



Youth Summit FAQs

Who can attend the Youth Summit?

Patients and their siblings ages 8 to 17 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 Disney park as one of their activities and 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.

How many family members can attend the Patient and Youth Summits?

In order to give as many families as possible an opportunity to attend the Summits, we are only able to offer one room (up to 4 guests) per family.

Will there be a virtual option for the Youth Summit?

The Youth Summit is in-person only. For the safety of our minor attendees, a virtual option will not be offered.



Patient Summit FAQs

My family has more than 4 people. What are my options?

Due to COVID-19, we've had to reduce our room block. To maximize the number of families we're able to accommodate, we're only able to offer one room (up to 4 people) per family. If you have a family larger than 4 people and would still like to attend, please contact Swan and Dolphin to see if they have room availability and book any additional rooms.

Note: NephCure will book one room for you. Your other option is to potentially book rooms at another hotel, but NephCure will not be able to cover the costs and will still require a registration fee. Before doing so, please contact Savannah Dauster at sdauster@nephcure.org to verify availability at the Patient Summit and Youth Summit if applicable.

Can I attend the Patient Summit but stay elsewhere?

This might be possible but will depend on our meeting room capacity. Those staying at Swan and Dolphin Resort will have priority. You would still need to register and pay the registration fee and NephCure would not provide reimbursement for lodging. Please contact Savannah Dauster at sdauster@nephcure.org to verify availability prior to registering.



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What's included in my Youth Summit registration fee?

NephCure will cover the hotel expenses for one room (up to 4 guests) for 3 nights per family (Thursday, Friday, Saturday). Food and beverages will be provided for a dessert reception on Thursday evening, breakfast, lunch and a snack on Friday, and breakfast and lunch on Saturday.

Youth Summit attendees will receive a gift bag of goodies, including a Youth Summit t-shirt. They'll also receive a half-day ticket to a Disney park (TBD).

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 17 years old. We aren't able to provide childcare for children younger than 8.

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 Savannah Dauster at sdauster@nephcure.org.



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

Unfortunately, we can't predict what the COVID-19 picture will look like in April of 2022. However, we are making every effort to provide a safe environment for our attendees. Those attending in-person will be required to either provide proof of full vaccination or a negative COVID-19 test completed within 3 days of April 28. We also welcome the use of masks, but cannot require them. We will have hand sanitizer readily available, and we have decreased the size of the Summit to avoid overcrowding in our sessions.

Is this a free trip to Disney?

We encourage our families to see this as an invaluable opportunity to learn and connect with others in a fun location. We request that registrants please attend all Summit sessions. We have scheduled time for you to enjoy being on Disney property and ask that you do so during the free time offered.

When is the registration deadline?

Registration will remain open until April 1, 2022, assuming there is availability. However, the Youth Summit is expected to sell out quickly!