

#RAREAWARE AT A GLANCE

RARE & RURAL



2025 CAMPAIGN SUMMARY

Under the theme “Rare and Rural,” the annual #RareAware public education campaign heightened awareness globally about rare liver diseases in areas where exposure would otherwise not be. Throughout February, we highlighted the challenges and experiences faced by rural patients, collaborated with institutions to promote education and research, and advocated for policies on the hill.



PATIENT STORIES

Sharing stories is key to raising awareness about the impact that rare liver diseases have on patients. Despite the 100+ rare liver diseases, the experiences patients face are similar. **14 rural patient stories** were featured, highlighting over 11 rare liver diseases.



IS YOUR LIVER HEALTHY?

In this special podcast episode, guests discussed the challenges that patients in rural areas face when seeking care and access to clinical trials – and the pillars that are needed to help these communities participate.



Cecilia Dueñas
Founder of PBC
Research Foundation



Kristin Hatcher
Pediatric & Rare
Liver Diseases
Director, Global Liver
Institute



Harsha Rajasimha, PhD
Caregiver and Founder of
Indo-US Rare



Teresa Davidson
LAN Member, Executive
Director, Mid-South Liver
Alliance

GLI IN THE MEDIA

3.8 BILLION

Press release total potential reach

~ 400,000

#RareAware impressions across social
media portals

~ 500

Post shares/reposts across social media
portals

FEATURE STORY

Healio Gastroenterology wrote a feature story on Kristin Hatcher's journey with Alpha-1 Antitrypsin Deficiency in Mississippi and the barriers to care.

ARTICLE SERIES

The Educated Patient featured a series of 4 articles, highlighting patient stories and rural healthcare in the US, Spain, and Israel.



RARE SCIENCE FAIRS

Our pilot Rare Science Fairs program connected students in rural and low-income settings with our council members (industry, patient advocacy groups, and clinicians) to create posters about rare liver diseases and spread awareness to other students.

500 +

students and educators
learned about rare liver
diseases

11

posters presented

10

students introduced to
KOLs in the liver disease
space

3

institutions participated



COLLABORATING COUNCIL MEMBERS



GLI's Kristin Hatcher & Alyssa Davenport
with Senator Hyde-Smith, Washington D.C

ACTION ON CAPITOL HILL

Alongside the Save Rare Task Force and Everylife Foundation's Week in Rare, we brought the ORPHAN Cures Act to the table in key meetings with Senator Hyde-Smith and the office of Senator Wicker, advocating for IRA reforms to protect rare disease treatments from price negotiations and preserve incentives for research and development.

New rural resources available on our website:

- [Rare Science Fair Webpage](#)
- Save Rare Task Force Addition of our [Orphan Cures Act One Pager to their Resources](#)

THANK YOU TO OUR SPONSORS

GOLD



CONTRIBUTORS

