

Family Planning: Thinking About the Future

There are different ways to think about your family after having a child with Severe Combined Immunodeficiency (SCID). Whether you decide to grow your family or not, the best decision is **your decision**. Use this resource to help you think through the different family planning options and special considerations after having your child with SCID.

*"Don't let other people who don't know what's going on in your lives and in your medical lives, hinder your thought process on whether or not to have children."
-Mother of 3*



Navigating your child's journey with SCID can be overwhelming and stressful with a number of life-changing decisions and experiences. While your child's journey with SCID is life-long, you may be ready to think about the next step for your family.

Remember, your decision to have children is an intimate and personal choice and it's important to recognize that thinking about your future may look different now. No matter what you ultimately choose - it is the right choice for you and your family.

Different Family Planning Options

There are different ways to think about your family now. You may be in the early phases of thinking about how to grow your family after having your child with SCID, or you may be considering not to have any more children. Regardless of what you decide, it's important to consult your healthcare team about any steps that you will need to take based on your unique health and your family's health. Below are options that you might choose after considering and assessing your benefits and risks.

KEY CONSIDERATIONS

To help you have an informed discussion with your healthcare team and family about having additional children, it's important to know and understand your child's type of SCID and whether you or your partner are carriers for this genetic condition.

- **What type of SCID does my child have?** (*X-Linked, ADA, RAG 1 or 2, IL7R, etc.*)
- **Am I carrier?**
- **Is my partner a carrier?**

Complete Family

The decision to not have any more children is an option that may be best for your family.

Consider:

- Discussing your contraception options with your healthcare provider
- Building a support system of SCID families

Natural Conception

Consider:

- Talking to a genetic counselor about prenatal genetic testing options
- Following up on your baby's newborn screening results shortly after birth

In Vitro Fertilization

Consider:

- Contacting your insurance provider to learn what services are covered
- Searching for a fertility clinic that meets your unique needs

Adoption

Consider:

- Thinking about what type of adoption fits your family's needs and preferences
- Being prepared to wait for varying amounts of time during the process

Consider:

- Discussing with your child's healthcare provider about recommended health precautions (e.g., isolation) for your SCID child
- Focusing on your mental health and seeking support when needed
- Thinking about the financial costs associated with each option

Ultimately, what you decide will be based on your family's own personal values and priorities. Here's a list of questions that can help you think through what will be best for your family. Use the space provided to jot down your thoughts, take notes, or to use it as a guide when you speak with your partner or your healthcare provider.

What do you believe are your family's greatest strengths? Consider specific qualities or characteristics that make your partner unique, your child unique, and your family as a unit unique.

What are your top priorities for your family's overall health and well-being? Consider your interpersonal relationships, financial well-being, and your physical and mental health.

When you think about these priorities, what worries or concerns do you have as it relates to your family planning goals?

What do you envision your family to look like in five years? Think about what steps you can take and what supports you need to get there.
