

# #RareAware 2023 Campaign Report

**Global Liver Institute**

Third Annual Rare Liver Diseases Month



#RAREAWARE



GLOBAL  
**LIVER**  
INSTITUTE



#RAREAWARE



GLOBAL  
**LIVER**  
INSTITUTE

**It all starts w**

with a patient

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“To protect the lives of these parents and their children, we call for enhanced primary care systems to promote timely diagnosis and comprehensive care for pregnant people and their babies.”



Donna R. Cryer, JD  
President & CEO  
Global Liver Institute

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# #RareAware 2022 at a Glance

## Campaign Summary

Global Liver Institute (GLI), the premier patient-driven nonprofit organization founded in the belief that liver health must take its place on the global public health agenda, led the third annual Rare Liver Diseases Month in February 2023. The annual #RareAware campaign aims to raise awareness and education about rare liver diseases. Under the theme of **Pregnancy and Parenthood**, this month-long, multifaceted, interactive campaign included robust digital communication, roundtables, educational resources and more. The campaign focused on improving the patient experience, removing barriers to access and care, and expanding on the need for more patient engagement in research protocols.

### KEY NUMBERS



**3.5 B**

Press Release



**421,871**

Impressions



**181,394**

Reach



**7,103**

Engagements

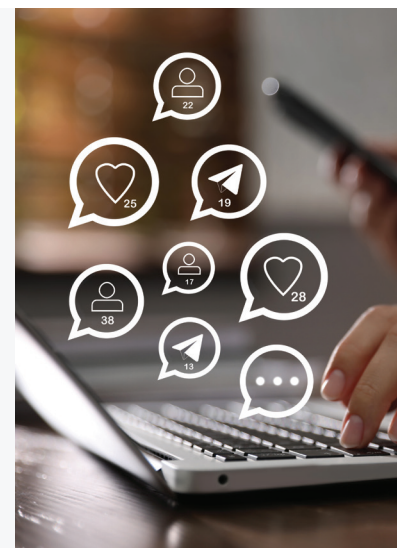


**3**

Roundtables

## KEY PROGRAM ACTIVITIES

- Digital Campaign
- Patient Highlights
- Patient and Caregiver Education and Resources
- Advocacy and Patient Engagement
- GLI LIVE episodes
- #RareAware roundtables




# Overview and Background

With estimated 400 million people worldwide living with rare diseases, rare liver diseases continue to pose a significant global challenge.<sup>1</sup> Unfortunately, the exact number of people with rare liver diseases is still unknown – and patients continue to wait for effective treatment options. This makes it critical to increase awareness of these diseases' existence and realities. To address this issue, the inaugural #RareAware campaign was developed in 2021. The #RareAware campaign prioritizes health equity, productive conversations between patients and the healthcare industry, and inclusivity across all age groups. It also brings together family members, caregivers, and members of GLI's Pediatric and Rare Liver Diseases Council for a month of support, advocacy, and advancement.

The 2023 campaign engaged with the social, emotional, and healthcare challenges related to rare liver diseases that pregnant women and parents face. To address the lack of awareness placed on rare liver diseases during pregnancy, the campaign utilized weekly themes to underscore the occurrence of rare liver diseases during pregnancy and throughout various life stages. We also facilitated conversations among industry, policymakers, clinicians, researchers, and regulators to enhance patient care and mitigate the presence of barriers and challenges to patient access and care from a patient, family, and provider perspective.

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**400 MILLION** people  
worldwide live with  
rare diseases.

# Campaign Goals



**Reach** out to patients, caregivers, families, medical societies, providers, industrial companies, patient advocacy groups, and more using GLI social accounts.

Through weekly patient features, Council member spotlights, and new guests on GLI LIVE, we connected with a new audience of parent interest groups and more to join the fight against pediatric and rare liver diseases.



**Advocate** for better health outcomes and lifestyle for pregnant women, neonates, pediatric patients, and parents who face rare disease.

GLI established new partnerships to identify and address gaps in maternal, neonatal, and pediatric care for rare liver disease patients to discuss challenges and advocate for effective solutions. Ongoing collaborations with medical professionals, patient advocacy groups, and community organizations will improve care and support for patients throughout their journey.



**Recognize** and address the unmet needs of women, parents, neonates and pediatric patients in rare liver diseases.

GLI identified key needs after robust conversations with maternal and pediatric communities during roundtable discussions and GLI LIVE episodes, as well as comments and feedback from the community.



**Educate** rare liver patients, families, providers, and other stakeholders about unmet needs and next steps in maternal, neonatal, and pediatric care.

We utilized social media to highlight less common diseases through a “Be #RareAware” series that highlighted daily diseases. Our social posts, GLI LIVE discussions, and roundtable conversations also served as a channel for information flow about unmet needs and potential solutions in maternal, neonatal, and pediatric liver disease.

