

RESEARCH SUMMARY:

# Educational and Support Needs for Families living with SCID

We asked families who have a child with SCID to tell us what educational and support resources are most needed.

## WE HEARD FROM 76 PARENTS IN AN ONLINE SURVEY

87%

mothers

13%

fathers

45%

of children were diagnosed through newborn screening

## BIGGEST INFORMATION NEEDS



Understanding all available treatment options



Knowing how to keep child healthy after treatment



Understanding what to expect across SCID lifespan



Knowing where to access specialists



Knowing what to expect during treatment and hospital stay



Understanding child's specific type of SCID

## BIGGEST EMOTIONAL SUPPORT NEEDS



Dealing with uncertainty about child's future



Having access to professional organizations knowledgeable about SCID



Opportunity to talk with other families



Managing emotions as a parent/caregiver



Understanding the importance of self-care

## THE SCID JOURNEY

We also conducted interviews with parents and learned that most families go through 5 stages during the SCID Journey.

1

### DIAGNOSIS

Newborn screening (NBS) test is positive and diagnosis is confirmed.

2

### PRE-TREATMENT

Care teams decide on treatment and seek donor match.

3

### TREATMENT

Donor is found, chemo drugs are administered, treatment is provided.

4

### POST TREATMENT

Families wait for treatment to take effect. Babies live in hospital for 2-6 months.

5

### THE NEW NORMAL

Families return home, seek support and community.

## WHERE ARE PARENTS CURRENTLY LOOKING FOR INFORMATION ABOUT SCID?

- 1  SCID Angels For Life Foundation
- 2  Immune Deficiency Foundation
- 3  NIH National Institutes of Health  
*Turning Discovery Into Health*
- 4  facebook

## PARENTS' PRIORITIES FOR SCID EDUCATIONAL RESOURCES

- Treatment options by type of SCID
- Personal success stories and reassurance
- Guide for preparing home for baby after treatment
- Connections with other families
- Stories about how to survive isolation
- A SCID journey map for parents
- How to advocate for your child
- How to explain isolation to family and friends who want to visit

## PREFERRED FORMAT FOR EDUCATIONAL RESOURCES

Interacting in-person with other families affected by SCID



Talking in-person to a healthcare professional



Interacting on social media



Reading printed information (brochure, newsletter, etc.)



Reading a website



## WHAT DOES THIS MEAN FOR FAMILIES?

We learned that parents have different education and support needs across the SCID journey. We learned that parents want specific information to inform treatment decisions, isolation, and preparation of their homes, but also that parents want connections with other families and support resources.



The SCID Compass website was developed in 2019 to meet the needs described by SCID families. Please visit <https://primaryimmune.org/scid-compass> to learn more about the SCID journey, review information about treatment options, and find support groups.

Raspa M, Lynch M, Squiers L, Gwaltney A, Porter K, Peay H, Huston A, Fitzek B and Boyle JG (2020) Information and Emotional Support Needs of Families Whose Infant Was Diagnosed With SCID Through Newborn Screening. *Front. Immunol.* 11:885. doi: 10.3389/fimmu.2020.00885

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