



## CRN 2023 Family Conference

July 13 – 15, 2023

Nashville Marriott at Vanderbilt University

**Draft 1/30/23**

### Wednesday, July 12th

12:00 pm – 8:00 pm

**CRN Board of Directors Meeting**

*Closed Session*

### Thursday, July 13th

9:00 am – 4:00 pm

**Scientific Symposium**

*Host: Christy Greeley, Executive Director, VP Research*

*Chair: Elena Levtchenko, MD, PhD*

9:00 am – 4:00 pm

**Speak Up/Speak Out: Cystinosis & Me**

4:00 pm – 5:00 pm

**First Time Attendee Orientation and Networking Session**

*Hosts: Jonathan Dicks, President/VP Development*

*Jen Wyman, VP Family Support*

5:00 pm – 7:00 pm

**CRN Welcome Reception**

*Hosts: CRN Board of Directors*

*Complimentary Dinner and Open Bar*

7:00 pm – 10:00 pm

**Family Introductions/Networking**

*Hosts: Jen Wyman, VP Family Support*

*Kristina Sevel, Board of Directors*

### Friday, July 14th

<b>7:00 am – 8:30 am</b>	<b>Breakfast</b> <i>Complimentary</i>
<b>8:00 am – 5:00 pm</b>	<b>Registration/Information Desk</b>
<b>8:00 am – 5:30 pm</b>	<b>Childcare and Teen Activities</b>
<b>8:00 am – 8:30 am</b>	<b>Welcome and Opening Remarks</b> <i>Jonathan Dicks, President</i>
<b>9:00 am - 11:00 am</b>	<b>Speak Up Speak Out: Cystinosis &amp; Me</b>
<b>8:30 am – 9:00 am</b>	<b>CRN – Your Advocacy Group</b> <i>Christy Greeley, Executive Director, VP Research</i>
<b>9:00 am – 9:30 am</b>	<b>Cystinosis 101</b>
<b>9:30 am – 10:00 am</b>	<b>Preparing for Kidney Transplant</b> <i>Paul Grimm, MD</i>
<b>10:00 am – 10:15 am</b>	<b>Break</b> <i>Complimentary</i>
<b>10:15 am – 10:45 am</b>	<b>Clinical Trials/Gene Therapy Introduction</b> <i>Craig Langman, MD</i>
<b>10:45 am – 11:30 am</b>	<b>Stem Cell Therapy</b> <i>Stephanie Cherqui, PhD</i>
<b>11:30 am – 12:00 pm</b>	<b>Speak Up Speak Out Presentation</b>
<b>12:00 pm - 12:30 pm</b>	<b>Group Photograph</b>
<b>12:30 pm - 1:30 pm</b>	<b>Lunch</b> <i>Complimentary</i>
<b>1:30 pm – 4:00 pm</b>	<b>Panel Sessions</b>
<b>1:30 pm – 2:45 pm</b>	<b>Panel Session 1</b> <b>Newly Diagnosed</b> <i>Host: Kristina Sevel, Board of Directors</i>
	<b>Middle Childhood</b> <i>Host: Chelsea Meschke, Board of Directors</i>
	<b>Teen Years</b>

*Host: Herberth Sigler, Board of Directors*

**Adult**

*Host: Karen Gledhill, Secretary*

**2:45 pm – 4:00 pm**

**Panel Session 2**

**Newly Diagnosed and Middle Childhood: Physician Q & A**

*Host: Tim Wyman, Treasurer*

**Adult (18+): Living with Cystinosis as an Adult**

*(closed session for adults 18 + and their partners)*

*Host: Megan Morrill, Board of Directors*

**Parents of Adults with Cystinosis Breakout**

*(closed session for parents of adults living with Cystinosis)*

*Panelists: Carol Hughes, Gail Potts*

**Transplant and Dialysis**

*Host: Marybeth Kruppenacker, VP Education & Awareness*

**4:00 pm – 4:15 pm**

**Break**

*Complimentary*

**4:15 pm – 5:30 pm**

**Medical Panel**

*Moderator: William A. Gahl, MD, PhD*

**Dinner on your own for general attendees**

*Conference Ballroom will be available for those who would like to meet up and connect.*

**6:45 pm**

**Speaker Dinner**

*Closed Event*

*The 404 Kitchen | American Restaurant in Nashville, TN ([the404nashville.com](http://the404nashville.com))*

*Bus will leave from hotel at 6:30 pm*

**Saturday, July 15th**

**7:00 am – 8:30 am**

**Breakfast**

*Complimentary*

**8:00 am – 4:00 pm**      **Registration/Information**

**8:00 am – 5:30 pm**      **Childcare and Teen Activities**

**8:30 am – 8:45 am**      **Opening Comments**

*Marybeth Krummenacker, VP Education and Awareness*

**8:45 am – 1:00 pm**      **A variety of topics are planned including updates from our industry partners, self-care for caregivers and individuals living with cystinosis, advocacy and rare disease community topics, updates from global cystinosis groups, and sessions for teens and young adults to meet with our Adult Leadership Advisory Board members**

**1:00 pm – 2:00 pm**      **Lunch**

*Complimentary*

**2:00 pm – 3:00 pm**      **Parents of Children and Adults with Cystinosis Panel**

*Moderator: Kristina Sevel, CRN Board of Directors*

**3:15 pm – 4:15 pm**      **Adults Living with Cystinosis Panel**

*Moderator: Ella Balasa, ALAB Mentor*

**4:15 pm – 4:30 pm**      **Closing Remarks**

*Jonathan Dicks, CRN President, VP Development*

*Christy Greeley, Executive Director, VP Research*

**6:00 pm – 10:00 pm**      **Farewell Dinner Dance**

*Dinner Complimentary/Open Bar*