# Weekly Areas of Focus

To further spread awareness on **pregnancy with liver disease and rare liver diseases related to pregnancy**, we proposed an ambitious, educational, and interactive set of programs, leveraging partnerships, technology, passion, and global perspectives to change the trajectory of rare liver disease and improve the patient experience.

## WEEK 1

*Realities of Parenthood and Pregnancy in Rare Diseases*

## WEEK 2

*Equity in Medicine for Parents and Pregnant Patients*

## WEEK 3

*Care in Rare for Moms, Parents, and Caregivers*

## WEEK 4

*Policy and Advocacy in Healthcare*





# Communications and Digital Media Campaign

Through a global outreach strategy, GLI expanded its audience, amplifying the voices of patients and caregivers and highlighting rare liver diseases. Parents, pregnant women, and rare liver disease patients were encouraged to share their stories with the public, medical community, legislators, and regulators through the form of videos, photos, and quotes.



FEBRUARY 2023 RARE LIVER DISEASES MONTH						
MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
<b>Week 1: Realities of Parenthood and Pregnancy in Rare</b>						
30	31	1 Pregnancy's Rare Liver Odyssey <a href="#">Go to video</a>	2	3 Patient highlight	4 Extraordinary! A Book for Children with rare liver diseases Rare Storytime	5
<b>Week 2: Equity in Medicine for Parents and Pregnant People</b>						
6 The Provider Perspective on Patient Access Roundtable	7	8 Driven to Fight Inequity in Maternal & Neonatal Care <a href="#">Go to video</a>	9	10 Patient highlight	11	12
<b>Week 3: Care in Rare</b>						
13 Parents and Partners Roundtable	14	15 Parenthood in Rare Liver Diseases <a href="#">Go to video</a>	16 Launch of educational resources	17 Patient highlight	18	19
<b>Week 4: Policy &amp; Advocacy in Rare</b>						
20 Patient Advocacy in Rare Liver Diseases Roundtable	21	22 Maternal and Neonatal Care in Italy and Cameroon <a href="#">Go to video</a>	23	24 Patient highlight	25	26
<b>Week 5: The Future of the Rare Community</b>						
27	28	1	2	3	4	5

This campaign featured the launch of the very first #RareAware branded merchandise including a hoodie, a beanie, and a mug.

GLI also provided a social media toolkit that included sample language, educational posts, and more. Through these initiatives, GLI promoted a more comprehensive and informed understanding of rare liver diseases while empowering patients and their families.

## Press Release

On February 1, 2023, a press release was shared on the newswire announcing the third annual rare liver diseases month campaign entitled “Obstetric and Neonatal Professionals Must Work More Closely with Pregnant People to Identify Liver Diseases Early.”



*The release earned a wide variety of media attention including placements in Yahoo Finance, the National Post, and Fox 8.*

### KEY METRICS



**3.5 B**

Press Release Total Potential Reach



**770**

Full Text Placements



**5.8K**

Total Views

### AUDIENCE



## Social Media

The #RareAware campaign showcased underrepresented communities and individuals at risk on Facebook, Instagram, YouTube, and LinkedIn with patient stories that highlighted the experiences of pregnant women, caregivers, parents, and children within the rare liver disease community.

