

MORE THAN YOU CAN IMAGINE

26 FEB
2026



KENTUCKY STATE CAPITOL
EDUCATION CENTER

706 CAPITAL AVE FRANKFORT, KY
12:30PM-2PM

EQUITY FOR RARE DISEASES MEANS
MORE BREAKTHROUGHS
THAN YOU CAN IMAGINE.



Hello, we're Ayça and Burak from Türkiye and we live with Spinal Muscular Atrophy (SMA).

EQUITY FOR RARE DISEASES MEANS
MORE COMMUNITY
THAN YOU CAN IMAGINE.

Hello, I'm Micah from the USA and I live with Danon's Disease.



EQUITY FOR RARE DISEASES MEANS
MORE HOPE
THAN YOU CAN IMAGINE.



Hello, I'm Linges Warry Apparao from Malaysia, and I live with Nemaline Rod Myopathy.

EQUITY FOR RARE DISEASES MEANS
MORE OPPORTUNITIES
THAN YOU CAN IMAGINE

Hello, I'm Mak from France and I live with an Ectodermal Dysplasia and a transplanted kidney.



Event Itinerary

Children's crafts available the entire duration of the event.

- ◆ 12:30pm-12:40pm- Raffle Tickets
 - Place raffle ticket in the sponsored raffle box of your choice, 1 per person
- ◆ 12:40pm-1:40pm- Speakers
 - Official 2026 Rare Disease Day video
 - **Kellie Vanasse** - President of The Kentuckiana Connective Tissue Foundation, Patient with hEDS
 - **Robert Myrick** - KY NORD Ambassador, Patient with AHUS
 - **Sarah Teeters** - Advocacy & Outreach Division Manager and ADA Coordinator for Louisville Metro Government
 - **Roger Davis II, DPT** - Clinic Director at Owensboro Health
 - **Ben Keeton** - Partner at RunSwitchPR
 - **Abby Pike, LPCA** - Psychotherapist
 - **Melissa Raley & Katie-Ryan Fotiadis** - Advocate & Chronic Illness Warrior
 - **Kayla Eggleston** - Patient with hEDS, Student in Bellarmine's Radiation Therapy Program
 - **Amanda Gabehart** - Independence Seekers Project, Community Engagement Coordinator, GPA Vasculitis Patient
 - **Kristie Jesionek** - Infusion Sales Trainer & Learning Manager at Optum
 - **Kristina Pond, MD** - Internal Medicine Physician, Patient with hEDS
- ◆ 1:40pm-2pm- Raffles Announced/Networking
 - Texas Roadhouse
 - Normalyte
 - Louisville Zoo
 - Southern Soirees Bakery
 - Thornberry's Bakery
 - Danni's Dessert
 - Moonstone Lashes
 - GM Cleaning Solutions

