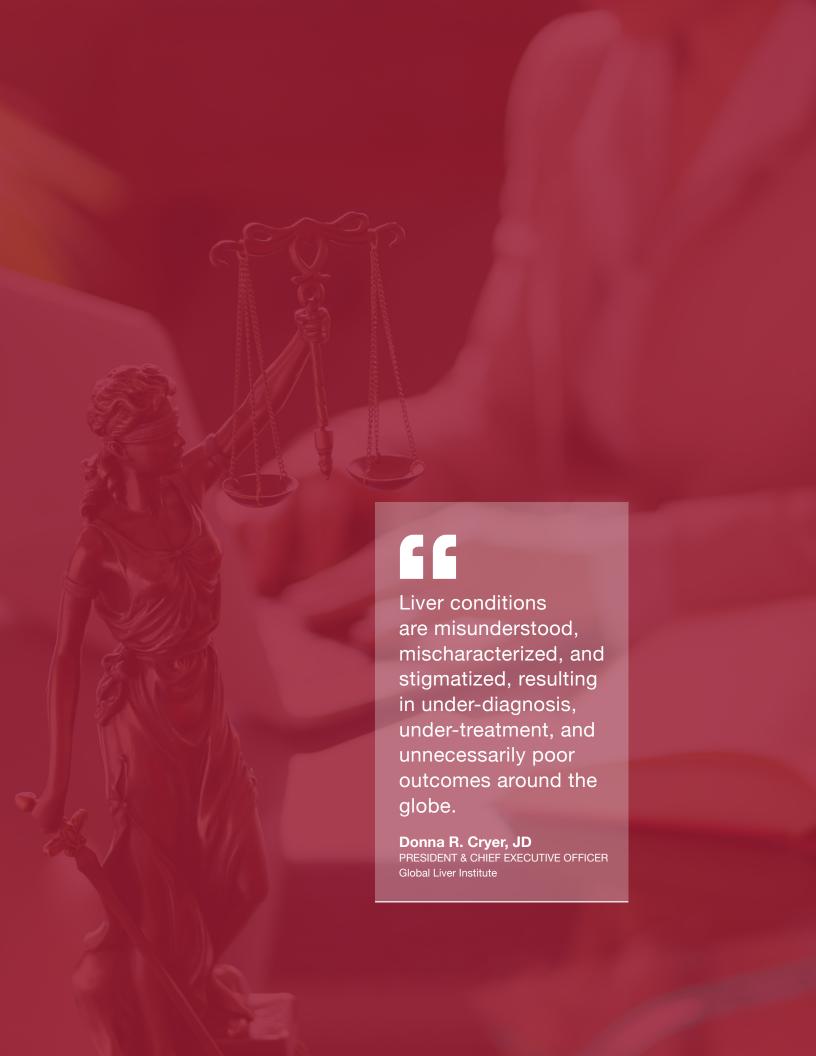


# Global Liver Institute 2022 Annual Report



**Strengthening Global Partnerships** 



# Global Liver Institute 2022 Annual Report



# Strengthening Global Partnerships

To launch one landmark program to reshape global advocacy in hepatology would be enough for most, so, of course, Global Liver Institute launched two in 2022 - the Liver Health is Public Health initiative and the Center for Liver Health Equity.

From cooking videos with celebrity Chef Daniel Thomas to a liver cancer awareness campaign with Major League Baseball legend Bernie Williams to conceiving a national hepatitis C plan with former NIH Director, now White House official, Dr. Francis Collins, we ensured that liver health was brought to the forefront of major conversations.

Through communication campaigns, podcasts, and TV interviews; presentations in Paris, Prague, and the UK; and articles in *Runner's World* and *Politico*, we carried the importance of liver health and the powerful potential of partnership with liver patients to **71** countries in **16** languages.

Our array of activities serve a singular purpose – to elevate liver health to a place on the global public health agenda so as to compel action commensurate with its prevalence and impact – which are enormous.

Over 1.5 billion people are currently living with some form of liver disease, an underestimation given our known gaps in screening, diagnosis, coding, and data capturing.<sup>1</sup>

Our growth is not for our own sake, but to be sufficient to nourish others. This year we were able to award almost \$100,000 USD



Donna R. Cryer, JD, & Chef Daniel Thomas



One Liver to Love campaign with Bernie Williams



Donna R. Cryer, JD, at Milken Institute Future of Health Summit



Donna R. Cryer, JD, & Francis Collins, MD, PhD

in community grants that increase the capacity of patients, caregivers, and providers, across the world, to design and deliver solutions in the most effective language and relevant culture. We have been recognized as a Healthy People 2030 Champion by the US Department of Health and Human Services and joined major advocacy organizations as a Member of the National Health Council.





NASH 24x7 Bike-a-Thon on International NASH Day in India



"Walking in the Wood" event in North Macedonia

Our visibility allows us to illuminate both problems and problem solvers as we did in our second Leadership in Liver Health Luncheon, honoring the work of Dr. Leana Wen, author, CNN on-air commentator, *Washington Post* contributing columnist and professor of health policy, as the first recipient of the Global Excellence in Health Communications Award and Dr. Michelle McMurray-Heath, Former President & CEO of Biotechnology Innovation Organization, recipient of our Global Excellence in Health Equity Award.