### KEY NUMBERS



**422**

Posts



**421,871**

Impressions



**181,394**

Reach



**7,103**

Engagements



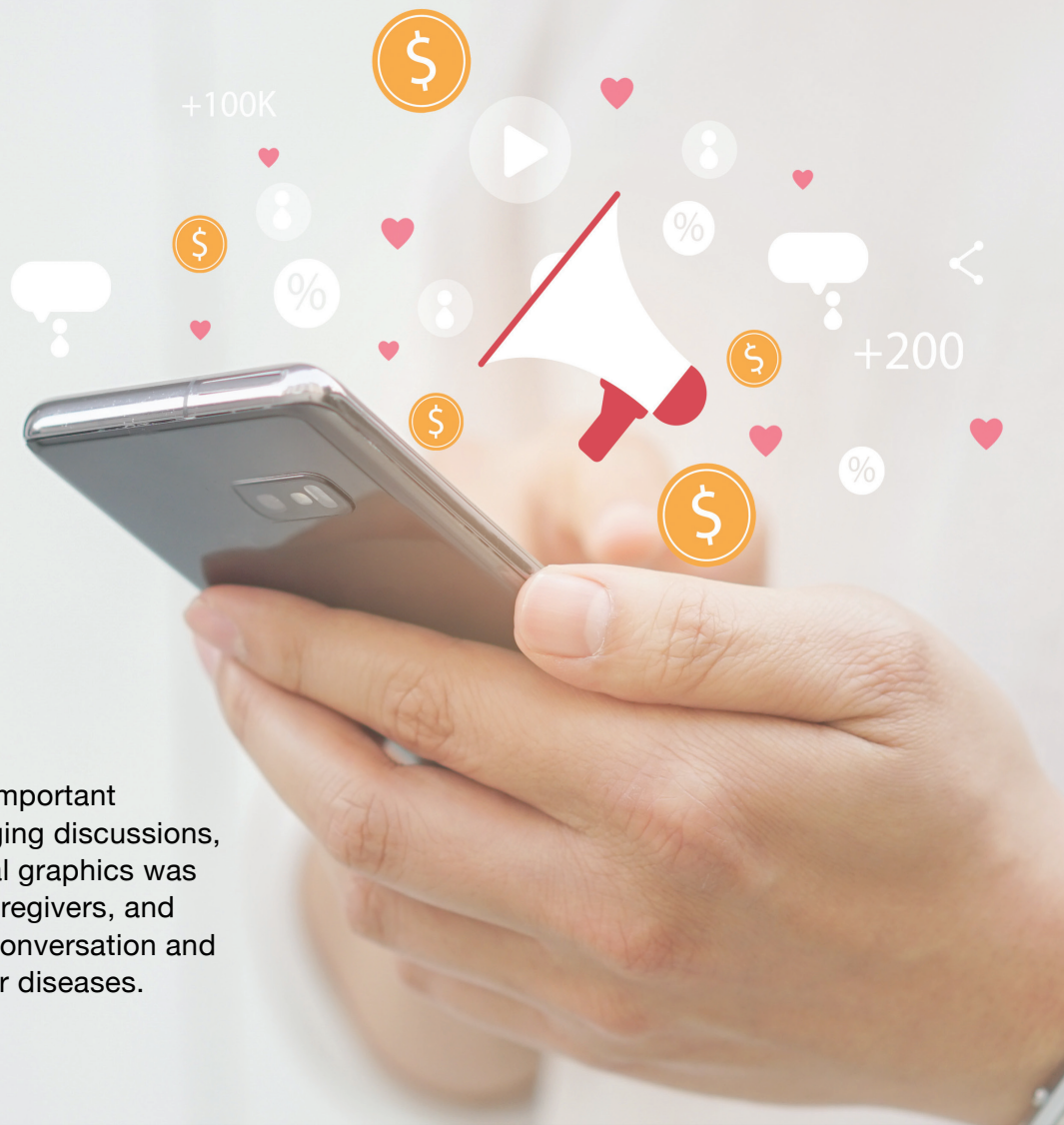
### COUNTRIES MOST ENGAGED IN THE CAMPAIGN

1. United States
2. United Kingdom
3. Canada
4. India



This year, Instagram was an instrumental advocacy tool, extending the campaign's reach and impact through increased interaction with the maternal health community.





## Toolkit

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

## SELECTED SOCIAL MEDIA TOOLKIT MATERIALS





## Be #RareAware Series

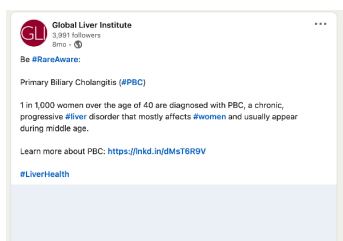
There are over 100 different rare liver diseases. Through our “Be #RareAware” series we focused on 13, often overlooked diseases, including: Intrahepatic Cholestasis of Pregnancy (ICP), Biliary Atresia (BA), Primary Biliary Cholangitis (PBC), Alagille Syndrome (ALGS), Lysosomal Acid Lipase Deficiency (LAL-D), Urea Cycle Disorder (UCD), Preeclampsia, Glycogen Storage Disease (GSD), Primary Sclerosing Cholangitis (PSC), Alpha-1 Antitrypsin Deficiency (AAT), Zellweger Spectrum Disorder, Infantile Liver Failure Syndrome, Wilson’s Disease.



### TOP POSTS

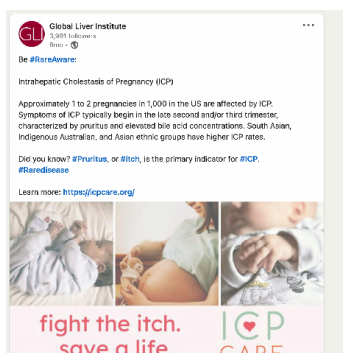
#### LYSOSOMAL ACID LIPASE DEFICIENCY (LAL-D)

LALD is a rare genetic condition in which individuals are unable to produce lysosomal acid lipase, an enzyme that breaks down fats and cholesterol. This causes an accumulation of fats in the body, including the liver.



#### PRIMARY BILIARY CHOLANGITIS (PBC)

1 in 1,000 women over the age of 40 are diagnosed with PBC, a chronic, progressive liver disorder that mostly affects women and usually appears during middle age.



#### INTRAHEPATIC CHOLESTASIS OF PREGNANCY (ICP)

Approximately 1 to 2 pregnancies in 1,000 in the US are affected by ICP. Symptoms of ICP typically begin in the late second and/or third trimester, characterized by pruritus and elevated bile acid concentrations. South Asian, Indigenous Australian, and Asian ethnic groups have higher ICP rates.



