

Sunday, April 26 6:45AM-8AM ET

Omni Boston Hotel at the Seaport
Boston, MA

Meeting Room: Ensemble Ballroom C



MULTIDISCIPLINARY CARE CONSIDERATIONS IN RARE DISEASE

SPOTLIGHT ON CYSTINOSIS

This symposium session will explore best practices and emerging perspectives for optimizing comprehensive, collaborative, and truly multidisciplinary care in rare diseases, using nephropathic cystinosis as a central case study.

OBJECTIVES

- Discuss evolving needs in rare disease management and opportunities to strengthen multidisciplinary collaboration as patients with cystinosis live longer into adulthood
- Review approaches to support the delivery of comprehensive, patient-centered cystinosis care across the lifespan, including successful transitions to adult and multispecialty providers
- Explore strategies to improve patient and provider experiences, care engagement, treatment adherence, and long-term outcomes in cystinosis

SPEAKERS



Deborah Stein, MD
Pediatric Nephrologist
Boston Children's Hospital
Harvard Medical School
Boston, MA



Robert Steiner, MD
Medical Geneticist
University of Wisconsin School of
Medicine and Public Health
Madison, WI



Christina Morris
Patient Living With
Cystinosis
Charleston, SC