Our strength through partnerships demonstrates the effectiveness of a collaborative model that incorporates more than 200 organizations in our Liver Action Network, councils, campaigns, and global events – fortifying partnerships around the world. Liver patients and the issues that matter to them are no longer isolated or ignored. As you read this report, I invite you to dream up how you and your organization might be involved in this global fight for liver health in the next year.



**Donna R. Cryer, JD**President & Chief Executive Officer

Global Liver Institute



GLI staff & advocates at The Liver Meeting®

# **Our Mission**

To improve the lives of individuals and families impacted by liver disease through promoting innovation, encouraging collaboration, and scaling optimal approaches to help eradicate liver diseases.

# **Our Vision**

For liver health awareness to be universal and for liver disease to take its proper place on the global public health agenda consistent with its prevalence and impact.

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# **Board of Directors**



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Board Chair

MANAGING DIRECTOR, HUMAN CAPITAL

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# Staff



**Donna R. Cryer, JD**PRESIDENT & CHIEF EXECUTIVE OFFICER
Global Liver Institute



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Larry Holden
CHIEF OPERATING OFFICER
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Cat Evans
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Program Operations



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Sarah Manes
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Liver Cancers



**Joel Ballew**DIRECTOR
Strategic Partnerships



Nicole Wells
PROGRAM MANAGER
Advanced Advocacy Academy



**Lily Benig**SENIOR COORDINATOR
Communications



Alexis Story
PROGRAM COORDINATOR
Advanced Advocacy Academy



Paige Brown
COORDINATOR
Graphic Design



Erik Soto
PROGRAM MANAGER
Liver Health is Public Health



Paula Boccalon
PROGRAM COORDINATOR
Liver Cancers



**Ainsley Amundson**MANAGER
Operations



Royze Cachero
PROGRAM MANAGER
Pediatric & Rare Liver Diseases

# 2022 at a Glance

# **January**

• VP of Liver Health programs provides insight on liver health in *Runner's World, Bicycles,* and *YahooLife* 

# **February**

- Second annual Rare Liver Diseases Month (#RareAware campaign)
- First primary biliary cholangitis (PBC) Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD)

# March

• Launch of #LiverHealthisPublicHealth (LHPH) initiative with a special feature in the 2022 Your Liver supplement in *The Guardian* 

# **April**

- GLI hosts virtual screening of *Burden of Genius* transplantation documentary and accompanying panel on equity in liver transplantation
- CEO Donna Cryer discusses LHPH on Washington ABC7

# May

- First GLI Advanced Advocacy Academy (A3) Caregiving and Well-Being Summit
- GLI publishes Op-ed published in The Hill about unexplained pediatric hepatitis
- CEO Donna Cryer discusses liver disease on Washington USA9

# **June**

- GLI's fifth annual International NASH Day, including NASH screening around the world
- Keynote NASH Day event, "From Progress in the Control of Viral Hepatitis to the Rising Epidemic of NASH" at the Embassy of Italy
- GLI participates in EASL, Aspen Ideas: Health, and ASCO conferences

# July

- · First A3 Payer Summit
- GLI elevates the patient voice at the AASLD/EASL NAFLD Nomenclature Consensus Conference in Chicago

# **August**

- Launch of One Liver to Love partnership with Bernie Williams, former NY Yankees player, musician, and caretaker to his mother with liver disease
- Donna participates in White House launch of hepatitis C elimination project with Dr. Francis Collins

# September

- Successful A3 symposium, featuring new ambassador tracks
- GLI speaks at Paris NASH and the Research! America Annual Forum Reception

# **October**

- Launch of the GLI Center for Liver Health Equity
- · Leadership In Liver Health Luncheon
- 5th annual #Octoberls4Livers campaign including the launch of a cooking series, Fighting Liver Cancers with Food, with celebrity Chef Daniel Thomas
- Donna discusses National Liver Awareness Month on Washington ABC7
- Launch of LHPH's inaugural Global State of Liver Health report

# **November**

- CEO Donna Cryer delivers the patient keynote address at The Liver Meeting®, "Liver Health Equity: Overcoming Stigma, Access, and Policy Barriers"
- Donna featured on Slater Success Live and Ellevate Network
- GLI participates in Global Genes Summit

# December

- Membership growth for GLI's NASH Council, Liver Cancers Council, and Pediatric and Rare Liver Disease Council
- Donna quoted in *Politico*, *Stat+*, and *Her Success Story*
- Donna speaks at Milken Institute Future of Health Summit

# **Special Initiatives** of the Office of the CEO

Launch of the Center for Liver Health Equity

A commitment to health equity has been at the heart of GLI since its inception; for instance in April, during Donate Life Month, we hosted a screening of the documentary Burden of Genius paired with an expert panel discussion on equity in transplantation. This commitment will be furthered through our Diversity, Equity and Belonging initiatives and now through our new Center for Liver Health Equity, launched at our Leadership in Liver Health Luncheon in October.





