

# SCID Connect

## Severe Combined Immunodeficiency (SCID) Family Support Group

Online support for SCID families with other families who are also on the lifelong SCID journey.



### What is SCID?

Severe Combined Immunodeficiency (SCID) is a serious and life-threatening genetic condition, where affected babies are unable to fight even simple infections.

Babies with SCID are often referred to as 'bubble babies', highlighting the threat that exposure to germs presents to them. This condition is considered an immunological emergency requiring immediate treatment.

### What is SCID Connect?

Receiving the diagnosis that your baby has SCID can be very confronting for parents. The treatment journey is also extensive and sometimes overwhelming.

Parents must navigate sudden physical and social isolation requirements, complicated medical procedures, disruptions to their work, relationships and finances, whilst also hoping for a successful treatment outcome and stable recovery for their SCID baby.

SCID Connect aims to provide a virtual private forum where parents of SCID children can share their experiences, provide emotional support and positive camaraderie for one another, so that no one feels alone on their lifelong journey with this rare condition.

### Who can join SCID Connect?

All parents of a child diagnosed with SCID in Australia are welcome - whatever the stage of the journey you are at. SCID Connect links families that:

- Have a newly diagnosed SCID baby.
- Have recently undergone a Stem Cell Transplant or Gene Therapy and are recovering.
- Are caring for older SCID children who have completed treatment.

### How do I join SCID Connect?

By joining IDFA (membership is free) and letting us know you care for a child with SCID, you can join SCID Connect and this community.

### What can members in SCID Connect expect?

- Connect with other SCID families.
- Ask any questions relating to SCID or their child's journey, at any point.
- Have their confidentiality maintained.
- Often it is enough to know there is someone to chat to who is going through what you are going through. You can participate in SCID Connect when you feel you need to.

## Family Support Groups

IDFA offers small family support groups on Facebook moderated by members. There are a number of benefits in joining:

- To feel part of an intimate community and feel comfortable to speak, seek clarification and advice, feel validated and supported and find out about other families' coping mechanisms and strategies;
- To seek information from other members who have personal experiences with Severe Combined Immunodeficiency (SCID) in their family;
- To allow you to feel able to share your journey and experiences and learn from other members.

A pre-requisite to becoming a member of this Facebook group is that you are a member of IDFA.

IDFA membership is free! To join visit:  
[idfa.org.au/become-a-member](https://idfa.org.au/become-a-member)

To join the Facebook support group, scan the QR code below.

Scan Me!



Non-Facebook users can email  
[info@idfa.org.au](mailto:info@idfa.org.au) to receive support.



## About Immune Deficiencies Foundation Australia (IDFA)

IDFA is a national not-for-profit and leading peak body offering education, advocacy and awareness for Australians living with a primary immunodeficiency (PID) or secondary immunodeficiency (SID).

In conjunction with our community-focused model of care, IDFA assists in achieving improved patient outcomes and quality of life. With the support of our medical advisory panel and through national and international relationships, IDFA is a respected organisation within the medical and patient community.



### Creating Awareness and Education

Increasing awareness through campaigns and community education. We also offer a range of resources, educational programs and events for Australians living with immunodeficiency.



### Building Community Care and Support

Building community through support groups and engagement events for our members as well as being able to answer all your questions about immunodeficiency.



### Driving Change - Advocacy

Advocating on a range of issues for patients with an immunodeficiency.

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