



Aria, living with ADA-SCID



Phoenix, living with ADA-SCID



Demari, living with ADA-SCID

ADA-SCID**INFO.COM**

## Living with ADA-SCID: Building a relationship with your doctor



Ray Ray, living with ADA-SCID



Clementine, living with ADA-SCID



Eliana, living with ADA-SCID

### Making the most of healthcare appointments throughout your treatment journey

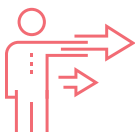
Active communication is key to building good relationships with your healthcare team throughout your ADA-SCID treatment journey. Being prepared and asking well-informed questions will help make your appointments as productive as possible. Use this guide to help you make the most of your time with your healthcare team. This will help you take an active role in your or your child's ADA-SCID management and treatment.

# Preparing for your visit



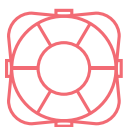
## Make a list

Before your appointment, make lists on your phone or in a notebook to keep track of medicines and dosages, symptoms, allergies, supplements, etc. It is most helpful to have an updated list of ALL medications, including over the counter medications, to bring to the healthcare provider visit. It will help to have them in front of you, so you don't forget to report anything to your doctor. Also, keep an up-to-date list of all your doctors' contact information, including phone numbers, email addresses, and postal addresses. Be certain to update the healthcare provider office with any changes to your contact or insurance information..



## Be proactive

It is helpful to take an active role in your or your child's healthcare management, which means bringing up questions to your healthcare provider and addressing issues as soon as they come up, whenever possible. You may have concerns that the doctor may not be aware of, so it is critical to address those in person when you can. Connect with the ADA-SCID community by visiting SCID Angels at [www.scidangelsforlife.org](http://www.scidangelsforlife.org).



## Take precautions

It is important for people with immune deficiencies to take precautions to avoid germs whenever possible. Practice good hygiene when visiting the doctor and follow your doctor's recommendations to help prevent the spread of infections. Be cautious about touching surfaces and maintain space around you to avoid others with active symptoms (cough, sneezing, runny nose, etc.). Many physicians' offices will separate SCID patients from other patients in order to prevent the spread of infection to those who are most at risk. Be sure to ask if there is a place reserved for immune compromised patients before the appointment.



## Keep records and bring them with you

Ask for copies of all test results and lab work and keep them organized in a binder or electronically. Remember it can be easier to share printed documents with your physician. Bring test results, names of current and past medications, details of hospital visits, and treatments to all your doctor's appointments. Often, you will be the only complete source of information about you or your child's medical history. Thorough records from all doctors and specialists that treat you or your child will help ensure they are providing the appropriate treatments. Ask about a patient portal (a way to electronically communicate with the doctor's office), so that you can access electronic information including lab tests and reports and have an opportunity to cross-check medications and ask questions.



## Report any side effects immediately

Always inform your doctor about new symptoms, reactions to medications, etc., so that they can help you manage any reactions and provide appropriate resources and treatments. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/Safety/MedWatch/](http://www.fda.gov/Safety/MedWatch/) or call 1-800-FDA-1088.



## Keep your doctor's appointments

It is important that you keep your scheduled doctor's appointments so that your doctor can monitor you or your child's condition. Missed or cancelled appointments should be rescheduled as soon as possible.

# Preparing for your visit

## Keep track of your questions

Even if you think you will remember all your questions, it's always a good idea to write them down. Bring your notebook to your appointments so you can write down the provider's answers, too.

**Use the questions below to help guide your conversation with your doctor and ask well-informed questions at your next visit.**

## Healthcare team

Will there be other doctors on my care team?

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Who will be my main point of contact?

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What is the preferred method of contact for questions?

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Do I need to see any other specialists?

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Who should I contact if I get sick and what is the preferred method of contact and fastest way to reach my or my child's physician? (Seek immediate medical care in case of an emergency.)

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## Living with ADA-SCID

What can I do to help prevent getting infections?

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Are there any restrictions on my activity level or diet?

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Can my child visit or attend daycare/school with other children?

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Is there a specific medical diet or are there nutritional guidelines that you would recommend?

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# Preparing for your visit

## Living with ADA-SCID (continued)

Are there regular blood draws necessary to monitor my child's immune status? How often should they be done?

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Are there any noticeable trends in my child's blood work that indicate changes in his/her immune status?

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What is dAXP and how is it measured? What is the preferred range for this value?

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Are there any co-pay assistance programs available for medications?

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Are any vaccines recommended at this point in treatment? If yes, are these live virus or inactive vaccines?

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What are the long-term health consequences of ADA-SCID?

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How often should my child's hearing be checked?

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How will I know if my child has outgrown his/her medication dosage?

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Should my child be screened for DFSP, dermatofibrosarcoma protuberans?

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Can ADA-SCID affect my child's physical and/or neurodevelopment? Are there tests to see if my child would benefit from early intervention education?

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Is there an ADA-SCID support group I can join?

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## Notes

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## ADA-SCID can have a significant impact on your day-to-day life

The good news is that with the right management, treatment and community support you can go ahead, and get out there. Use the resources below to learn more, start a conversation with your healthcare team, and educate your family and friends about immunity and living with ADA-SCID.



Emily, living with ADA-SCID

**These organizations and online communities provide valuable tools, information, and support for you and your family.**

### Key organizations

**Immune Deficiency Foundation**  
[primaryimmune.org](http://primaryimmune.org)

**IPOPI**  
[ipopi.org](http://ipopi.org)

**Jeffrey Modell Foundation**  
[info4pi.org](http://info4pi.org)

**SCID Compass**  
[scidcompass.org](http://scidcompass.org)

### Support groups

**SCID Angels for Life Foundation**  
[scidangelsforlife.org](http://scidangelsforlife.org)



**To learn more about ADA-SCID, talk to your doctor and visit [ADA-SCIDInfo.com](http://ADA-SCIDInfo.com)**