During the month, we aired four episodes of GLI LIVE with a focus on rare liver diseases. The discussions provided insights into the unique challenges faced by rare liver disease patients and their families and identified potential solutions and opportunities for improvement in care and research. The episodes reached over **2,750 individuals**.



February 1, 2023

### **The Rare Odyssey in Pregnancy**

Donna R. Cryer was joined by Dr. Guadalupe Manrique-Maldonado, PhD, a Pennsylvania ICP Care ambassador, and Colette Kenny Verdes, a licensed professional counselor with experience in maternal liver disease for in a conversation about the difficulties encountered by members of the rare liver disease community during pregnancy.



February 8, 2023

### **Driven to Fight Inequity in Maternal & Neonatal Care**

Donna R. Cryer hosted Anna Beeman, JD, President & CEO of Liver Mommas & Families, Inc; Trashaun Powell, MA, Vice President of Programs at the New Jersey Family Planning League; and Jodi Long, Director of Health Equity at Healthy Birth Day, Inc, to discuss the significant disparities in rare liver diseases in maternal, neonatal, and pediatric health.

February 15, 2023

**Parenthood in Rare Liver Diseases**

Donna R. Cryer hosted Brittany Kinsley, a BARE Inc. advocate, along with Taylor and Ashley Rhoades, parents of John, a toddler with biliary atresia, and advocates for the rare disease. The guests delved into the complexities of being a parent of a child with a rare liver disease.



February 22, 2023

**Maternal and Neonatal Care in Italy and Cameroon**

Donna R. Cryer was accompanied by Dr. Pietro Vajro, Chairman of Pediatrics at the University of Salerno, Italy; Dr. Mbianke Livanciff, a researcher of NCDs, alumnus of the Bosch Fellowship, and CEO of the Empower Women Foundation in Cameroon; and Mme. Nasah Judith Lainsi, an NCD researcher and an advocate for pediatric liver health in Cameroon. The discussion focused on the challenges and opportunities in rare liver disease care and research in different parts of the world.



# Patient and Caregiver Education and Advocacy

## Patient Highlights

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, diagnostics, complications, and joy, readers are capable to identify and relate with the story and learn from the perspectives of individuals living with rare liver diseases and the steps they took to manage their conditions.

“

I was diagnosed with HELLP during my first pregnancy. Since then I went on to have a **miscarriage at eight weeks and a pregnancy loss of our daughter at 13 weeks in 2021.**

Although we wanted a larger family, we are grateful for our family today.



**Colette Kenny Verdes**  
Mother and Licensed Professional Counselor



# #RareAware Roundtables

February 6, 2023

## The Provider Perspective on Patient Access



Doctors Bonebrake and Schwarz joined GLI CEO Donna R. Cryer to highlight ways to improve rare liver disease care, emphasizing interdisciplinary collaboration, research on mothers' long-term health, closer OBGYN relationships, and faster, safer, and cheaper noninvasive diagnostic methods. They also addressed mental health needs during the "fourth trimester" and advocated for more access to maternal care.

February 13, 2023

## Parents and Partners



Alex Summers, Kara Ayik, and Jordan Sarbaugh joined GLI CEO Donna R. Cryer to discuss gaps in rare liver disease care and identified actionable steps to address challenges. This conversation underlined the need to prioritize patients' and caregivers' time, improve caregiver education, provide more support for caregivers, increase liver nurse navigators and social workers, and strengthen advocacy and support systems.

February 20, 2023

## Patient Advocacy in Rare Liver Diseases



Patient advocates Donna Benavides and Jennifer Lau joined GLI CEO Donna R. Cryer to emphasize the importance of early detection methods for liver diseases and the need for physicians, patient advocates, and patients to collaborate. They called for more attention to be given to rare liver disease, including during prenatal stages, and for a global effort to find solutions and answers collaboratively, particularly in finding a cure for biliary atresia and intrahepatic cholestasis of pregnancy.

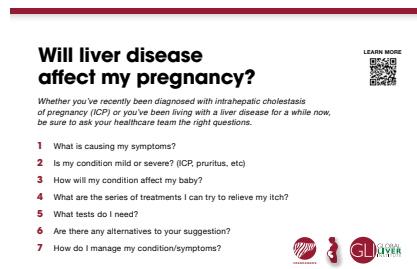
# NEW!

During Rare Liver Disease Month, GLI released three educational resources for patients: Will Liver Disease Affect My Pregnancy?; Questions about Cholestatic Pruritus to Expect from your Healthcare Provider; and Managing your Cholestatic Pruritus.

These resources emphasize the importance of effective communication between healthcare providers and individuals diagnosed with rare liver diseases. With a focus on cholestatic pruritus and rare liver diseases during pregnancy, these resources provide comprehensive guidance to patients who are wondering what they should expect at their next doctor's visit and how to be better prepared to manage their own care.

