

Who can attend the Patient Summit?

Anyone who is impacted by a primary, rare, protein-spilling kidney disease is encouraged to attend the NephCure Patient Summit. Each year we welcome both patients (and their care partners) with all types of rare kidney diseases (RKD), including nephrotic syndrome, FSGS, IgA nephropathy, C3G, minimal change disease, and more.

Why should I attend the NephCure Patient Summit?

The NephCure Patient Summit brings together a diverse and supportive community of patients, caregivers, healthcare professionals, and advocates who understand your journey, offering a network of educational and emotional support. The summit provides an invaluable opportunity to learn from leading experts in RKD, which can empower you to make informed decisions about your or your loved one's condition.

Through informative workshops, seminars, and panel discussions, you'll acquire practical tools and strategies for managing your or your loved one's disease and stay up-to-date with the latest developments in newly approved treatments, research, and clinical trials in the RKD space.

Beyond the education and support you will receive, the summit includes social activities and a chance to simply enjoy your time with other members of the RKD community. Attending the summit is often a life-changing experience that equips you with knowledge, support, and a sense of purpose in the fight against RKD.

What's included in my \$50 Patient Summit registration fee?

Your registration fee includes:

- Access to all NephCure Patient Summit sessions taking place on-site at the Hyatt Regency Riverwalk. For a list of activities view our Patient Summit agenda.
- Food and beverages provided on:
 - Thursday evening dessert reception
 - Friday breakfast, lunch, afternoon snack
 - Saturday breakfast and lunch

You will also receive a gift bag including a journal, pen, and other NephCure swag!

How do I secure a hotel room?

For a fee of \$300, NephCure will reserve a double or king room at the Hyatt Regency Riverwalk for 2 nights on:

- Thursday, May 9
- Friday, May 10

You can ask about hotel availability and pricing for the night of Saturday, May 11 by contacting <u>patientsummit@nephcure.org</u>

What type of hotel room should I request and what if I need more than I hotel room for my family?

We have access to a limited number of king and double rooms for families who attend the summit. Please determine which type of room will best accommodate your party. We would like to be able to offer lodging for as many patient families as possible under our limited room block. Please consider this when determining the amount of space and number of rooms your party will need.

If you have more than 4 attendees in your party, please select two hotel room fees upon registration to ensure you will have two separate rooms to accommodate your party.

If you have questions, please contact <u>patientsummit@nephcure.org</u> for more information.

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

We recommend arriving the afternoon of Thursday, May 9. The Youth Summit begins at 6 pm and the Patient Summit begins at 7 pm Central on May 9 with a Welcome Reception, State of NephCure and dessert. Registration will be open beginning at 3 pm on Thursday, May 9.

The Summit ends at 1:30 pm Central 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. Please note, the hotel will not have record of your summit reservations until we submit our master room list the first week of May.

When will I receive my hotel confirmation?

Upon registration, NephCure will ensure that you are included in our room block. However, NephCure will not submit the room block until the end of April. By early May, you will receive a confirmation number for your hotel room. The hotel will not have a record of your stay until the beginning of May.

Can I attend the Patient Summit but stay elsewhere?

Yes, you are free to stay elsewhere if you would like.

Please contact <u>patientsummit@nephcure.org</u> to let them know that you do not intend to stay at the Hyatt Regency Riverwalk so we do not purchase a room for you.

When is the registration deadline?

Registration will remain open until April 16, 2024, assuming there is availability. However, the summit generally sells out quickly.

Does NephCure provide activities to connect with other patient families?

Yes! NephCure has been extremely thoughtful to provide adequate time and a conducive environment to promote peer to peer connections. Much of this "patient connection" time is built into the agenda. Also, once registered, attendees will receive information on additional activities that will allow even more connection opportunities.

What is the dress code for the NephCure Patient Summit?

The NephCure Patient Summit is held mostly in the hotel conference center which tend to be chilly with air conditioning. We recommend casual, comfortable clothing and bring layers!

Can I volunteer for the NephCure Patient Summit or Youth Summit?

Yes! We will consider volunteers who are 20 years of age or older for both the Patient Summit and the Youth Summit. For more information, please contact patientsummit@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.

Will there be a virtual summit?

NephCure remains committed to educating and connecting patients virtually, throughout the year. For that reason, there will not be a dedicated virtual summit this year.

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.