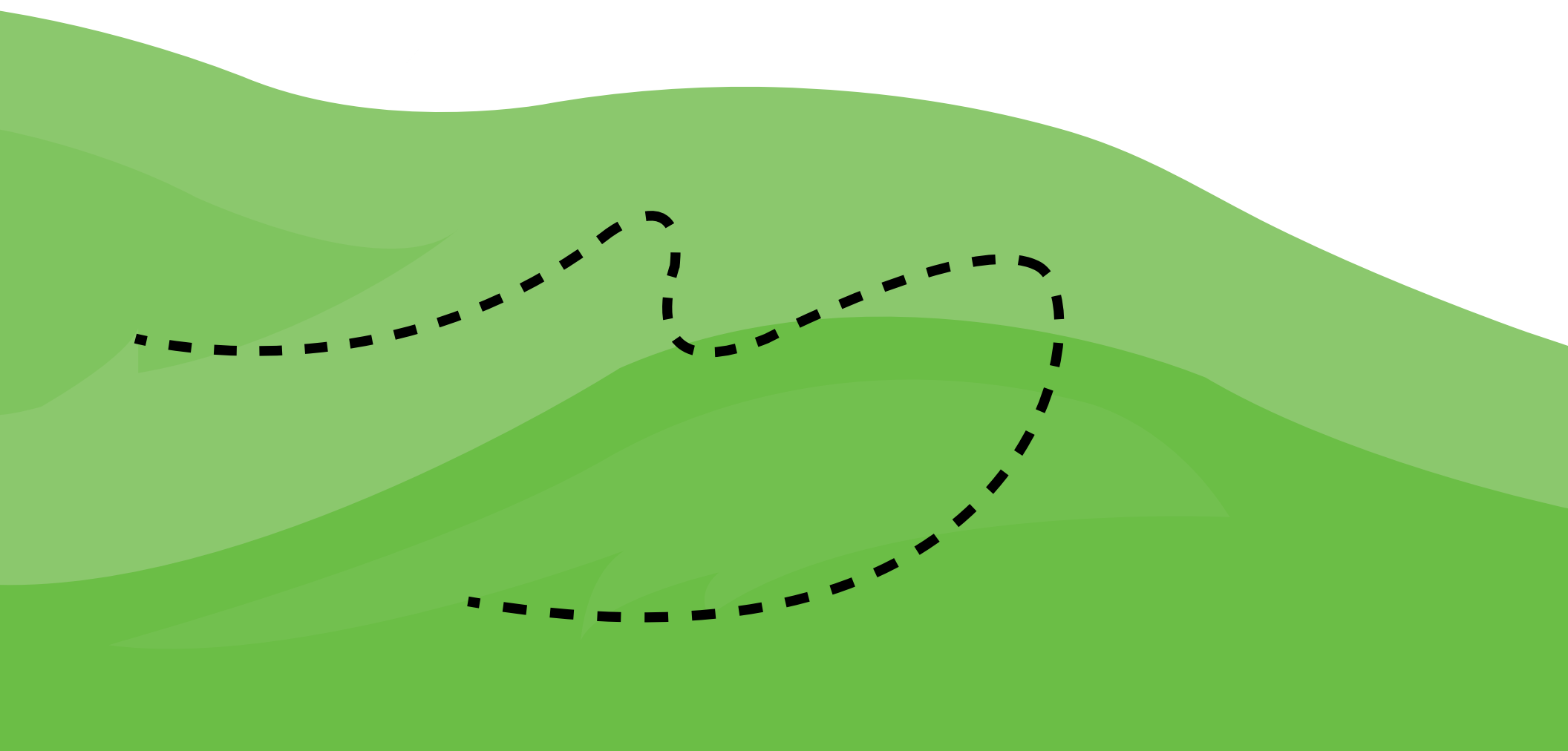


SEVERE COMBINED IMMUNODEFICIENCY (SCID): Questions to Ask Your Child's Healthcare Team

As you navigate through your child's journey with SCID, you will be talking to your healthcare team and making decisions regarding medical care, treatment, or other support resources. Some of these conversations and decisions may be difficult and complex. Many families have a hard time knowing what questions to ask. This resource contains some important questions that can help guide your discussions with the healthcare team in each stage of your SCID journey. To learn more, click on each stage of the journey below.



Diagnosis

Your child has received a positive newborn screening result and the next step is to get confirmatory testing to diagnose whether your child has SCID. During this stage, you may have many questions about SCID, how to keep your baby safe while waiting on test results, and possible treatment options. You may be looking for ways to connect with other SCID families or mental health services.

SCID COMPASS RESOURCES

About SCID

<https://scidcompass.org/about-scid>

SCID newborn screening

<https://scidcompass.org/newborn-screening>



Types of SCID

<https://scidcompass.org/types-scid>



SCID treatment overview

<https://scidcompass.org/scid-treatment-overview>



Connect to other families

<https://scidcompass.org/connect>



Mental health considerations

<https://scidcompass.org/mental-health-considerations>



QUESTIONS FOR THE HEALTHCARE TEAM

What is the difference between newborn screening and confirmatory testing?

