

# 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      Breakfast**

Governor's Room

**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**

*Francesco Bellomo, PhD*

**9:35 am - 10:05 am      Hypothesis: Taurine Therapy of Nephropathic Cystinosis May Correct the Deficiencies of Cysteamine Therapy**

*Jess Thoene, MD*

**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**

*Gordon Freedman*

**10:35 am - 10:50 am      Break — Refreshments provided**

**10:50 am - 11:20 am      Nephrology Pediatric-to-Adult Transition Clinic: A Retrospective Review of 11 Years of Programmatic Development and Outcomes**

*Lauren Suchy Marzinelli, LCSW, MSW, MPH*

**11:20 am - 11:50 am      What Brainwaves Tell Us About Cognitive Control Systems in Cystinosis**

*Sophie Molholm, PhD*

**11:50 am - 12:10 pm      SELECT for Cystinosis: Building an International Guideline**

*Ewa Elenberg, MD*

**12:10 pm - 12:30 pm NAPRTCS Cystinosis Registry***Reeti Kumar, MD*

---

<b>12:30 pm - 1:00 pm</b>	<b>Advancing Patient-Centered Outcomes in Cystinosis: Development of the QUALIFY HrQoL Questionnaire for Pediatric and Young Adult Populations</b>
	<i>Stefanie Witt, PhD</i>

---

**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 Board Meeting - CRN Scientific Advisory Board and Medical Advisory Committee***Fine Arts Room  
Lobby Level***Closed***Acting Chair: Rick Kaskel, MD, PhD, FAAP, FASN**Open to registrants only.**All sessions held in the Senator Vandenberg Room unless noted.*