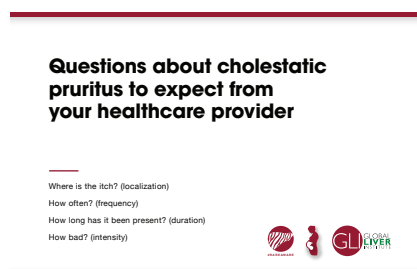
NEW

## Rare Liver Disease Resources



### Will Liver Disease Affect My Pregnancy?

Asking the right questions can help you better understand your condition, its severity, and how it may affect your baby. This resource supports expectant mothers with intrahepatic cholestasis of pregnancy (ICP) or liver disease during pregnancy. It provides tailored information and guidance, empowering expectant mothers to understand the condition's impact and engage effectively with their healthcare team.



### Questions about Cholestatic Pruritus to Expect from Your Healthcare Provider

This resource addresses questions about cholestatic pruritus that patients can expect from their healthcare provider. It emphasizes the importance of discussing symptoms and encourages patients to share their opinions and concerns. By doing so, patients can actively contribute to the development of a comprehensive treatment plan to their condition.





## Managing Your Cholestatic Pruritus



### Avoid items or situations that cause you to itch

Try to **identify** what's causing your symptoms and avoid it. This might include wool clothing, rooms that are too warm, frequent hot baths, or a specific cleaning product.



### Moisturize daily

Apply **hypoallergenic** and **fragrance-free** moisturizer to affected skin at least once a day. For dry skin, thicker creams and ointments may work better than lotions.



### Treat your scalp

You might need to try several products before finding one that works for your hair and condition, or you may find that alternating between products helps. For a dry, itchy scalp, consider trying **over-the-counter (OTC) medicated shampoos** designed to treat dandruff. Don't use a medicated shampoo right after a chemical relaxing process — rather, use a neutralizing shampoo.



### Reduce stress and anxiety.

Stress and anxiety can worsen itching. Many people have found that techniques such as **counseling**, **behavior modification therapy**, **acupuncture**, **meditation**, and **yoga** can help reduce stress or anxiety.

## Managing Your Cholestatic Pruritus

This resource focuses on managing cholestatic pruritus, a condition that causes discomfort and disrupts daily life. It highlights various effective management tools in order to help individuals cope with symptoms and improve their quality of life.

check out these resources and more at <https://globalliver.org/pediatric-rare-liver-diseases-council/resources/>



## Liver Action Network

The Liver Action Network has been built to learn, share, and train to become a force that ensures that liver diseases have their proper place on the global public health agenda. The LAN members showed their support to the campaign by sharing the social media graphics from the toolkit, hosting webinars, and shining a light on the many barriers present in the rare community.



*February is*

**RARE  
LIVER  
DISEASES  
MONTH**

Global Liver Institute's **Liver Action Network** supports increased awareness of rare liver diseases particularly those affecting children and pregnant women.

### LAN MEMBERS





# Next Steps

## Emerging Priorities

The healthcare gaps faced by the rare liver disease community were substantial, particularly within maternal, neonatal, and pediatric populations. As GLI takes the next steps, we recognize the importance of identifying and prioritizing key areas of focus in the field of maternal and neonatal health in rare liver diseases.



## Action Areas

To drive positive change and address the needs of individuals and families affected by pediatric and rare liver diseases in pregnancy, we will focus on three key areas.

1. Actively improve health literacy for patients by developing resources focused on rare liver diseases, including during pregnancy.
2. Collaborate with research institutions and key stakeholders to establish and drive policy adoption and implementation of an agenda that recognizes and addresses rare liver conditions at all stages, including during pregnancy.
3. Invite and empower affected patients to join GLI's Advanced Advocacy Academy (A3), equipping them with the skills to effectively advocate for their needs and rights during all stages of rare liver disease, including pregnancy.

Through targeted initiatives, partnerships, and advocacy efforts, we will drive action in each of these priority areas. Individuals with cholestatic pruritus manage their symptoms and improve their quality of life.

## Sponsors

We appreciate the support of Global Liver Institute's 2023 #RareAware program by the following sponsors:

### GOLD



### CONTRIBUTORS



## Reference

1. Fabris, L., & Strazzabosco, M. (2021). Rare and undiagnosed liver diseases: challenges and opportunities. *Translational gastroenterology and hepatology*, 6, 18. <https://doi.org/10.21037/tgh-2020-05>

# Appendix

## GLI LIVE host and roundtable moderator

**Donna R. Cryer, JD | President & CEO | Global Liver Institute**



Donna R. Cryer, JD, is Founder and Chief Executive Officer of Global Liver Institute (GLI), the premier patient-driven liver health nonprofit operating with offices and partnerships across five continents. Moved by her own experience as a 28-year liver transplant recipient, Mrs. Cryer serves as a fierce advocate for the transformative potential of patient engagement in health policy, research, data, and system design.

