



Beyond the Newborn Screen: *Family Planning After Having a Child with SCID*

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Funding Disclosure

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Thank you to the parents that took the time to candidly and vulnerably share their experiences with having and raising a child with SCID and their family planning journeys since.

Overview

- **Background** – Why this project?
- **Methods** – What did we do?
- **Results** – What did we learn?
- **Follow-Up** – What's next?



Background

- SCID affects about 1 in 58,000 babies born.*
- SCID is now included in public health newborn screening in all 50 states!
- What happens after NBS?



* Immune Deficiency Foundation -
<https://primaryimmune.org/scid-overview>

Goal: Conduct individual interviews with parents of a child with SCID in order to identify and address resource gaps around family planning after having a child with SCID.

Interview Guide

- 9 overarching questions and several probing questions
 - Introduction to the Interview
 - Family Planning Story and Considerations
 - Positive and/or Negative Aspects of the Experience(s)
 - Resources for Family Planning

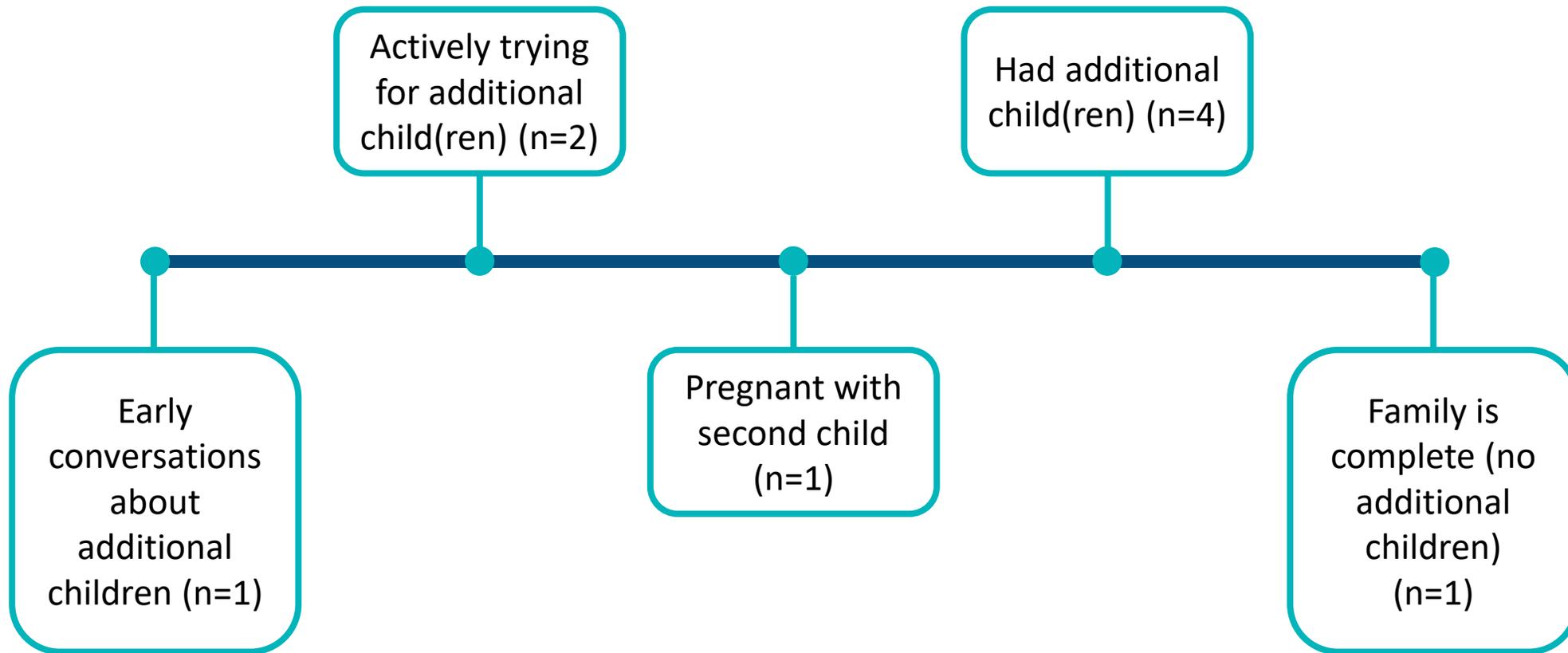


Interviews



- April 2021
- Semi-structured interviews done via Zoom
- 9 participants
- All interviews were audio recorded and transcribed.
- All interviews were deidentified for coding and analysis.

