Deficiency (PID) Treatment Consortium (PIDTC) consists of 42 centers in North America whose shared goal is to improve the outcome of patients with rare, life threatening, inherited disorders of the immune system. The PIDTC helps patients learn about the disorders, connects them with experts in a PIDTC center near them, and provides information on treatment options and research studies. PIDTC also answers questions physicians may have about immune disorders, and offers connections to patient support groups. For more information, visit https://www.rarediseasesnetwork.org/cms/pidtc/

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