



SCID
Compass
An educational program of the
Immune Deficiency Foundation

A Carrier's Perspective

April 6th, 2022



IDF MISSION

Improving the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency through fostering a community empowered by advocacy, education and research.



HOUSEKEEPING

- Attendees will not have access to their microphone or webcam throughout the event.
- To see the full slides, you can adjust the settings on the speaker view panel on the top of the Zoom screen and select "side-by-side" in the dropdown option.
- Please submit all questions for the presenter via the Q&A box

DISCLAIMER

Immune Deficiency (IDF) education events offer a wide array of educational presentations, including presentations developed by healthcare and life management professionals invited to serve as presenters. The views and opinions expressed by guest speakers do not necessarily reflect the views and opinions of IDF.

The information presented during this event is not medical advice, nor is it intended to be a substitute for medical advice, diagnosis or treatment. Always seek the advice of a physician or other qualified health provider with questions concerning a medical condition. Never disregard professional medical advice, or delay seeking it based on information presented during the event.

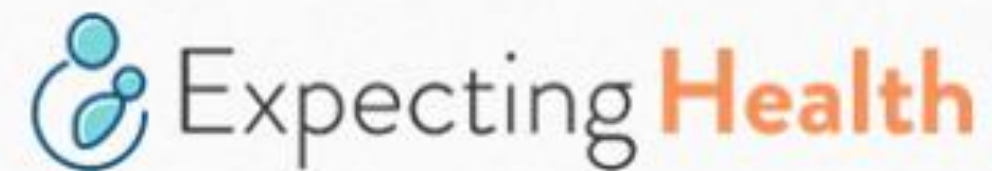


SCID Compass, a program of the Immune Deficiency Foundation, is a HRSA-funded program designed to guide parents of infant diagnosed with severe combined immunodeficiency (SCID), people living with SCID, and the medical community through the journey of learning about this rare life-threatening medical disorder and finding support to navigate the lifelong health challenges.

HRSA Acknowledgement Disclaimer: This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$2.97 million with 0% financed with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government



PROJECT PARTNERS



Where are you in your SCID journey?

Wherever you are on your journey with Severe Combined Immune Deficiency (SCID), use the links below to find the information and support you need.

[SCID Compass Home / SCID Compass Home](#)



UNDERSTAND SCID

Go here if you're just getting started.

[Learn More](#)



EXPLORE TREATMENT OPTIONS

Go here to learn more about treatment options.

[Learn More](#)



NAVIGATE HOSPITAL STAY

Find out what to expect as your child undergoes treatment.

[Learn More](#)

¿En qué parte del trayecto de la IDCG está?

Dondequiera que esté en el trayecto de la inmunodeficiencia combinada grave (IDCG), use los siguientes enlaces para buscar la información y el apoyo que necesita.

[Scid Compass / SCID Compass Home](#)



ENTENDER LA IDCG

Vaya aquí si está comenzando.

[Más Información](#)



EXPLORAR LAS OPCIONES DE TRATAMIENTO

Vaya aquí para aprender más sobre las opciones de tratamiento.

[Más Información](#)



ORIENTARSE SOBRE LA ESTADÍA EN EL HOSPITAL

Descubra qué esperar cuando su hijo comience el tratamiento.

[Más Información](#)

To view all SCID Compass Resources and Materials, visit: www.SCIDCompass.org

PROGRAM OFFERINGS



- [Monthly Lunch & Learns](#)- medical experts present on various topics relating to SCID
- [Get Connected Groups](#): share experiences, receive information, and gain support
- SCID Compass Summit
- IDF Forums
- [Ask IDF](#)



