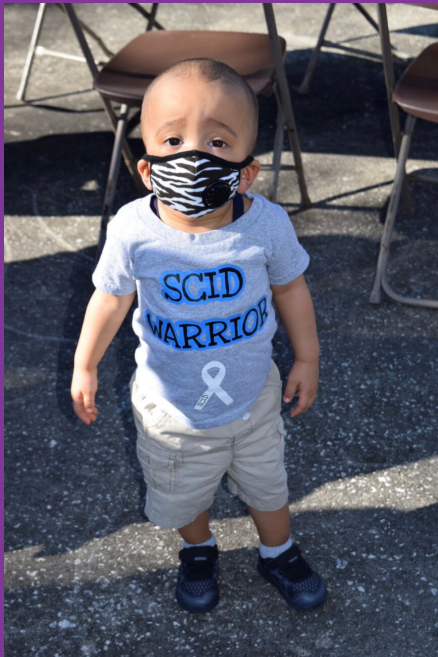


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Primary Immune Deficiency
Treatment Consortium
www.rarediseasesnetwork.org

Genetic Alliance
www.geneticalliance.org

American Academy of Allergy,
Asthma and Immunology
www.aaaai.org

Association of Public Health
Laboratories
www.aphl.org

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www.rti.org

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www.scidcompass.org



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SCID: A PARENT'S PERSPECTIVE

A Guide for Providers



SCID
Compass
An educational program of the
Immune Deficiency Foundation

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THE SCID JOURNEY

Parents of a baby with SCID navigate a complicated medical journey immediately after diagnosis. The first year of the baby's life is marked by distinct stages: diagnosis, pre-treatment, treatment, post-treatment, and adjustment to life at home.

Families fall under tremendous stress as they seek care for their children. They express a deep need for understanding information related to their child's condition and desire a connection with other families whose children also have SCID.

Listed below are challenges faced by families and suggestions for what providers can do to help parents during this critical time. The information is based on interviews with parents of children with SCID.



Diagnosis

How Parents Feel

Parents of children diagnosed with SCID are confused as they wait for the final diagnosis of SCID and overwhelmed upon learning their baby has a life-threatening and rare genetic condition.

These feelings are exacerbated by unclear communication from the pediatrician, a lack of general information about SCID, and an absence of examples of other children with SCID living healthy lives.

Parents grapple with how to move forward when they don't understand the diagnosis or the treatment, and their fears are further heightened if their baby is sick with an infection.

How Providers Can Help

- Explain the newborn screening results to parents and how SCID is diagnosed.
- Discuss how SCID affects a baby's health.
- Present an overview of the treatments and refer the family to a specialist who can assist them in moving to the next level of care.
- Refer parents to the SCID Compass Program; SCID, Angels for Life; and other resources.

Pre-Treatment

How Parents Feel

Parents struggle with understanding treatment options. They feel uncertain and fearful about the future. Parents are frustrated and angry about provider unfamiliarity with SCID and lack of standard of care for SCID patients.

How Providers Can Help

- Share information on treatment options.
- Explain that the hospital stay could last several months.
- Consult fellow providers, peer-reviewed literature, and professional organizations.

Treatment

How Parents Feel

Parents are both happy and nervous when their child receives treatment. They may not understand the treatment process, particularly conditioning and post-treatment complications.

How Providers Can Help

- Explain the treatment steps including placement of the central line, administration of immunoglobulin and immune suppressing drugs, and cell replenishment timeline.
- Inform parents of complications such as infection, graft versus host disease, failure to engraft, and chemotherapy side effects.

Post-Treatment

How Parents Feel

Parents worry about the success of the treatment and feel helpless watching their babies struggle with recovery. They also feel loneliness and despair in isolation at the hospital.

Several months into the treatment process other stressors develop. Relationships with extended family may be strained. Parents' employment may be threatened due to lengthy absences. Finances may be in disarray. The relationship between the parents may be fraying as they decide on the best care for their baby and, at the same time, parent their other children.

How Providers Can Help

- Clearly explain the recovery process and the length of time it can take for T cells to reach optimal levels.
- Offer parents resources about extended stay options while their baby is in treatment.
- Refer parents to social workers who can assist them with hospital living tips, insurance processes, financial matters, mental health referrals, and support groups.
- Allow parents to take an active role in assisting to care for their baby.
- Encourage parent-baby bonding activities.

Life at Home

How Parents Feel

Parents feel anxious and apprehensive when they return home with their baby. They must deep-clean their home to reduce germs, restrict visitors, and keep their baby isolated from the general public. They are nervous about caring for their baby without support from the hospital.

Some parents report that instead of feeling happy, they are anxious and depressed.

How Providers Can Help

- Refer parents to mental health experts, suggest ways to reduce stress, and connect them with support groups.
- Provide parents with tips on how to prepare their homes for the baby's transition from isolation in a medical setting to isolation in a home setting.
- Inform parents the baby will require lifelong follow-up to monitor immune system function and manage side effects from treatment.