From Burden of Genius to Benefit of Genius: Creating an Equitable Organ Donation and Transplant System

Moderator:

Panelists:

Donna R. Cryer, JD Nicole Golden, DNP, FNP-BC Edward Drake

Co-Founder

Black Liver Health Initiative

Founder & CEO

The YNOTT? Foundation

"

What if every patient had the opportunity to live their fullest life? That's what we intend to do by helping advocacy organizations be more diverse and welcoming."

**Donna R. Cryer, JD** from remarks at the luncheon

Pervasive inequities in prevalence and outcomes in liver health among disadvantaged communities necessitate the coordination, prioritization, and leadership of the new Center.

GLI has convened an expert advisory board diverse as the group of liver patients around the world to guide the direction of the Center. Following their leadership we will more sustainably advance a future for liver health without inequities in access and outcomes.

Following this launch, Mrs. Cryer advanced the essence of the Center in her patient keynote address at The Liver Meeting® on November 5, during which she discussed "Liver Health Equity:

Overcoming Stigma, Access and Policy Barriers."



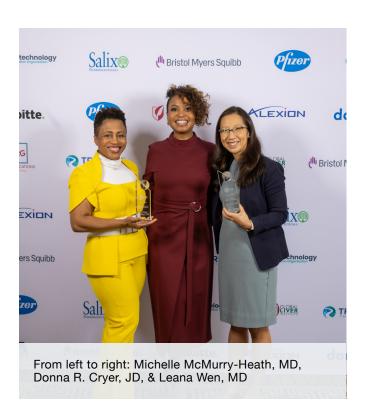


See more of our leadership in health equity on page 62

# **Leadership in Liver Health Luncheon**

GLI's Leadership in Liver Health Luncheon returned for its second year on October 17, at the Hay-Adams Hotel in Washington, D.C. While recognizing key leaders, we raised awareness and support for liver health as a critical pillar of public health.

We were delighted to recognize Dr. Michelle McMurry-Heath, Former President & CEO of Biotechnology Innovation Organization, and Dr. Leana Wen, author and professor of health policy and management at George Washington University Milken Institute School of Public Health and author, for their trailblazing in health equity and health communication.





"

# Public health hinges on public trust



"What if each & every one of us walked in our calling & our truth & stood by it no matter what the consequences? That is how we are going to change the world."

Michelle McMurry-Heath, MD



Donna R. Cryer, JD, Michelle McMurry-Heath, MD, & guests



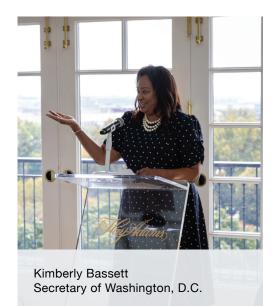
Giusi Condorelli MD, Science Attaché for Health at the Embassy of Italy in Washington



Donna R. Cryer, JD, & Victor J. Reyes, MBA, GLI Board Chair



GLI Team (from left to right): Joel Ballew, Daniel Nam, Christine Maalouf, Donna R. Cryer, JD, Jeff McIntyre, Larry Holden







# Liver Health Policy

GLI's Policy efforts created opportunities for liver advocates and Liver Action Network organizations and worked collaboratively with regulators, research agencies, and public health departments on a variety of initiatives with the goal of urging a full recognition of the unique perspective and ability of patients to contribute to the understanding of their condition and treatment management.

In 2022, Global Liver Institute worked at the national and global levels to actively shape public policy by:

- Elevating liver health as public health
- Encouraging collaboration across sectors
- Collectively implementing legislative and regulatory approaches that are patient-centric
- Advancing community goals and initiatives specific to liver health
- Increasing collective collaboration



# **2022 GLI Policy Impact**

Successfully elevated liver health within 7 U.S. Federal Agencies and Task Forces and:

- Promoted liver research initiatives
- Released the NASH External Led Patient -Focused Drug Development (EL- PFDD) meeting outcome report
- Led stakeholder groups to hold PBC EL-PFDD meeting
- Supported a letter by Consumers for Quality Care that Urges Approval of Rule to Reinstate Critical Nondiscrimination Protections in the Affordable Care Act
- Supported the Medical Nutrition Therapy (MNT) Act
- Submitted comments on the Institute for Clinical and Economic Review (ICER) draft scoping document for assessing treatments for NASH
- Supported a letter to House and Senate Appropriations leaders regarding funding for the NIH's Office of Nutrition Research (ONR)
- Led the first A3 Caregiving and Well-Being Summit and Payer Summit

# Primary Biliary Cholangitis Externally-Led Patient-Focused Drug Development Meeting (PBC EL-PFDD)

On February 4, GLI held an EL-PFDD meeting focused on PBC, thereby facilitating communications between the liver health advocacy community and the U.S. Food and Drug Administration (FDA). Clinical and patient experts joined GLI to discuss the unmet needs of PBC patients, providing input on the condition's impact on daily life, therapy risk and benefit tradeoff, and urgency for developing therapies for regulators' and clinical researchers' considerations. These perspectives can inform the FDA's decisions and oversight during both drug development and during review of a marketing application.