Through GLI, Mrs. Cryer has raised more than **\$10 million** for liver health initiatives and convenes more than 200 organizations within the liver cancers, nonalcoholic steatohepatitis (NASH), pediatric and rare liver diseases, and general liver health communities across GLI's Councils and its Liver Action Network, facilitating collaborative multi-stakeholder agenda setting and bringing accountability to innovation, regulation, and adoption of best practices to optimize outcomes.

Her expertise and effectiveness in advancing the voice of patients in defining and designing equitable healthcare has been recognized by the United States Congress and the White House. In 2021 Mrs. Cryer received both the Global Genes RARE Champions of Hope Founder's Award and the American Association for the Study of the Liver (AASLD) Distinguished Advocacy Service Award. She has been named one of the Top Blacks in Healthcare by the Milken Institute at the George Washington University School of Public Health and BlackDoctors.org, one of the Top 10 Patients Who Make An Impact by Health 2.0, and one of PharmaVoice's 100 Most Inspiring People.

Mrs. Cryer serves on the Boards of Directors for the Council of Medical Specialty Societies (CMSS), Sibley Memorial Hospital/Johns Hopkins Medicine, and the Color of Crohns and Chronic Illness (COCCI). She also serves on the Executive Committee for the Clinical Trials Transformation Initiative and the Board of Advisors for ChronWell, Inc, a digital health and therapeutics company. She was the first patient to serve on the American Board of Internal Medicine Gastroenterology Specialty Board, was one of the founding members of the AASLD Patient Advisory Committee, and is the Community Representative on the AASLD NASH Task Force.

Mrs. Cryer makes frequent appearances on broadcast media and podcasts; on platforms such as The Washington Post Live, SXSW, and *The Atlantic*; and speaks at top healthcare and business conferences including Biotechnology Innovation Organization (BIO), Pharmaceutical Research and Manufacturers of America (PhRMA), America's Health Insurance Plans (AHIP), National Minority Quality Forum (NMQF), National Comprehensive Cancer Network® (NCCN), and the National Academy of Medicine (NAM).

Mrs. Cryer received an undergraduate degree from Harvard and a Juris Doctorate from the Georgetown University Law Center.

# **GLI LIVE Speaker Biographies**

February 1, 2023

## Pregnancy's Rare Liver Odyssey



### **Colette Kenny Verdes | Licensed Professional Counselor, Parent & Family Solutions, LLC**

Colette, a Licensed Professional Counselor, offered care, compassion, support, and a safe space for individuals to process and honor their experiences. With a passion for grief work, Colette specializes in areas such as miscarriage, perinatal loss, pregnancy complications, maternal health, and the NICU experience. She was a certified Compassionate Bereavement Care Provider via the MISS Foundation, Elisabeth Kubler-Ross Family Trust, and the Center for Loss and Trauma. Colette employed the ATTEND model, emphasizing mindfulness as a way of being and working with grief.

Colette's advocacy and work were informed by her personal experience with preeclampsia and the development of extreme hemolysis, elevated liver enzymes, and low platelet count (HELLP) syndrome shortly after her first pregnancy. The HELLP syndrome caused bleeding outside the brain, providing Colette with a unique perspective on the challenges faced by patients dealing with rare liver diseases during pregnancy and parenthood.



### **Guadalupe Manrique-Maldonado, PhD | ICP Care Ambassador, Pennsylvania Science Writer, Teknova Neuropharmacologist**

Guadalupe Manrique-Maldonado is the Pennsylvania Ambassador for ICP Care. In 2017, she experienced the most common symptom of intrahepatic cholestasis of pregnancy (ICP): itchiness in the palms of the hands and soles of the feet. Her healthcare provider dismissed her symptoms, causing a delay in diagnosis. Fortunately, she gave birth to a healthy baby at 37 weeks. Two years later, when she became pregnant again, she was proactive about researching and advocating for herself. With a supportive healthcare provider, they caught ICP at 35 weeks. At 36 weeks, she was at the hospital for a non-stress test when her baby went through fetal distress. Guadalupe emphasizes the importance of raising awareness about ICP, as it is still treated as an uncommon disease, and of the mental exhaustion and trauma that pregnant mothers and their families may experience. She believes that every pregnant woman should be informed about ICP and that advocacy for oneself is crucial. ICP Care was a valuable resource for her during her pregnancy.

February 8, 2023

## Driven to Fight Inequality in Maternal and Neonatal Care



### **Anna Beeman, JD | President & CEO, Liver Mommas & Families, Inc**

Anna has over ten years of experience in the nonprofit sector, serving as a Director, Board member, and volunteer. Her career has been focused on nonprofit capacity building. In her most recent roles as Director of Volunteer Northwest Mississippi and Director of Community Education with the Foundation, she engaged with over 140 nonprofit organizations, providing support in volunteer recruitment & retention, grant writing, development, and overall strategic organizational management. Currently, Anna is the CEO and President of Liver Mommas & Families, a nonprofit organization dedicated to supporting families, pediatric liver transplant facilities, and advocating for pediatric patients and their families.