Spectrum of Family Planning



Family Planning Paths

Surprise natural
conception of
additional children
(n=2)

Planned natural
conception of
additional children
(n=1)

Planning adoption of
additional child
(n=1)

Planning for
additional child via
IVF (n=2)

Have additional
children conceived
via IVF (n=2)

Family is complete
(no additional
children) (n=1)

Analysis

- Following the conclusion of the interviews we deductively developed a codebook to analyze the interview transcripts.
- This codebook was used to code each transcript and highlight key themes or areas of similarity.
- Two team members coded each transcript and compared to ensure reliability and accuracy.



Category	Code
Influences on Family Planning Decision	Motivations to have additional children
	Deterrents from having additional children
Family Planning Process	Barriers to or challenges with family planning process
	Resources or supports during family planning process
Social Support	Positive support
	Discouragement or lacking social support

Category	Code
Desired Resources	SCID specific resources
	Genetics resources
	Family planning resources
Financial costs	Cost related to having another child
	Cost related to caring for SCID child
Health care Providers	Positive or encouraging aspects of HCPs
	Negatives or discouraging aspects of HCPs



Finding 1: Varying SCID Diagnosis Experiences





“

And we live in [state], and at the time, she was born in 2013. At the time, [state] did not have newborn screening for SCID.





“

When you're a carrier, because you have your child's diagnosis, and then your own diagnosis, and then like, what are you going to do with that information?

And since I wasn't a carrier, he said it was likely just a random mutation in him...But I think [the doctor] kind of expressed that the chances of having another SCID baby were really, really low.





“

He is like 100%. He goes to school. He eats dirt. He like likes shopping cart handles. Like he is a typical three and a half year old. I actually find that he is sick less often than his peers.

And so she, you know, ended up having to go on life support in the ICU for 15 days.



Finding 2:
Multifactorial Family
Planning Decisions





“

And then in terms of having another child, I really wanted to have another child. I wanted her to have a sibling. I wanted her to have somebody you know, when [father] and I are gone, that can you know, be there with her.





“

I think that's partly because of the smooth recovery that we did get back to a somewhat normal life, actually more normal than what life is right now when he was like six or seven months old.





“

And so then he was worried we're gonna have to put her back in isolation, she's not gonna be able to socialize, she survived, the second child might not survive, you know, is our marriage going to even last through another medical, you know, trauma like this?





“

I was really hesitant to go through IVF because I also didn't want my daughter to think that there was something so wrong with her that we would spend \$30,000 to avoid having another child like her.



Finding 3: Lack of Family Planning Support and Resources





“

So we have federal BlueCross BlueShield, like one of the major ones, they will not cover IVF.

But none of those benefits are triggered without an infertility diagnosis. So my dream would be for the benefits to be triggered by an infertility or a genetic carrier diagnosis, because I'm still not getting all the coverage, like my insurance would cover up to \$5,000 in medication support.





“

But I spoke to him just because he's a genetic counselor. I thought maybe... and he deals with pregnant women. And that was the first time I was like, really shocked by his response because he was like, you cannot have a child. You cannot bring a child into this world just to like be giving their bone marrow to your other child.





“

People want to be able to make the choice that's right for them. And it just, it just seems like there's not really support in that area.



NEED: A resource to support and encourage families during their family planning journey after having a child with SCID.

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 a 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.

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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.

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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

https://scidcompass.org/sites/default/files/SCID%20and%20Family%20Planning_V4.pdf



A Closer Look

- 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.

Final Thoughts

- **The decision to have or not have a child(ren) is an incredibly complex and intimate experience.**
- **Each parent/family knows what is best for them.**
- **More resources and support for families wanting additional children after having a child with SCID could be helpful.**

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Questions?