



2024 CAMPAIGN REPORT

RAREWARE

Rare Liver Diseases Month



TABLE OF CONTENTS

INTRODUCTION	#RareAware 2024 At a Glance	2
CAMPAIGN ACHIEVEMENTS	GLI LIVE #RareAware Series	3
	Expert Q & A Empowerment Day	4
	Educational Patient Resource Advocacy in Washington, DC	5
COMMUNICATIONS & DIGITAL MEDIA CAMPAIGN	Social Media Strategy Toolkit Patient Highlight Reels	6
APPENDIX: SPEAKERS & CONTRIBUTORS		8

“We take so many medications every day and sometimes we have to take breaks during school to make sure we get our medication.”

– Brinley, Wilson Disease, 13



#RareAware 2024 at a Glance

Campaign Summary

Under the theme of **Transitions in Care**, the annual #RareAware campaign united patients, caregivers, healthcare professionals, and key stakeholders to raise awareness and elevate the patient voice surrounding the challenges and successes faced. Together we emphasized the need for improved dialogue and support across multiple stages of care, offering actionable steps for all stakeholders to improve transitions in care processes for rare liver disease patients globally.

Key numbers

-  **3.7B**
Press Release Total Potential Reach
-  **~500,000**
Social Media Impressions
-  **~210,000**
Social Media Reach
-  **15**
Rare Diseases Highlighted
-  **33**
Countries reached
-  **4**
GLI LIVE episodes, **6** diseases
(Wilson, PSC, AIH, ASMD, PBC, PLD)



First virtual empowerment day inspired children as young as 7 to share their rare liver disease experiences and become advocates for their healthcare needs

Thank you to our Sponsors

Gold




Silver





Contributors




CAMPAIGN ACHIEVEMENTS

GLI LIVE #RareAware Series



During the month, we aired four episodes of GLI LIVE spotlighting expert patient opinions. These discussions captured the obstacles faced by individuals affected by rare liver diseases and their families and pinpointed strategies for enhancing care across various transitional phases. The episodes reached over 1,258 individuals.



From Pediatrics to Adult Care
FEBRUARY 7, 2024

Young patient advocates Evren Ayik and Sophie Hansen emphasized the need for healthcare systems to have resources and early intervention programs available that discuss challenges like insurance, obtaining medical records, and more to prepare pediatric patients for their transitions.



Forging a Path after Diagnosis
FEBRUARY 14, 2024

Cecilia Duenas and Tina Money stressed the need for healthcare professionals and industry leaders to involve patients in the decision-making process.



Navigating Liver Transplantation
FEBRUARY 21, 2024

Maria Morais emphasized the need for empathy from healthcare professionals and beyond to support recovery, especially during both the pre- and post-transplant processes.



Caregiving through Transitions
FEBRUARY 28, 2024

Kathy Spence and Alice Williams emphasize that caregivers are vital support systems for patients advocating for enhanced support systems and specific resources to combat these challenges.

EXPERT Q&A

Physician experts provided insights into the challenges encountered by patients during major transitions in care:



Six tips to Help Your Patients through Organ Transplantation

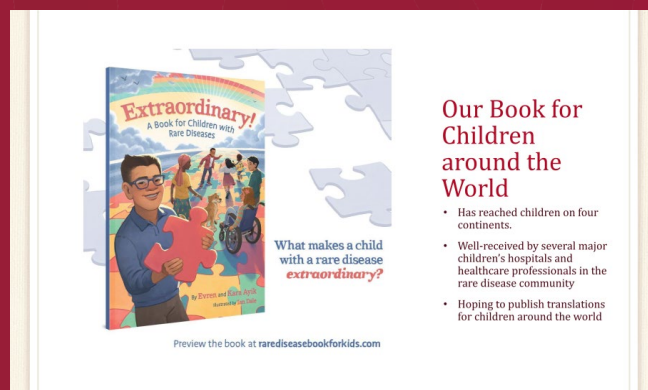
Alin Gragossian, DO, shared crucial aspects of patient care post-transplant, including areas that require additional attention from healthcare providers during the transition phase.

