

CRN 2025 SCIENTIFIC SYMPOSIUM AGENDA

Friday, July 11, 2025

Open to registrants only.

*All sessions held in the **Senator Vandenberg Room** unless noted.*

8:00 am – 9:00 am Governor's Room	Breakfast
9:00 am - 9:05 am	Opening Remarks
9:05 am - 9:35 am	Ketogenic Diet and Progression of Kidney Disease in Animal models of nephropathic cystinosis <i>Francesco Bellomo, PhD</i>
9:35 am - 10:05 am	Hypothesis: Taurine Therapy of Nephropathic Cystinosis May Correct the Deficiencies of Cysteamine Therapy <i>Jess Thoene, MD</i>
10:05 am - 10:35 am	Bridge-Building: Organizing the Mitochondrial Research and Clinical Communities in Order to Assist in Rare Disease Mitigation and Solutions <i>Gordon Freedman</i>
10:35 am - 10:50 am	Break — <i>Refreshments provided</i>
10:50 am - 11:20 am	Nephrology Pediatric-to-Adult Transition Clinic: A Retrospective Review of 11 Years of Programmatic Development and Outcomes <i>Lauren Suchy Marzinelli, LCSW, MSW, MPH</i>
11:20 am - 11:50 am	What Brainwaves Tell Us About Cognitive Control Systems in Cystinosis <i>Sophie Molholm, PhD</i>
11:50 am - 12:10 pm	SELECT for Cystinosis: Building an International Guideline <i>Ewa Elenberg, MD</i>

12:10 pm - 12:30 pm NAPRTCS Cystinosis Registry

Reeti Kumar, MD

12:30 pm - 1:00 pm Advancing Patient-Centered Outcomes in Cystinosis: Development of the QUALIFY HrQoL Questionnaire for Pediatric and Young Adult Populations

Stefanie Witt, PhD

1:00 pm - 2:00 pm Lunch + Poster Session

Governor's Room

2:00 pm - 2:30 pm Developments in Ocular Cystinosis Research

Rachel Bishop, MD, MPH

2:30 pm - 3:00 pm Addressing the problems with cysteamine treatment: An update on the development of CF10

Stephen Waldek, FRCP

3:00 pm - 3:30 pm Targeting Cellular Injury in Nephropathic Cystinosis: A Novel Combination Therapy to Preserve Kidney Function

Minnie Sarwal, MD, PhD, FRCP, DCH

3:30 pm

*Fine Arts Room
Lobby Level*

Board Meeting - CRN Scientific Advisory Board and Medical Advisory Committee

Acting Chair: *Rick Kaskel, MD, PhD, FAAP, FASN*

Closed

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