### **Jodi Long | Health Equity Director, Healthy Birth Day, Inc.**

Jodi Long serves as the Health Equity Director for Healthy Birth Day Inc. Long advocates for stillbirth prevention, addresses racial disparities that exist in birth outcomes and leads efforts to expand the conversation about health equity and stillbirth prevention in America. Jodi previously worked as a morning television news anchor at WHO-13 on Today in Iowa. She began her career at WHO-13 in 2013 as a multimedia journalist before moving to the anchor desk. Jodi has received numerous accolades, awards, and Emmy nominations for her journalism work on maternal health disparities, human trafficking, and racial justice issues in Iowa.

For Jodi, the best part about working in the news industry was connecting and informing. She has had the opportunity to meet celebrities and politicians but it's the everyday people in the community who have an important story to tell who are the most influential in Jodi's life. Jodi considers herself an Iowa native although she was born in Illinois. She graduated from Ankeny High School and returned to Iowa after graduating college from the University of Northwestern – St. Paul in St. Paul, Minnesota. She lives in Clive with her husband, Ra Shaan and their son Bishop.



### **Trashaun Powell, MA | Vice President of Programs, New Jersey Family Planning League**

Trashaun Powell is a Certified trauma specialist and maternal health advocate based in New Jersey. She experienced a near-death pregnancy as a result of HELLP Syndrome, which led to the birth of her daughter Mia Jane at just 23 weeks. Sadly, Mia passed away two days later due to severe prematurity. Trashaun uses her voice to raise awareness about the maternal mortality health crisis and advocate for continued research and funding for a cure for Preeclampsia. She serves as an advocate with the Preeclampsia Foundation and a Certified Patient Family Partner with MoMMA's Voices, drawing on her professional and personal experience to create meaningful change.

February 15, 2023

## **Pregnancy's Rare Liver Odyssey**



### **Ashley Rhoades | Mother and Advocate**

Taylor and Ashley Rhoades are the parents of John Anthony Rhoades, who was diagnosed with biliary atresia at one month and three days old. After the Kasai Procedure failed, John was placed on the transplant list in September 2021 and received a new liver on April 26th, one day before his first birthday. John has been thriving since the transplant, and he is cared for and loved by his two sisters, Arabella Marie and Avalynn Jane. The Rhoades family currently resides in Newcastle, Oklahoma, but they are originally from Texas.



### **Brittany Elliser | Board Member, Louisiana Organ | Procurement Agency | Board Member, BARE Inc.**

Brittany Elliser is a CPA who specializes in working with exempt organizations. Her youngest son was diagnosed with biliary atresia and underwent three liver transplants within his first year of life. This experience inspired Brittany to become an advocate for organ donation, and she currently serves as an active board member of the Louisiana Organ Procurement Agency and BARE, Inc.



**Taylor Rhoades | Director of Cardiology, Pulmonary, and Pain Management Services (Mercy Hospital Ardmore) | Diversity Officer (Oklahoma Communities)**

Taylor Rhoades is a healthcare leader with a passion for improving the healthcare field. He is currently the director of Cardiology, Pulmonary, and Pain Management Services at Mercy Hospital Ardmore. With a background in hospital operations, Taylor has led several teams in various healthcare systems, delivering financial department goals while maintaining the best patient quality measures and outcomes. He is currently pursuing a Master of Healthcare Administration from George Washington University and the Milken Institute School of Public Health. Taylor and Ashley Rhoades are the parents of John Anthony Rhoades, who was diagnosed with biliary atresia at one month and three days old.

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February 22, 2023

## **Maternal and Neonatal Care in Italy and Cameroon**



**Mbianke Livancliff Mforjock, MD, MPH | NCD researcher | Bosch Alumni Fellow | CEO, Empower Women Foundation**

Dr. Mbianke Livancliff Mforjock serves as the National Coordinator in Cameroon for Value Health Africa for Value Health Africa, demonstrating exceptional leadership and expertise in his role. With a deep commitment to the well-being of the country's healthcare system, Dr. Mforjock has made significant contributions towards improving healthcare access and quality. His dedication and tireless efforts have positively impacted the lives of countless individuals in Cameroon.



**Nasah Judith Lainsi, MPH | NCD Researcher | Liver Health Educator**

Nasah Judith is a public health epidemiologist with specialized knowledge of human research and a particular focus on HIV/AIDS research in Cameroon. She played a significant role in facilitating the implementation of the project on the website and organizing, planning, and implementing the first October liver day event in Cameroon, bringing together patients, caregivers, and health personnel. Judith holds a Master's



degree in public health and a Bachelor of Education in Curriculum Studies and Teaching from the University of Buea, as well as a diploma in nursing. She is currently a Research Officer for the International Epidemiological Database to Evaluate AIDS (IeDEA-CA), and she heads research development at Empower Women Foundation, where she has contributed significantly to research implementation, particularly in relation to HIV and comorbidities.