Six Ways to Ease Financial Stress for Patients with Chronic Liver Conditions

Nneka Ufere, MD, offered recommendations to enhance financial support within hospital systems. Robust financial support can be critical to success for patients transitioning to outpatient care or accessing new healthcare specialists.

EMPOWERMENT DAY

Our inaugural virtual empowerment seminar created a chance for children to share their stories about living with rare liver diseases, with guidance from experts. This virtual webinar successfully amplified the pediatric patient voices to begin their advocacy journeys.



Our Book for Children around the World

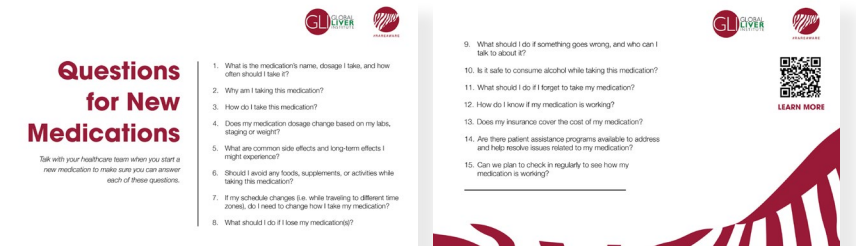
- Has reached children on four continents.
- Well-received by several major children's hospitals and healthcare professionals in the rare disease community
- Hoping to publish translations for children around the world

Our speakers, Dr. Ahmad Anouti and Evren Ayik, shared their experiences with their own rare liver diseases.

- Children as young as 7 bravely shared their experiences
- Diseases: Wilson disease, biliary atresia, acid sphingomyelinase deficiency
- 4 children took the opportunity to share their story with the group, and one noted it was the first time they had ever shared.

EDUCATIONAL PATIENT RESOURCE

We collaborated with GLI ambassadors to develop a resource to support all liver disease patients since medication usage and comprehension can be daunting for patients during care transitions.



ADVOCACY IN WASHINGTON D.C.

On the Hill

GLI partnered with Everylife Foundation for Rare Disease Week on Capitol Hill to advocate for the Medical Nutrition Equity Act (H.R. 6892) and reform in FDA drug approvals for rare diseases. We have obtained the endorsement of at least one Republican senator for H.R. 6892.



At NIH

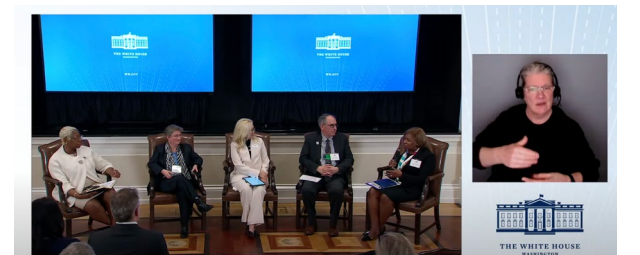
GLI participated in Rare Disease Day at the National Institutes of Health (NIH) on February 29, 2024, by initiating conversations with new and existing advocacy partners, researchers, and healthcare experts to amplify the patient voice in advocacy. Through collaborative conversations, we discussed challenges and explored solutions to seize advocacy opportunities in the upcoming year.



Left to Right:
1) Alpha-1 Foundation and GLI
2) PBC Foundation and GLI
3) Harsha K Rajasimha, Founder of IndoUS and Kristin Hatcher, GLI's Pediatric and Rare Liver

At the White House

GLI Board of Directors member Shonta Chambers moderated an enlightening session on technological breakthroughs in rare diseases during the White House Rare Disease Forum.

