



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

**Marcia Boyle**  
**IDF President & Founder**

July 31, 2015

# 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](http://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](http://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 24<sup>th</sup>, 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.

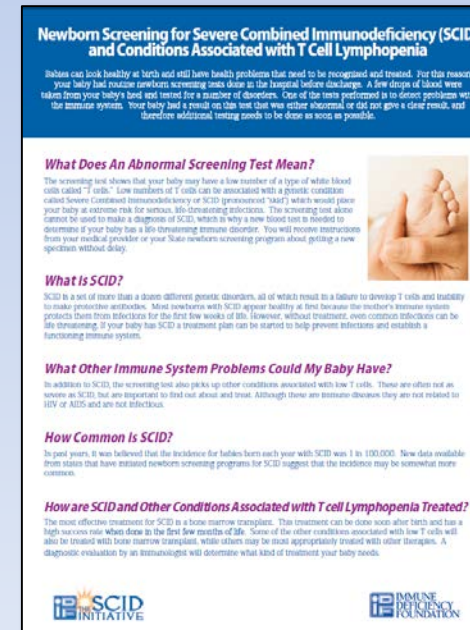
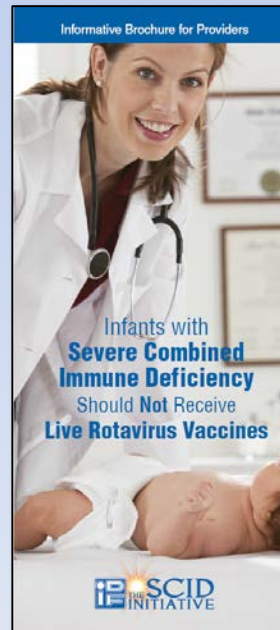
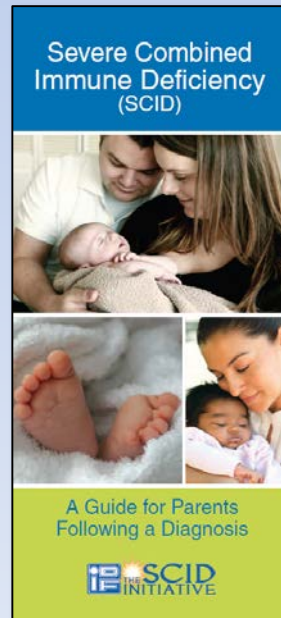
- Last year, IDF received grant funds from APHL to develop a new resource for parents of children with SCID
- Produce a video specifically addressing the urgency of isolation while providing comfort and hope to new parents
- This innovative video:
  - Completes knowledge gaps
  - Showcases the realities 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

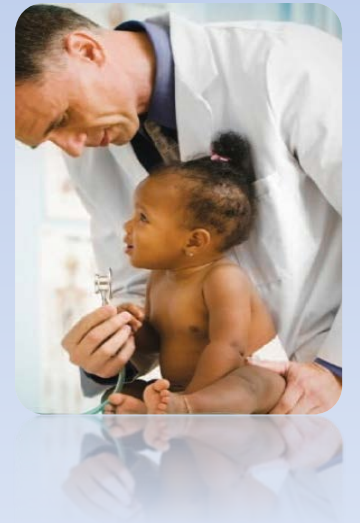




# Help us help you in the states

How can the Immune Deficiency Foundation help you?

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



And now.....

Alissa, Chris, Presley, and Riley

