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

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.

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

Understanding the importance of self-care

Managing emotions as a parent/caregiver
WHERE ARE PARENTS CURRENTLY LOOKING FOR INFORMATION ABOUT SCID?

1. SCID Angels for Life Foundation
2. Immune Deficiency Foundation
3. 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

<table>
<thead>
<tr>
<th>Format</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interacting in-person with other families affected by SCID</td>
<td>76%</td>
</tr>
<tr>
<td>Talking in-person to a healthcare professional</td>
<td>67%</td>
</tr>
<tr>
<td>Interacting on social media</td>
<td>57%</td>
</tr>
<tr>
<td>Reading printed information (brochure, newsletter, etc.)</td>
<td>55%</td>
</tr>
<tr>
<td>Reading a website</td>
<td>54%</td>
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</tbody>
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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.


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