### **Pietro Vajro, MD | Chairman of Pediatrics at University of Salerno**

Professor Pietro Vajro is a renowned pediatrician with extensive training in Italy, France, and the USA. He currently works at the Faculty of Medicine and Surgery - Baronissi (Salerno), University of Salerno as a Full Professor of Pediatrics, Director of the Clinical Pediatrics Section, and Director of the Residency Training Program in Pediatrics. His research is focused on Gastroenterology, Hepatology, Nutrition, and Pediatrics, and he has published numerous papers in these fields.

# **Roundtable Speaker Bios**

February 6, 2023

## **“The Provider Perspective on Patient Access” Roundtable**



### **Kathleen Schwarz, MD | Pediatric Gastroenterologist, Rady Children's Hospital**

Dr. Kathleen Schwarz is a distinguished pediatric gastroenterologist at Rady Children's Hospital-San Diego and an Associate Physician Diplomate at UC San Diego School of Medicine. She is certified by the American Board of Pediatrics in pediatrics, pediatric gastroenterology, and pediatric transplant hepatology, with a research focus on both typical (hepatitis B and C) and atypical viral infections of the liver, which can act as triggers for biliary atresia and autoimmune hepatitis.



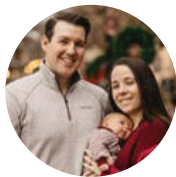
**Laura Bonebrake, MD | OB/Gyn Physician | Board Member, ICP Care**

Nasah Judith is a public health epidemiologist with specialized knowledge of human research and a particular focus on HIV/AIDS research in Cameroon. She played a significant role in facilitating the implementation of the project on the website and organizing, planning, and implementing the first October liver day event in Cameroon, bringing together patients, caregivers, and health personnel. Judith holds a Master's degree in public health and a Bachelor of Education in Curriculum Studies and Teaching from the University of Buea, as well as a diploma in nursing. She is currently a Research Officer for the International Epidemiological Database to Evaluate AIDS (IeDEA-CA), and she heads research development at Empower Women Foundation, where she has contributed significantly to research implementation, particularly in relation to HIV and comorbidities.

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February 13, 2023

**“Parents and Partners” Roundtable**



**Alex Summers | Partner of preeclampsia patient, Cristina Summers**

Alex Summers has an educational background in public health and environmental science and works with a company that manages clinical trials for clients. He and his wife, Cristina Summers, have a son named Leo and enjoy spending time outdoors with their three dogs, Roscoe, Leia, and Ripley, as well as relaxing at home with their two cats, Rosemary and Wednesday, and two bunnies, Cooper and Connie.



**Jordan Sarbaugh | Co-Founder & VP at BARE Inc**

Jordan Sarbaugh has over a decade of experience in the business sector, specializing in logistics/supply chain and real estate/property management. She has excelled in implementing operating best practices, establishing and maintaining key performance metrics, adhering to current compliance requirements, business transition/implementation, and operational training. Her roles have developed her key skills in project management, business process management, and employee development.



### **Kara Ayik | Author of “Extraordinary! A Book for Children with Rare Diseases”**

Kara, an experienced educator of over twenty years, and her son Evren co-authored the children’s book *Extraordinary* to uplift children with rare diseases. They promote compassion and respect for children with rare diseases and special needs, believing that children must cultivate true self-worth and values to help them navigate life’s journeys. Evren’s advocacy work for people with ASMD began in 2017, and he has since spoken to audiences in several states to raise awareness and support for treatments for rare diseases. He plans to become a special education teacher and currently attends California State University, Fresno.

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February 20, 2023

## **“Patient Advocacy in Rare Liver Disease” Roundtable**



### **Donna Benavides | Founder & Board Chair, ICP Care**

Donna Benavides is the Founder and CEO of ICP Care, the world’s largest patient advocacy group for cholestasis of pregnancy, a condition she experienced in all of her pregnancies. She is the mother of three children, two healthy boys, Branden and Evan, and an angel baby, Jorden. ICP Care provides patient support and education, provider education, raises public awareness, and supports the advancement of research to improve healthcare practices.



### **Jennifer Lau | Co-Founder & President, BARE Inc**

Jen Lau holds a Bachelor’s degree in Mass Communications from Southern Illinois University-Carbondale and has taken Master’s level courses in Human Resources Management from Keller Graduate School of Management. With over 20 years of experience in Business Management and Human Resources, she has worked in Higher Education, Banking, Healthcare, and IT industries. After her oldest son was diagnosed with Biliary Atresia and received a liver transplant at nine months old, Jen discovered her passion for advocating for pediatric liver disease and transplantation. She has held leadership roles in various transplant organizations and co-founded BARE Inc. in January 2022. Jen currently lives with her husband and two children in the western suburbs of Chicago, IL.







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