



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

San Diego Ballroom B

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 - 9:00 AM

STATE OF NEPHCURE

Josh Tarnoff, NephCure Chief Executive Officer

San Diego Ballroom A

9:00 AM - 9:10 AM

A SPECIAL SAN DIEGO WELCOME

Eric Dube, Traverre Therapeutics 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
San Diego Ballroom A

Preventing Caregiver & Care Partner Burnout

Jessica Patay, Founder/President of We Are Brave Together
Rancho Santa Fe 1 & 2

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

Sayna 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

San Diego Ballroom A

1:00 PM - 2:00 PM

INTERACTIVE PATIENT BREAKOUTS

Peer Connections Adult Support Group - Live!

Marla Cass, Adult Patient & NephCure Volunteer
San Diego Ballroom A

RKD & Me Writing Workshop

Mari Andrew, Author, Artist, & Speaker
Torrey Pines 2

Parents' Place Support Group - Live!

Dana Levine, Patient Parent & NephCure Volunteer
Rancho Santa Fe 2

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, U.S. FDA
Kirtida Mistry, M.D. — Pediatric Nephrologist,
Division of Cardiology & Nephrology, U.S. FDA
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 - 8:30 AM

EXHIBIT HALL

Presidio Rooms

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**

Al Freedman, Ph.D., FCA

San Diego Ballroom A

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