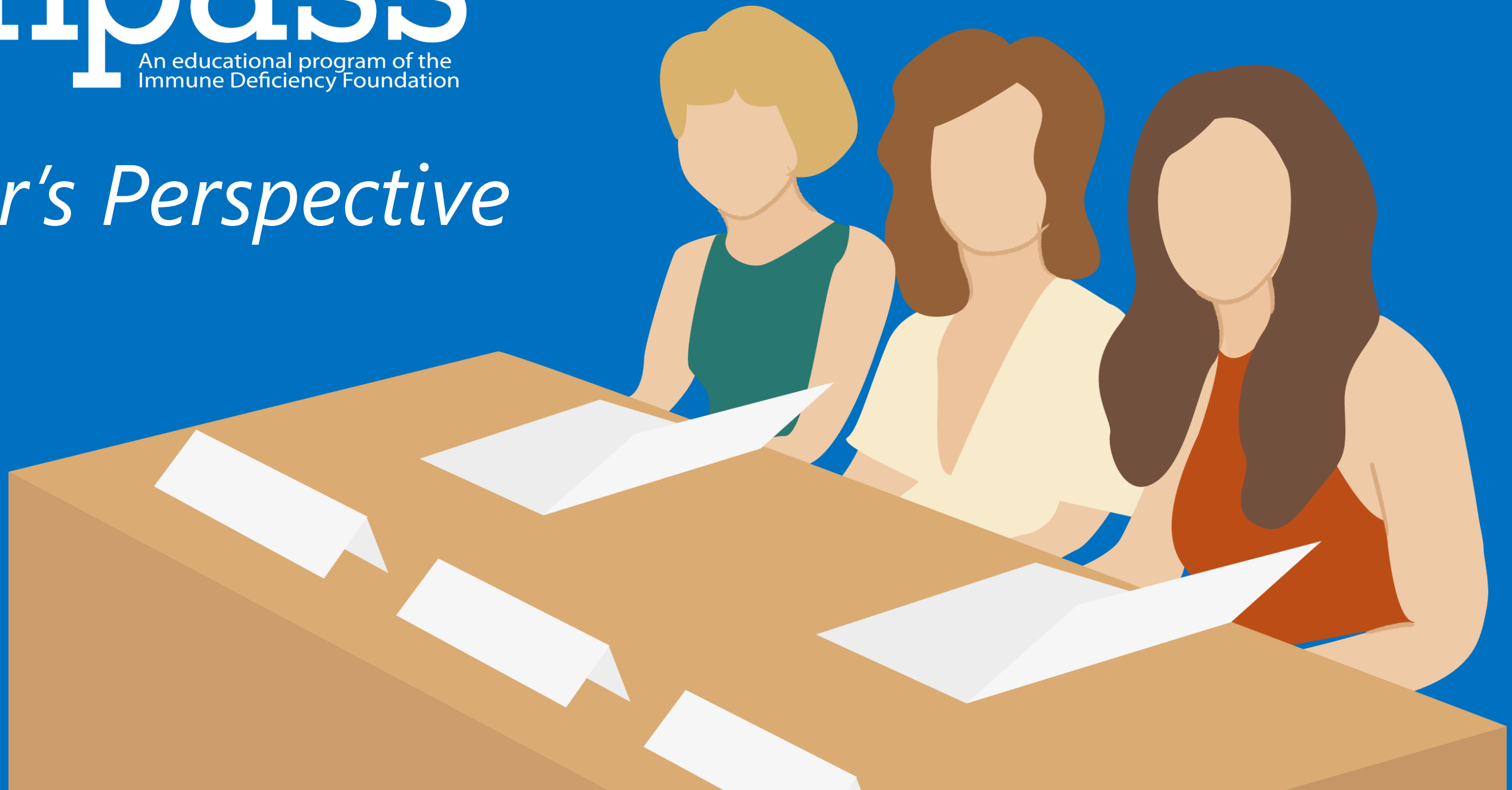
2022 SCID Compass Summit June 23-24, 2022

To view a list of all upcoming SCID Compass events, visit: scidcompass.org/scid-events

SCID Compass

An educational program of the
Immune Deficiency Foundation

A Carrier's Perspective





**Q&A SESSION:
YOUR QUESTIONS ANSWERED**

THANK YOU!

Moderator: Heather Smith

Panelists: Audrey, Caroline, Cindy



**Have more
Questions?**



primaryimmune.org/ask-idf

800-296-4433

RESOURCES & PUBLICATIONS

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 a carrier?
- Is my partner a carrier?

Complete Family	Natural Conception	In Vitro Fertilization	Adoption
<p>The decision to not have any more children is an option that may be best for your family.</p> <p>Consider:</p> <ul style="list-style-type: none"> • Discussing your contraception options with your healthcare provider • Building a support system of SCID families 	<p>Consider:</p> <ul style="list-style-type: none"> • Talking to a genetic counselor about prenatal genetic testing options • Following up on your baby's newborn screening results shortly after birth 	<p>Consider:</p> <ul style="list-style-type: none"> • Contacting your insurance provider to learn what services are covered • Searching for a fertility clinic that meets your unique needs 	<p>Consider:</p> <ul style="list-style-type: none"> • 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



Toolkit for Parents



Find a Clinician | Ask IDF | My Account | How can we help you

Immune Deficiency Foundation

About PI | Living with PI | Education and Events | Stay Informed | Get Involved | Ways to Give | Healthcare Professionals

Genetic Testing

Genetic testing may fast-track your diagnosis.



Why get a genetic test for PI?

- Help you make informed choices about your healthcare
- Obtain a quicker diagnosis
- Learn the risk for your family members and inform your family planning
- Find resources, like patient communities and organizations, specific to your condition
- Better understand your options for taking part in clinical research

<https://primaryimmune.org/genetic-testing>

<https://primaryimmune.org/scid-compass/publications-and-resources>

WE VALUE YOUR FEEDBACK!

Please take a moment to complete our
Program Evaluation Survey:



SCID Compass Lunch & Learn Post-Webinar Survey

Thank you for participating in this month's SCID Compass Lunch & Learn. Please evaluate the event by rating each category. Your comments will assist the SCID Compass team in planning future programs. You can also email our team directly at scidcompass@primaryimmune.org. Thank you!

* Required

1. Were you able to participate in the event? *

Yes

No

Submit

NEXT PROGRAM

SCID Compass Lunch & Learn: The Importance of Long Term Follow-up

Wednesday, May 18th, 2022
11:00 AM-12:00 PM ET

www.scidcompass.org/events

