

#RARE  
DISEASE  
DAY

# 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

THIS EVENT IS PRESENTED BY THE KENTUCKIANA CONNECTIVE TISSUE FOUNDATION,  
A QUALIFIED 501(C)(3) TAX-EXEMPT ORGANIZATION. EIN: 99-4789427

