

A SCID FAMILY'S JOURNEY



Diagnosis



Newborn screening (NBS) test is positive for SCID. Diagnosis is later confirmed.

Pre-Treatment



Baby is admitted to hospital and isolated. Care teams decide on treatment (e.g., bone marrow transplant, gene therapy) and seek donor match. Baby may also be discharged to home and isolated.

Treatment



Donor match is found. IV "PICC" central line (peripherally inserted central catheter) or "port" (portacath) is inserted. Chemo drugs are administered (e.g. Campath). Treatment is provided (donated blood/bone marrow).

Post Treatment



"Waiting game" for treatment to take effect and lymphocytes to appear. Babies live in hospital for 2-6 months. Babies discharged once T Cell threshold is reached. A 2nd round of treatment is administered if needed.

The New Normal



Babies are discharged and families create a "new normal" at home and in their community. Parents often seek volunteer opportunities to help other families. Post-treatment can take months or even years.

Emotions

- Confusion and uncertainty waiting for final diagnosis.
- Shock, disbelief, feels like a "whirlwind."
- Fear from not knowing any success stories of babies with this condition.

- Uncertainty waiting for donor.
- Fear when doctors are unfamiliar with SCID.
- Anger when nurses/techs do not follow isolation protocols.
- Feeling alone from long hospital stay or baby isolated at home.

- Happiness when donor is matched.
- Nerve wracking when PICC or port is inserted.
- Fear and worry about something going wrong ("failure to thrive").
- Transplants often described as "uneventful".

- Worry while waiting to see if the treatment worked.
- Isolation at the hospital is lonely and challenging.
- Sad to miss holidays/special events and be away from other family/kids while living at the hospital.

- Happiness to return home.
- Anxiousness about caring for baby at home, keeping baby germ-free (relatives want to visit, taking baby outside).
- Ongoing depression or anxiety post-crisis.

Challenges & Pain Points

- Symptoms of infection possible (rash, virus) prior to diagnosis
- Unclear communication from pediatrician.
- Lack of information/resources about SCID and NBS in general.

- Doctors' lack of knowledge on SCID.
- Waiting for a donor.
- Nurses/techs not complying with contact protocol.
- Relying on hospital for treatment decisions; no national standards.

- Lack of information about treatment-related decisions.
- Lack of information about treatment processes.
- Strain on relationships, employment, and finances.

- Confusion and miscommunication about anticipated length of waiting.
- Hard to balance life (e.g. work, other children) outside the hospital.
- Treatment complications (e.g. mouth sores, seizures).

- Providing medical care at home.
- Keeping home germ free (e.g. Clorox wipes, other children).
- Adjustment to new routines and schedules.

What Makes a Difference

- Calming and clear communication from pediatrician about NBS results.
- Smooth referral and transition to specialist.

- Caring hospital staff.
- Hospital familiar with SCID.
- Hospitals that provide opportunities for connection with other families.
- A strong support network.

- Caring hospital staff.
- Providers explain treatment process.
- In-person or digital connections to other SCID families.
- Education materials.
- Hospital programs/events.

- Caring hospital staff.
- Connections to other SCID families.
- Therapy/counseling services.
- Hospitals that provide support groups or events for extended-stay families.
- Comforts at the hospital.

- Hearing from other families about how they cared for baby at home (e.g., masks, filters, covers for strollers)
- Recognizing and treating ongoing depression or anxiety.

Information Needs

- Connections to other SCID families.
- Other family's stories
- Web-resources that do not describe SCID as just fatal and provide information about modern treatments.

- Information that it will be a long hospital stay.
- Connection with another SCID family (at hospital would be best).
- Description of all possible treatment options for SCID.

- Connections or stories from other SCID families.
- Pamphlets/brochures on treatment-related decisions and processes/steps (e.g. PICC, port, Campath).

- Connection with another SCID family.
- Information on average time it takes for T cells to develop.
- Clarification on what parents can do to help (e.g. saline rinses).
- Tips for living at the hospital.

- How to prepare home for baby.
- How to keep baby germ-free while living life.
- Recognizing depression or anxiety symptoms.
- What to expect in years to come.