



Immune Deficiency Foundation (IDF) Awarded \$4 Million HRSA Grant For Nationwide Screening and Education Program for Severe Combined Immunodeficiency (SCID)

Association of Public Health Laboratories (APHL) and RTI International to serve as collaborative partners with IDF to implement new initiative targeting people with SCID in underserved areas

August 23, 2018 (Towson, MD) – The Immune Deficiency Foundation (IDF), the national patient organization for people with primary immunodeficiency diseases (PI), recently announced they will be awarded a \$4 million grant from the U.S. Health Resources and Services Administration (HRSA) to design and implement an advanced screening and education program for people with Severe Combined Immunodeficiency (SCID) in rural areas or underserved communities.

The goal of the two-year program, awarding \$2 million each year, is to improve outcomes for infants with SCID detected through newborn screening by increasing awareness and knowledge about SCID, supporting state newborn screening programs, linking families, especially those living in medically underserved areas, to services and developing long-term follow-up strategies for infants identified through newborn screening.

To develop and implement the programs, IDF is partnering with the primary professional association responsible for supporting newborn screening programs, Association of Public Health Laboratories (APHL), and one of the world's largest nonprofit research institutes, RTI International.

Currently, 47 states have fully implemented newborn screening for SCID, which covers approximately 95% of births in the U.S. (<https://www.newsteps.org/>). Despite this success, significant challenges remain for patients, families, clinicians, and public health professionals. These challenges include communication between the screening community, healthcare providers, and families; disparities in knowledge and care for patients with SCID in rural and underserved communities; and general awareness and knowledge about SCID and SCID newborn screening for all stakeholders.

“While monumental advancements in testing and treatment of SCID have occurred over the past 40 years, critical gaps still do exist,” said John G. Boyle, President & CEO of the Immune Deficiency Foundation. “We are grateful to HRSA for their confidence in our ability to maximize and leverage the collective resources of IDF, APHL and RTI to have a transformational impact on improving the lives of people with SCID and helping to enhance the knowledge base of testing and treatment for these diseases.”

HRSA operates under the Department of Health and Human Services (HHS) and works to improve healthcare among underserved and vulnerable populations.

About SCID

SCID is a potentially fatal primary immunodeficiency in which there is combined absence of T lymphocyte and B lymphocyte function.

There are at least 13 different genetic defects that can cause SCID. These defects lead to extreme susceptibility to very serious infections.

This condition is generally considered to be the most serious of the primary immunodeficiencies.

Fortunately, effective treatments, such as stem cell transplantation, exist that can cure the disorder.

“We are honored to join IDF and RTI to bring the benefits of newborn screening to even more families,” said Jelili Ojodu, Director of APHL’s Newborn Screening and Genetics program. “This effort is a significant step toward addressing the challenges that still exist for many families and patients with SCID.”

APHL supports implementation of SCID screening within state newborn screening programs, providing technical assistance, training, and access to resources; and RTI provides expertise in communication science, evaluation, and family/patient studies.

“RTI is pleased to partner with IDF and APHL on this important program,” said Don Bailey, Distinguished Fellow and Director of the Center for Newborn Screening, Ethics, and Disability Studies at RTI.” Despite the many advances in SCID screening, much needs to be done to assure that every child is identified and that families receive the best possible information and care.”

The RTI International Center for Newborn Screening, Ethics, and Disability Studies includes a multidisciplinary team of professionals from special education, psychology, medicine, chemistry, genetic counseling, and public health who conduct research, implement pilot studies, evaluate programs, and provide technical assistance to support evidence-based strategies that inform state and national policy.

IDF and its partners plan to take a family-centered approach to developing the program with all activities incorporating family members as partners in planning, with the assumption that family members are the ultimate consumer of services.

The team will take a systematic approach to communication science, building on family and clinician needs to develop and evaluate a variety of communication strategies along with creation of new materials related to SCID.

New research will be conducted to assess the outcomes experienced by families as a result of SCID newborn screening. In addition, IDF and its partners will create an enhanced telehealth and peer support model that can be used to support families in rural and underserved areas.

For more information about SCID, please visit this link: www.primaryimmune.org/SCID

About the Immune Deficiency Foundation

The Immune Deficiency Foundation (IDF), founded in 1980, is the national nonprofit patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

There are approximately 250,000 people who have been diagnosed with a primary immunodeficiency disease in the U.S. IDF provides programs, services and publications for patients and families as well as for healthcare professionals caring for those living with primary immunodeficiency diseases. IDF works to address patient needs through public policy programs by focusing on issues such as insurance reimbursement, patient confidentiality, ensuring safety and availability of immunoglobulin therapy, and maintaining and enhancing patient access to treatment options.

About APHL

The Association of Public Health Laboratories (APHL) works to build effective laboratory systems in the US 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.

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.

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