



2023
NEPHCURE PATIENT SUMMIT
AGENDA

THURSDAY, APRIL 20

3:00 PM - 7:00 PM

REGISTRATION OPEN

North Tower Convention Foyer

7:00 PM - 9:00 PM

DESSERT WELCOME RECEPTION

Coronado Terrace

FRIDAY, APRIL 21

7:45 AM - 8:30 AM

BREAKFAST

San Diego Ballroom A

8:30 AM - 8:40 AM

WELCOME

Kelly Helm, NephCure

Executive Director of Patient Engagement

San Diego Ballroom A

8:40 AM - 9:10 AM

STATE OF NEPHCURE

Josh Tarnoff, NephCure Chief Executive Officer

San Diego Ballroom A

9:15 AM - 10:15 AM

INTERACTIVE BREAKOUTS

Kidney-Friendly Cooking & Nutrition

Chef Duane Sunwold, Chef & FSGS Patient

Chef Sachet Walker, Chef & Patient Parent

Rancho Santa Fe 2

9:15 AM - 10:15 AM

INTERACTIVE BREAKOUTS

Preventing Caregiver & Care Partner Burnout

Jessica Patay, Founder/President of We Are Brave Together
San Diego Ballroom A

10:15 AM - 10:45 AM

BREAK/EXHIBIT HALL

Presidio Rooms

10:45 AM - 11:45 AM

PHYSICIAN-LED BREAKOUTS

The Impact of RKD Research: Where We Are Now

Sanya Norouzi, M.D. – Loma Linda University Medical Center
Chia-shi Wang, M.D., MSc – Children’s Healthcare of Atlanta
San Diego Ballroom A

Innovations in Kidney Transplant

Paul Grimm, M.D. – Stanford University
Rancho Santa Fe 1

Pediatric RKD: Your Questions Answered

Gabriel Cara-Fuentes, M.D. – Children's Hospital Colorado
Rancho Santa Fe 2

Adult RKD Foundations & Updates

Laura Mariani, M.D. – University of Michigan
Torrey Pines 1

11:45 AM - 1:00 PM

LUNCH/EXHIBIT HALL

Presidio Rooms

1:00 PM - 2:00 PM

INTERACTIVE PATIENT BREAKOUTS

Peer Connections Adult Support Group - Live!

San Diego Ballroom A

RKD & Me Writing Workshop

Michelle Huie, Travers Therapeutics Senior Manager of Corporate Communications
Rancho Santa Fe 1

Parents Place Support Group - Live!

Rancho Santa Fe 2

FRIDAY, APRIL 21

2:10 PM - 3:15 PM

COPING WITH CO-MORBIDITIES PATIENT PANEL

Moderated by Montrez Lucas, LMSW,
NephCure Associate Director of Patient
Navigation

San Diego Ballroom A

3:15 PM - 3:45 PM

SNACK BREAK/EXHIBIT HALL

Presidio Rooms

3:45 PM - 4:45 PM

FDA FIRESIDE CHAT: THE PROMISE OF RARE

Aliza Thompson, M.D., M.S., Deputy Director of
the Division of Cardiology & Nephrology, Center
for Drug Evaluation and Research at the U.S.
Food and Drug Administration

San Diego Ballroom A

4:45 PM - 5:00 PM

CLOSING

San Diego Ballroom A

5:00 PM - 6:00 PM

EXHIBIT HALL/PHARMA INFORMATION SESSION & POSTER PRESENTATIONS

Presidio Rooms

SATURDAY, APRIL 22

8:00 AM - 9:00 AM

BREAKFAST

San Diego Ballroom A

8:45 AM - 9:00 AM

MORNING WELCOME

San Diego Ballroom A

9:00 AM - 10:15 AM

STRATEGIES FOR COPING WITH RARE DISEASE

25 Years of Lessons Learned (Key Note)

Al Freedman, Ph.D., FCA

San Diego Ballroom A

SATURDAY, APRIL 22

10:15 AM - 10:45 AM

BREAK/EXHIBIT HALL

Presidio Rooms

10:45 AM - 12:00 PM

BEING YOUR BEST ADVOCATE PATIENT PANEL

Moderated by Kelly Helm, NephCure Executive
Director of Patient Engagement

San Diego Ballroom A

12:00 PM - 1:30 PM

COMMUNITY CONNECTIONS

LUNCH & AWARDS

San Diego Ballroom A

1:30 PM - 1:45 PM

CLOSING

San Diego Ballroom A

1:45 PM - 2:30 PM

EXHIBIT HALL

Presidio Rooms