As delineated in the PBC EL-PFDD Report (see page 50 to learn more about the report), a few key themes emerged:

- O The diagnosis and treatment pathway for PBC patients remains riddled with stigma, isolation, and resulting despair, in large part because of common perceptions of liver disease and the rarity of the disease.
- O Although PBC patients are interested in participating in clinical trials, many barriers preclude their access and involvement, including distance, accommodation, and costs. The vast majority of surveyed patients, as a result, had not participated. Additional remote/ decentralized trial options and additional participant support could alleviate these obstacles.
- O Fatigue, even more than hallmark symptoms of PBC, emerges as the most disruptive symptom to quality of life for most patients. As new treatments are developed, this concern should be front-of-mind.

"The medicine seems to be doing its job slowing the progression down. What isn't slowing down, though, is the pain and fatigue

### **Bob Tyler**

Patient advocate, PBC/AIH patient of 9 years



# Advanced Advocacy Academy

# **Overview**

On September 17-18, Global Liver Institute successfully held its sixth annual Advanced Advocacy Academy (A3), a two-day virtual symposium for liver patients, caregivers, and professionals seeking to elevate their advocacy knowledge and skills needed to advocate for liver health.

The virtual experience, hosted on an interactive platform, was constructed to introduce participants to a broad set of advocacy areas in which they could focus their future endeavors as an effective patient advocate. These areas included media, storytelling, research and development, clinical trials, state and federal legislation, support, self-care and more. A3 is the first step in GLI's ongoing training and support for advocates, which provides them with the information, skills, and opportunities needed to advocate effectively for liver health.



# 

"Patients, families, and providers all know how important the liver is to the body. We should know it as policymakers... We want to make sure we listen and act on your needs. We support you!"

Congresswoman Sheila Jackson Lee 18th District - Texas



# A3 2022 at a Glance

4	CONTINENTS
	•
9	COUNTRIES
81	ADVOCATES
23	U.S. STATES
23	SPEAKERS
2	DAYS OF LIVE ONLINE SESSIONS AND WORKSHOPS

# **A3 Impact**

**Empowered** liver advocates to effectively champion the diverse needs and concerns of the liver patient community

**Convened** a global cohort of liver health advocates to learn advocacy methods and identify intersections of needs and capabilities for patient and caregiver action

**Instructed** interactive media training to maximize impact of public speaking opportunities

**Conducted** interactive media training to enhance advocates' public speaking skills and effectively share their stories

**Educated** on how to advise best on the design of patient-centered clinical trials, support patients' enrollment and recruitment to appropriate trials, and create long-term relationships between principal investigators and patients/patient organizations in their communities



"We have an opportunity, perhaps once in a generation, to not only address HCV, but to cure it... there is no reason to delay, we just have to figure out how to do it."

**Francis Collins, MD, PhD**Acting Science Advisor to President Biden

"The real power of an organization are the strong advocates around the country. Advocates spend a good deal of their time educating members of Congress. Make sure your legislator is aware of how the legislative agenda affects you."

### **Dale Dirks**

Digestive Disease National Coalition's (DDNC) Washington Representative

### GLI Ambassador Kickoff Conversations:

Among the curriculum offered, GLI's Patient Ambassador workshops were for the first time available to returning advocates.

### **Clinical Trials Ambassadors**

During the session, moderators discussed the characteristics of patient-centered protocols, identified barriers to enrollment and retention in clinical trials, and instructed participants on building relationships with clinical trial researchers in academics and the community.

### **Digital Health Ambassadors**

Moderators discussed the nuances of digital literacy, including selecting and connecting health apps, privacy and security issues related to patient-generated health data, patient access, and data sharing through patient portals.

### **Support Group Ambassadors**

As part of this workshop, participants learned why support groups are important and how to develop their own support networks to benefit patients and caregivers.

# A3 Caregiving and Well-Being Summit

On May 13, GLI held its first A3 Caregiving and Well-Being Summit, which focused on the intricacies of being a caregiver, ways to promote one's own well-being, and more.

The summit comprised three sessions:



Robert Mitchell-Thain led a panel discussion, with caregivers Geri Lynn Baumblatt Samantha Melaney, and Michael Pritchett about the challenges that caregivers face, including distraction at work and obstacles to time off.



Roy Remer from the Zen Caregiving Project led a well-being and mindfulness overview on simple mindfulness practices and benefits, including resilience, minimized reactivity, and healthy self care.



Nichole Goble, Associate Director for Community Initiatives at the Caregiver Action Network reviewed the important social health and equity concerns of caregiving – including doubled rates of depression, anxiety, and chronic illness than non-caregivers.

# **A3 Payer Summit**

On July 22, GLI hosted its first A3 Payer Summit to foster a healthy dialogue and cultivate mutual understanding in health coverage among patient and nonprofit advocates and payer professionals.

