

Association of Public Health Laboratories Severe Combined Immunodeficiency In-Person Meeting

Marcia Boyle IDF President & Founder

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Mission Statement

Founded in 1980, the Immune Deficiency Foundation is the national patient organization in the United States dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

www.primaryimmune.org





IDF SCID Newborn Screening Campaign



For many years, IDF has advocated tirelessly for the addition of SCID to the newborn screening panels of all 50 states.

- In 2009, IDF conducted a survey of SCID families to provide data for IDF's testimony at the Seventeenth Meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (February 26, 2009)
- Data from this survey provided the basis for an article published in Clinical Immunology
 - "Early vs. Delayed Diagnosis of Severe Combined Immunodeficiency: A Family Perspective Survey"
 - Alice Chan, MD, PhD; Christopher Scalchunes, MPA; Marcia Boyle, MS; Jennifer Puck, MD



In 2010

- Secretary Sebelius accepted the recommendation of Advisory Committee on Heritable Disorders in Newborns and Children and urged all states to include SCID in newborn screenings
- IDF began its campaign to see that SCID testing be included in newborn screening protocols in all 50 states and territories
 - www.primaryimmune.org/advocacy_center/scid/scid_newborn_screening_initiative.asp
- IDF participated as the patient advocacy group at the CDC-APHL: "Newborn Screening for SCID: Implementation, Challenges, and Update" meeting in Atlanta in October, 2010



Since 2010

- Periodic surveys of all state health departments to learn their process for adding a new condition to the newborn screening panel
- SCID Newborn Screening blog to share volunteer activities and news
- Development of SCID Newborn Screening Toolkit
- Development and distribution of Rotavirus Vaccine brochure
- Development and distribution of Abnormal Screening flyer
- Development and distribution of A Guide for Parents Following a Diagnosis flyer

http://primaryimmune.org/idf-advocacy-center/idf-scid-newborn-screening-campaign



And the work continues...

- Connects bi-monthly with those states not yet screening for SCID
- Providing public comment at state Newborn Screening Advisory Committees
- Supports volunteer activities in the states
- When needed IDF has:
 - Given media interviews
 - Had articles and op-eds published
 - And even held rallies
- IDF's National Conference in New Orleans, Louisiana June 24th, 2015 IDF received:
 - 3 published articles
 - 6 television spots
 - a radio story and interview



Since IDF's participation in the 2010 CDC SCID Screening meeting in Atlanta, IDF has valued its relationship with APHL.

- Last year, IDF received grant funds from APHL to develop a new resource for parents of children with SCID
- Produce a video specifically addressing the urgency of isolation while providing comfort and hope to new parents
- This innovative video:
 - Completes knowledge gaps
 - Showcases the realities of how SCID affects a family while providing candid reactions about a family's journey with SCID
 - Answers questions that some parents don't know to ask or are afraid to ask
 - Highlights a success story and provides valuable tools to help others cope with the challenges of SCID





Future Activities

In 2016, IDF will begin:

- Promoting and distributing the video
- Possibly translating the video into Spanish, contingent on funding
- Updating and distributing IDF's existing resource materials





Newborn Screening for Severe Combined Immunodeficiency (SCID and Conditions Associated with T Cell Lymphopenia

Bakes one look heality it which and still have bashing problems that need to be recognized and freezed. For this resouryour bairy has characine meltoms resempting uses done as the housing labories shadings. A five drips of that were taken from your bairy had in tents for a number of dourders. One of the tents performed is to done problems with the memory symmetry. Your bairy had a result on the set that we starter shorters of do not give a date result, and therefore additional tenting gaves to be done as soon as possible.

What Does An Abnormal Screening Test Mean?

The screening loss of bary sure hely may have a low number of a type of which blood one claids T enth's low numbers of T claids on the monotation that sprents contains called Severe Lonzone limitscoold site on the contact of the sprents contains called Severe Contained Instanceousles and SCO, which is hely a new should test in sources for the second series and a diagram of SCO, which is hely a new should test in soled to distantial system birth on a lob series, all for claims distants of any direct second spectrum stype second second second second second second second spectrum stype second second

What is SCID?

SCID is a set of more than a above different general classes, all of which result in a failure to develop T cells and handling to state protective antifections. For the first set of the set of the set of the set of the tenter of the more system protect shows them the tenter of the first set of the direction and the set of the direction and the set of the direction and the set of the set o

What Other Immune System Problems Could My Baby Have?

In addition to SCID, the servering loss also picks up other conditions associated with low T usits. These are often not as secret as SCID, but are important to find out about and triad. Although these are immane diseases they are not related to HV or AUS and we not infections.

How Common Is SCID?

In past yours, it was believed that the incidence for lables form each yoar with SCID was 1 in 100,000. New data multible from status that have mitiated newborn screening programs for SCID suggest that the incidence may be somewhat more common.

How are SCID and Other Conditions Associated with T cell Lymphopenia Treated? The next effective manness for SCID is show marker sampling. This insumes can be done seen after that not then adjust surves on dwark done is the first by semifich diff. Simon the other cardinas and could with user the could also be instant with how marker targeting, while others may be made approximately from the semiantice of the semi-semi-semificiant semificiant semi-semi-semi-semidiagnostic evaluations to us manufacility with others may be made approximately seeds.





Help us help you in the states How can the Immune Deficiency Foundation help you?

- Grassroots advocacy for implementation
- Family support
- Advocating on behalf blood spot research issues
- New resource materials







Alissa, Chris, Presley, and Riley