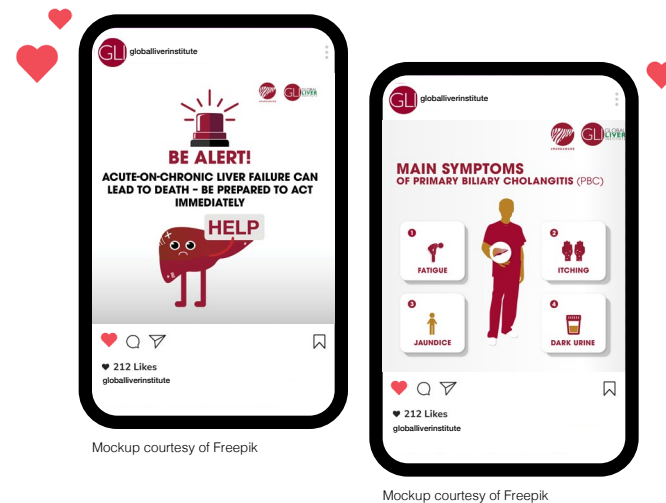


COMMUNICATIONS AND DIGITAL MEDIA CAMPAIGN

Social Media Strategy

Drawing from lessons from previous years and campaigns, the team decided to boost engagement and impact of social media content.

GLI focused on short-form videos, which consistently have the greatest reach and engagement and can be created from roundtable, panel, and GLI LIVE episodes; these posts, as expected, were some of the most successful.



Mockup courtesy of Freepik

Mockup courtesy of Freepik



Toolkit

To stimulate the circulation of important information and to spark engaging discussions, GLI provided a digital toolkit with educational graphics for patients, caregivers, and advocacy partners to join the conversation and raise awareness about rare liver diseases.

Patient Highlight Reels

GLI sought to bring a human element to the discussion of liver diseases and provide a platform for those impacted by these conditions to share their stories.

By sharing stories of hope, tragedy, diagnosis, challenges, and triumph; we elevated the stories of individuals living with rare liver diseases and shed light on the steps it took to manage their conditions.



Ahmad Anouti, MD - Biliary Atresia Patient and Postdoctoral Fellow in Hepatology

APPENDIX: SPEAKERS & CONTRIBUTORS



Donna R. Cryer, JD
 Founder and Chief Executive Officer
 Global Liver Institute
[LinkedIn](#)



Ahmad Anouti, MD
 Postdoctoral Research Fellow in Hepatology
 University of Texas Southwestern
[LinkedIn](#)



Evren Ayik
 Acid Sphingomyelinase Deficiency Advocate
 Co-Author, *Extraordinary! A Book for Children with Rare Diseases*



Anna Lin
 Pediatric & Rare Liver Diseases
 Program Coordinator
 Global Liver Institute
[LinkedIn](#)



Sophie Hansen
 PSC and AIH Patient and Advocate
 University of Utah



Cecilia Dueñas Fryckman, MD
 Licensed Clinical and Pediatric Psychologist
 PBC Patient and Advocate
[LinkedIn](#)



Tina Money
 Polycystic Liver Disease Patient and Advocate



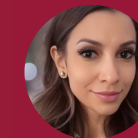
Maria Morais, RN
 Registered Nurse and Patient Advocate
[LinkedIn](#) [Canadian PBC Society](#)



Alice Williams
 Board Member
 Wilson Disease Association
[LinkedIn](#) [Wilson Disease Association](#)



Kathy Spence
 Board Member
 Childrens PSC Foundation
[LinkedIn](#) [Childrens PSC Foundation](#)



Alin Gragossian, DO
 Emergency/Critical Care Doctor
 Equum Medical
[LinkedIn](#) [Personal Blog](#)



Nneka Ufere, MD
 Transplant Hepatologist
 Massachusetts General Hospital
[LinkedIn](#) [Massachusetts General Profile](#)

ABOUT

GLOBAL LIVER INSTITUTE

Global Liver Institute (GLI) is a 501(c)3 nonprofit organization founded in the belief that liver health must take its place on the global public health agenda commensurate with the prevalence and impact of liver illness. GLI promotes innovation, encourages collaboration, and supports the scaling of optimal approaches to help eradicate liver diseases. Operating globally, GLI is committed to solving the problems that matter to liver patients and equipping advocates to improve the lives of individuals and families impacted by liver disease. GLI holds Platinum Transparency with Candid/GuideStar, is a member of the National Health Council, and serves as a Healthy People 2030 Champion. Follow GLI on [Facebook](#), [Instagram](#), [LinkedIn](#), and [YouTube](#) or visit www.globalliver.org.



“This is the first time I’m talking about my disease, I have never told my story to anyone before.”

- Meadow, 10 | Wilson Disease

It all starts with a patient.