# The summit featured several insightful speakers:

In his introduction, Matthew Eyles, President and CEO of America's Health Insurance Plans (AHIP) provided a high-level overview on health insurance in the U.S. and emphasized impacts of the Affordable Care Act (ACA).



Patient, advocate, and A3 alumnus, Bruce Dimmig and Donna Cryer discussed his long journey in managing health care coverage, barriers to accessibility, and the value of care navigators and self-education.

Keynote speaker Alexander Oshmyansky, MD, PhD, founder and CEO of Cost Plus Drugs, shared the story of the innovative Mark Cuban-backed company. The Cost Plus Drugs direct-to-consumer business model aims to increase accessibility of pharmaceuticals and change the lives of liver patients and others with chronic conditions.



Dr. Yvette Oquendo-Berruz, Medical Director for CareFirst BlueCross BlueShield, and Michael Thompson, President & CEO of the National Alliance of Healthcare Purchaser Coalitions, shared prominent concerns that payers have in establishing fair, efficient health insurance programs – including case management, improved understanding of chronic conditions, and increased patient input.



The summit ended with discussions from nonprofit leaders on issues their members face as they navigate health insurance. Bill Foley, Health Insurance Advocate at Cancer Legal Care, Michael Ward, VP of Public Policy at the Alliance for Aging Research, and Rachel Derby, Executive Director of Policy and Advocacy at Patients Rising Now, each offered insight.





# LAN Chair Appointment

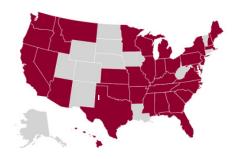
Scott Suckow of the Liver Coalition of San Diego and the Northeast Ohio Liver Alliance was appointed as the first LAN Chairperson in January and served throughout 2022. Scott's experience helped increase alliance management, facilitate collaboration within the network, and advance strategic program design and execution.

# LAN



GLI's Liver Action Network (LAN) facilitates grassroot efforts to advance liver policy at the local, state, national and international levels. The LAN operates as a first-of-its-kind network that provides community member organizations a central structure for the formulation of collective health policy and programmatic solutions.

### The LAN'S GEOGRAPHIC REACH



# Our members include

























# **Joint Advocacy Work**

The LAN actively supported and participated in GLI's campaigns, particularly International NASH Day and #Octoberls4Livers. Throughout the year, the LAN co-created and disseminated multiple statements and proclamations in response to key awareness days and campaigns such as:

- A proclamation on World Obesity Day focused on increasing awareness and acknowledgement of the strong connection between NASH and obesity.
- A statement recognizing Living Donor Day focused on urging increased awareness of living organ donation.
- O A proclamation on World Hepatitis

  Day focused on urging governors
  to formally recognize World Hepatitis

  Day by committing to instituting free
  hepatitis testing for all state employees.



# **LAN Breakfast**

Washington, DC

On November 6, GLI's Liver Action Network members and A3 advocates gathered at The Liver Meeting®. This was the first in-person activity since the inception of the LAN. Members discussed their goals, shared upcoming plans and activities, assessed policy priorities, and brainstormed potential partnerships.



# **Amplifying LAN Member Impact**

In addition to the policy work of the LAN, GLI launched a joint YouTube playlist entitled Knowledge from the Liver Action Network that consolidates liver health educational videos, interviews, and more.



# Liver Health is Public Health



During March, GLI launched *Liver Health is Public Health*, a multi-year international initiative which aims to bring liver health to the focal point it deserves in public health agendas around the world.

This initiative urges the medical field globally to consider holistic liver health as an integral part of public health from nutrition, activity, prevention, early diagnosis and management of risk factors to education, support, optimized clinical pathways, and policy for children, adults, and seniors.

The initiative was launched with a special feature in the "Liver Health" supplement in the Guardian.



# "Everyone is at risk of liver disease and should be concerned about their liver health"

Donna R. Cryer, JD President & CEO



The Liver Health is Public Health initiative will educate the public about liver health and disease prevention and will pave the way for best practices that account for differences in:

- Geographic
- Health system
- Access to care
- Culture
- Socioeconomic status
- Concurrent disease
- Prevalence

# **Initiative Goals**



**Educate** patients, providers, payers, and policymakers



**Disseminate** educational resources



Stimulate a dialogue about liver health that empowers patients, medical providers, caregivers, legislators, and payers

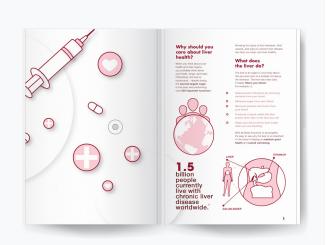


Advocate for policies that support liver health best practices

# **Initiative Resources**

### Liver Health Basics Booklet

Launched in June, this booklet provides a foundation for understanding liver health, providing the function of the liver, common symptoms of liver disease, an overview of the major types, and an outline of liver-healthy habits.