What signs or symptoms of SCID should I be looking for?

How should I protect my baby while awaiting the diagnosis?

- Does my child need to be isolated from other people, or can friends and family visit?
- Can I breastfeed?

Should my child get any vaccines?

What type of SCID does my child have?

What causes SCID?

How is SCID treated?

How can I get connected to others who can support me and my family (e.g., mental health services, family support groups)?

Pre-Treatment

In the pre-treatment stage, you are making decisions about your child's treatment plan. Your child's healthcare team may be talking about hematopoietic stem cell transplant (sometimes called a bone marrow transplant), gene therapy, or other treatment options that are possible choices for your child's SCID type. You may also discuss pre-treatment procedures such as pre-treatment conditioning (e.g., chemotherapy).

SCID COMPASS RESOURCES

Treatment Options

<https://scidcompass.org/explore-treatments>



Hematopoietic stem cell transplantation

<https://scidcompass.org/hematopoietic-stem-cell-transplantation>



Gene therapy

<https://scidcompass.org/gene-therapy-0>



Enzyme replacement therapy

<https://scidcompass.org/enzyme-replacement-therapy>



Pre-treatment conditioning

<https://scidcompass.org/pre-treatment-conditioning>



Support resources

<https://scidcompass.org/additional-support-resources>



QUESTIONS FOR THE HEALTHCARE TEAM

What treatment options are available for my child's type of SCID?

- What is a hematopoietic stem cell transplant?
- Who can be a donor for my child?
- What is gene therapy?

What new or emerging treatment options such as a clinical trial might be available for my child?

What are the risks and benefits of each treatment option available for my child's type of SCID?

Will my child need pre-treatment conditioning before treatment?

What are the different types and intensities of chemotherapy?

What are the potential side effects and long-term risks of chemotherapy?

Are there types of pre-treatment conditioning other than chemotherapy that are options for my child?

How much of my child's treatment will my insurance/Medicaid plan cover?

How many children with SCID have been treated at this facility and what is the success rate?

Treatment & Post-Treatment

Families often have questions as they plan for treatment and post-treatment in the hospital. After your child undergoes treatment, your child's immune system is monitored to see if the treatment was successful.

SCID COMPASS RESOURCES

Navigating the hospital stay

<https://scidcompass.org/navigate-hospital-stay>



Hospital Tips

<https://scidcompass.org/hospital-tips>



Transplant Day and Recovery

<https://primaryimmune.org/transplant-day-recovery-process>



Treatment complications

<https://primaryimmune.org/complications-hsct>



Coping with post-treatment

<https://primaryimmune.org/complications-hsct>



QUESTIONS FOR THE HEALTHCARE TEAM

How long can I expect my child to be hospitalized during treatment?

Can I stay with my child during and after treatment?

- What can I expect during the hospital stay?
- Who can I talk to about family support resources while my child is in the hospital?

How will you monitor if the treatment is working?

What are the possible short- and long-term complications of my child's treatment?

Will my child need to take medication after the treatment?

The New Normal

When you return home with your child, you may need to stay in isolation for a period of time. As your child's immune system improves, you will be able to leave the house more. During this stage, families are adjusting to living day-to-day with SCID.

SCID COMPASS RESOURCES

Your return home

<https://scidcompass.org/return-home>



Preparing your home

<https://scidcompass.org/preparing-your-home-post-treatment>



Coping with isolation at home

<https://scidcompass.org/coping-with-isolation-home>



SCID support groups

<https://scidcompass.org/scid-support-groups>



Planning for the future

<https://scidcompass.org/plan-future>



QUESTIONS FOR THE HEALTHCARE TEAM

How long will my child need to stay in isolation after we return home from the hospital?

- What activities can I do with my baby during the isolation period?
- When can I introduce my child to friends and family?
- When can I do activities in public with my baby?
- Can we have a pet in our home?

Are there support groups for me where I can meet other families whose child with SCID has gone through treatment?

How often should we follow-up with our healthcare team?

- What kinds of lab tests will my child get to monitor the long-term success of the treatment?
- Who will be my primary contact on the healthcare team after we are discharged?
- What role does my child's pediatrician play now that we are home?

Are there resources to help us explain my child's SCID to the pediatrician?

Who do I contact first if my child gets sick?

What type of precautions should family members take around my child with SCID?

- What cleaning protocols should we implement at home?
- Is there anything we should consider before enrolling my child who has SCID, or my other children, in school or childcare?
- When can my child with SCID get vaccines?
- What type of vaccines can my baby get post-treatment and when?
- What type of vaccines can members of my family get?

NOTES



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