



Who can attend the Youth Summit?

Patients and their siblings, ages 8 to 18, whose parent(s) are attending the Patient Summit, are eligible to attend the Youth Summit. We feel it's important to include siblings because they are also impacted by their sibling's condition and miss out on enough!

Note: Attendees will be visiting a local attraction off-site, as one of their activities. We do not recommend registering patients who are not able to participate fully. We are also unable to support children with high medical/special needs, safely. If you have a concern, please contact Kelly Helm at khelm@nephcure.org prior to registering.

Why should my child(ren) attend the Youth Summit?

We know that living with a rare kidney disease has many challenges and the feelings of isolation and being different rank among the top. We also know that siblings are impacted by RKD in the home and their sacrifices and struggles are often not addressed. The Youth Summit is a place where both patients and siblings make connections with other children who are on similar paths and have common understanding of the challenges each other face.

Your child(ren) will leave feeling validated and part of a community who gets it. They will learn coping strategies through professionally led art therapy, Talk it Out and Write it Out sessions. They will learn how to talk about RKD, how RKD impacts their bodies and how to manage their diets. Most of all, they will have fun building community through team building activities, games and off-site adventures!

What's included in my Youth Summit registration fee?

Your registration fee gives attendees access to all NephCure Youth Summit sessions taking place on site at the Hyatt Regency Riverwalk and off-site activities to be determined. For a list of activities view our Youth Summit agenda.

Food and beverages will be provided for:

- Thursday evening dessert reception
- Friday breakfast, lunch, afternoon snack
- Saturday breakfast and lunch

Youth Summit attendees will receive a gift bag of goodies, including a Youth Summit t-shirt. They'll also receive tickets/admission to the off-site activities!

What dates and times should I book travel and plan to arrive?

We recommend arriving early afternoon on Thursday, May 9. The Youth Summit begins at 6pm with team building and dessert. Registration will be open beginning at 3pm on Thursday, May 9.

The Summit ends at 2pm on Saturday, May 11. We encourage you to book travel that allows you to participate fully on Saturday and then head to the airport. The airport is a 15-minute drive from the Hyatt Regency Riverwalk.

Can I extend my stay at the Hyatt Regency Riverwalk?

Those who would like to arrive early and stay late will need to contact the Hyatt Regency Riverwalk directly at [\(210\) 222-1234](tel:210-222-1234). Please note, the hotel will not have record of your summit reservations until we submit our master room list the first week of May.

How does NephCure ensure my child(ren) connects with others?

The Youth Summit staff carefully construct an agenda that ensures each child, both patient and siblings have the opportunity to connect with others who are similar age and who have been on similar journeys with kidney disease. We start with purposeful teambuilding activities on Thursday evening to help attendees feel supported and accepted. During the remainder of the Youth Summit, we plan an agenda of learning, connection time, and just fun to balance difficult topics and growth opportunities, with fun activities that will make wonderful memories!

What is the dress code for the Youth Summit?

The Youth Summit will be held both inside the hotel conference area and outside for various activities. We will send attendees a specific packing list in April, but we suggest packing comfortable clothing and layers to keep warm in the air-conditioned conference center and cool enough outside in the spring Texas heat.

How are my children kept safe during the Youth Summit?

The Youth Summit is run by qualified staff and trained volunteers. All adults working at the Youth Summit have passed background checks and participate in extensive training on our policies and procedures designed to keep the youth attendees safe and ensure they enjoy their time with us. If you would like more information on our safety policies feel free to reach out.

Note: For the children's best interest, we are not able to accommodate all special needs. Please contact khelm@nephcure.org with questions prior to registering.

Is childcare offered for children younger than 8 years old?

The Youth Summit is open to patients and their siblings between the ages of 8 and 18 years old. There will not be childcare provided for children under the age of 8 or those not registered for the Youth Summit.

When is the registration deadline?

Registration will remain open until April 16, 2024, assuming there is availability. The Youth Summit has limited capacity and will sell out quickly.

Can I volunteer for the Youth Summit?

We will consider volunteers for the Youth Summit who are 20 years of age or older. For more information, please contact Kelly Helm at khelm@nephcure.org.

What is NephCure doing to reduce the spread of COVID-19?

We will make every effort to provide a safe environment for our attendees. We welcome the use of masks, but cannot require them.

Can I request a refund?

Summit registration fees will not be refunded after April 1, 2023. Prior to this date, fees can be refunded minus a 50% service charge.