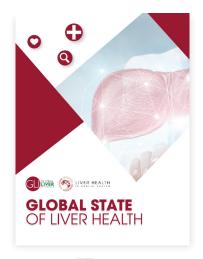
# Global State of Liver Health Report

Launched in November 2022, the Global State of Liver Health report draws from a wealth of studies and the perspectives of community experts; it defines and analyzes the landscape of liver health around the world. It is both a foundational resource and a rallying cry for clinicians, policymakers, and other community leaders to fight liver disease.

The first edition of the Report focused on 14 countries from each region of the world: Bulgaria, United Kingdom, Canada, United States, Brazil, Mexico, Argentina, South Africa, Kenya, Cameroon, Türkiye, Lebanon, India, and the Philippines.

GLI compiled scientific data and interviewed key opinion leaders from the specified countries to understand the state of liver health from experts on the ground and to reflect the different approaches taken to battle this health crisis.

Thus, the report highlights best practices and compares different outcomes from diverse health systems so that it can be used as a tool for policy makers, key clinical groups, patient groups, and the media to stimulate discussion and leverage change.





# **Endorsements**







































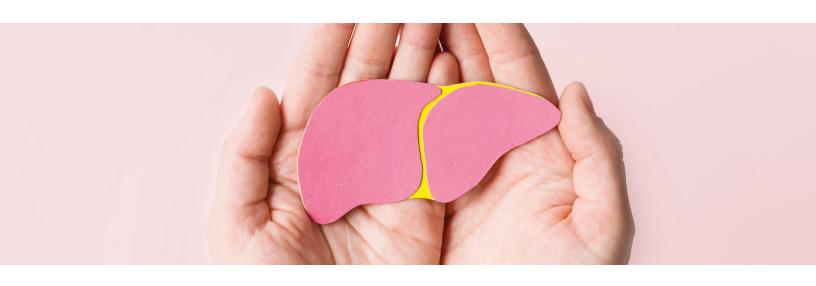












# Personal Endorsements

- Dr. Raymond Chung, AASLD Past President
- Dr. Scott Friedman, AASLD Past President
- Dr. Phil Newsome, EASL Past President
- Dr. Diana Payawal, APASL Past President
- Dr. Shivaram Singh, INASL President-Elect
- Dr. Graciela Castro, ALEH President
- Dr. Juanita Perez-Escobar, ALEH Secretary
- Dr. Mark Swain, CASL CEO
- Dr. Fulya Gunsar, TASL President
- Dr. Zobair Younossi, President of Inova Medicine
- Dr. Alessio Aghemo, Secretary of AISF

This initiative is made possible thanks to the support of Salix Pharmaceuticals and Sanofi.



sanofi

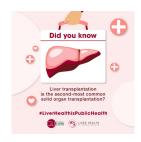


# **Social Media Toolkit**

In order for individuals and endorsing organizations to spread awareness of liver health with their communities, we prepared a social media toolkit with sample messages and graphics:











## **GLI Around the World**



### World Patients Conference | Rome, Italy

On October 15-16, Giacomo Donnini, GLI's Liver Health is Public Health Program Director, represented GLI and the voices of liver health patients at the World Patient Alliance's 1st global conference in Rome, Italy.

### Sanofi's 3rd Global Liver Health Forum

On October 7, our CEO Donna R. Cryer participated in Sanofi's 3rd Global Liver Health Forum alongside international speakers to discuss the latest updates in NAFLD. Speakers included Prof. Marek Hartleb, Head of the Gastroenterology and Hepatology Department at the Medical University of Silesia, Poland; Prof. Gert Fricker, Institute of Pharmacy and Molecular Biotechnology in the Faculty of Biosciences, University of Heidelberg, Germany; and Prof. Yimin Mao, Research Centre of Shanghai Fatty Liver Disease and Gastroenterology Department, Renji Hospital, China. Donna R. Cryer announced the launching of the first Global State of Liver Health Report, why this report is essential for policymakers as well as the general public, and how leveraging liver health can improve patient outcomes.



### Shout-Out for Liver Care

On October 10, GLI CEO Donna R. Cryer gave a presentation entitled "Living Out Loud; Creating the Next Level of Patient Advocacy for Liver Health" as part of Sanofi's Shout-Out for Liver Care Webinar series. In her presentation, Mrs. Cryer discusses the importance of patient advocacy and the essential need for an initiative such as Liver Health is Public Health.





# International Liver Congress™ London, United Kingdom

On June 22-26, the GLI team participated in EASL's International Liver Congress™ 2022 – the first international conference after the emergence of COVID-19. In addition to representing the organization at the exhibitor hall, we had the chance to reconnect in person with many of our partners and meet new leaders in the field.



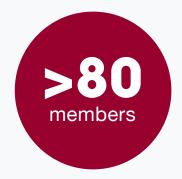
# **NASH Programs**

GLI's NASH programs mobilize stakeholders to collaboratively develop mechanisms to address the NAFLD and NASH epidemics around the world. For a disease that affects more than **1 in 4 people** in the world, progresses to cause further damage without intervention, and is linked to many other metabolic conditions that are on the rise, our portfolio helps ensure that patients are at the center of conversations about new treatments, care pathways, and diagnostic advancements amongst experts in the field.<sup>2</sup>



# **NASH Council**

The NASH Council shines a spotlight on and coalesces a set of stakeholders, including and beyond hepatology, around the urgency quantifying and addressing the silent, global epidemic of NAFLD and NASH. The NASH Council convenes twice per year and creates campaigns, materials, and monthly workgroups to advance specific concepts and programs. In 2022, the GLI NASH Council grew to more than **80 members** and expanded its global reach, welcoming new member organizations and partners in pharmacology, diagnostics, and research; as well as medical societies, patient organizations, and NGOs.





# **Beyond the Biopsy**

This multifaceted awareness campaign accelerates the acceptance and adoption of noninvasive diagnostics as an alternative to liver biopsy. Target avenues to achieve this goal include legislative, regulatory, and coverage/reimbursement changes.

# **U.S. NASH Action Plan Scorecard**



The U.S. NASH Action Plan 2022 Scorecard, a year-end scorecard for the field of NAFLD and NASH, lists the accomplishments achieved according to the detailed agenda in the U.S. NASH Action Plan. The scorecard is organized according to each relevant stakeholder group — patients/caregivers, clinicians, medical societies, patient advocacy organizations, industry, payors, health systems, regulators, and policymakers. While gaps and challenges remain, tracking and acknowledging NASH successes according to the U.S. NASH Action Plan is pivotal for the field to respond on a national scale in 2023 and beyond.





# NASH EL-PFDD Report







# On March 9, GLI launched the final NASH EL-PFDD Meeting Outcome Report.

The report provided an overview and key takeaways from the GLI-led EL-PFDD meeting on NASH on November 4th 2021 that provided regulators and drug developers the invaluable opportunity to hear from patients and caregivers directly about the challenges and burdens of this lifethreatening condition. Results from the NASH EL-PFDD meeting were also presented at the Paris NASH conference.

"I want people to know that yes, lifestyle changes can help, but there has got to be some other treatments.

### Megan Lazarone

Patient Advocate, NASH Externally-Led Patient-Focused Drug Development (EL-PFDD) Report



### **NASH Core Curriculum**

GLI, in collaboration with NASH Council member Clinical Care Options, provided the CME coursework NASH Core Curriculum: A Comprehensive Online Resource Center to improve clinician understanding of foundational concepts in NASH diagnosis, management, and emerging pharmacologic treatment strategies.

### **New Patient Resources**

# GLI produced two new printable patient resources:

- A Guide to Participating in Clinical Trials
   For Patients with NAFLD/NASH
- NASH Patient Pocket Card: 10 Questions to Ask My Doctor



These resources are designed to help patients, their families, and communities understand and assess clinical research opportunities to address NAFLD/NASH diagnosis as well as encourage dialogue with their doctors regarding clinical care. Since NAFLD/NASH are progressive, chronic, life-threatening, and global diseases, these brochures are available for patients and stakeholders throughout the world in **16 different languages**.



### GLI co-authored a report

 A Rallying Cry: Improving Coordinated Care for People With Nonalcoholic Steatohepatitis



NASH symptoms are often silent in early stages, making it difficult to diagnose. As a result, NASH patients can remain unaware of their condition or undiagnosed until it progresses to cause irreversible harm, requiring complex and costly treatment. Donna R. Cryer, JD, GLI founder and CEO, co-authored a white paper that summarized a discussion by an expert roundtable convened by the National Committee for Quality Assurance (NCQA) and outlined recommendations for increasing early diagnosis and optimizing primary care support for patients with NASH.

# **GLI Around the World**



### Surfing the NASH Tsunami Podcast

In this weekly podcast hosted by Roger Green, MBA, corporate executives, drug developers, investors, and researchers come together to discuss what is happening in the commercial development of NASH medications. GLI's President and CEO Donna Cryer and VP of Liver Health Programs Jeff McIntyre appeared as featured guests throughout season 3 of *Surfing the NASH Tsunami* and covered topics such as NASH in Black Americans, patient advocacy in **drug discovery**, and NASH/NAFLD nomenclature.



# 5th Global NASH Congress

The 5th Global NASH Congress focused on exciting advances, such as *in vivo* liver models, noninvasive diagnostic biomarkers, and preclinical and **clinical challenges** in NASH research. Jeff McIntyre, presented the patient perspective during his talk on May 26, entitled "The Voice of the Patient in Screening, Diagnosis, and Treatment of NAFLD/NASH."



# Paris NASH Meeting I Paris, France

As global leaders strategized to combat the growing prevalence of NASH, Jeff McIntyre provided the sole **patient advocacy** perspective at the 8th Paris NASH Meeting on September 8.





# Clinical Development and Operations Prague, Czech Republic

In September, GLI participated in the first Clinical Development and Operations Summit in Prague by Boehringer Ingelheim. Our VP of Liver Health Programs, Jeff McIntyre had the chance to discuss big ideas in **clinical trials** with others in the broader patient community.



# VCU Stravitz-Sanyal Institute Inaugural Academic Symposium Richmond, Virginia

On October 14 and during the inaugural symposium, Jeff McIntyre spoke about how to create a culture of participation in liver research by focusing on the role that advocacy plays.



#### The Liver Meeting® I Washington, DC

# Pan-Society Presentation of NAFLD Nomenclature Consensus Process at The Liver Meeting®

On November 6, Donna R. Cryer, J.D. presented the patient perspective on the NAFLD nomenclature consensus process and highlighted the disruption that a name change will cause for patients. She provided a critical voice – only one other speaker among the nineteen shared as a patient advocate.



#### State of the Art Lecture: Hepatocellular Carcinoma and NAFLD

On November 7, Jeff McIntyre provided the patient perspective on NAFLD, highlighting that screening efforts are needed and the importance of multidisciplinary care to improve survival, which should be considered as standard of care for patients with HCC.





#### First Annual Primary Care NAFLD and NASH Summit

On December 1, Jeff McIntyre discussed "A Solution for Every Stage: Patient Empowerment in NAFLD/NASH Care" with Heather Watson.





#### Biomarkers in NASH

On December 7, Jeff McIntyre joined patient care and industry experts for Biomarkers for NASH Symposium. His remarks, "Patient Perspective on Biomarkers and the Patient Care Pathway," discussed the role of noninvasive testing in an optimized NASH patient pathway.





# International NASH DAY # NASH DAY

The 5th International NASH Day was a tremendous global success. We felt the power in the movement as more than 70 partners from over 71 countries participated. International NASH Day 2022 garnered a record-breaking endorsement from 22 prominent organizations from around the globe.



A renewed commitment to high-quality, in-person awareness events followed the COVID-19 pandemic: Across the globe, partners hosted bike-a-thons, school seminars, held press conferences and interviews on live talk shows, and more. all as part of our efforts to #StopNASHNow. At the same time, partner organizations developed timely messages to promote liver health on social media, produced high-quality videos, and convened experts for virtual webinars to combat NASH. From the United States to Ghana to India and more, GLI's partners have stepped up to the occasion and met their community's needs in thoughtful, creative ways.





# International #NASHDay at a Glance

**78** 

**#NASHDAY PARTNERS** 

8

71

**COUNTRIES** 

515

FREE LIVER HEALTH SCREENINGS

22

INTERNATIONAL ENDORSEMENTS

**,...** 

4.3 B

PRESS RELEASE POTENTIAL REACH

0

>15 M

**#NASH DAY IMPRESSIONS** 











### Keynote Event at the Embassy of Italy

The Embassy of Italy in the US, in tandem with Global Liver Institute, hosted a series of presentations on June 14 entitled "From Progress in the Control of Viral Hepatitis to the Rising Epidemic of NASH" to highlight the bilateral efforts to improve liver health in Italy and the United States. Italy is one of only 12 countries in the world on track to achieve the objectives set by the World Health Organization in 2016 for the elimination of hepatitis. Ambassador Mariangela Zappia and subsequent speakers emphasized the collaboration between Italy and the US on longstanding and emerging challenges in liver health. GLI's CEO, Donna Cryer, JD, provided concluding remarks recognizing the transformative, collaborative work in science, medicine, and public health between the two nations.



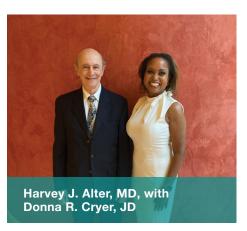


In liver disease, progress takes leadership, as we've seen by Italy's screening program. It takes leadership, as we've seen in Italy's invitation to the Global Liver Institute today and its invitation in hosting so many transformative men and women in science. And it also takes patient leadership.

Donna R. Cryer, JD



The event included presentations from Harvey J. Alter, MD, Distinguished NIH Scientist Emeritus, Department of Transfusion Medicine, Clinical Center, National Institute of Health (NIH), 2020 Nobel Prize Winner in Medicine; Michael Lederman, MD, Professor Emeritus, Departments of Medicine and Pathology, Case Western Reserve University School of Medicine, Cleveland Medical Center, Editor in Chief of *Pathogens and Immunity;* Michael F. Iademarco MD, MPH, Rear Admiral and Assistant Surgeon General in the US Public Health Service, Deputy Assistant Secretary for Science and Medicine in the Office of the Assistant Secretary of Health; Carolyn Wester, MD, Director of the Division of Viral Hepatitis, CDC; and Patrizia Farci, MD, Chief, Hepatic Pathogenesis Section, Laboratory of Infectious Diseases, National Institute of Allergy and Infectious Diseases, NIH.





# Liver Cancers Programs

GLI's Liver Cancer programs convene interested parties across the field to innovate in treatment and prevention of the sixth most common and third deadliest cancer in the world. Given the fact that over 70% of cases of liver cancer are preventable with available knowledge and technology, the portfolio of multifaceted interventions and communications meets a critical global need to close the gap for vulnerable populations and increase the five-year survival rate of liver cancers.

#### **Liver Cancers Council**

With nearly 60 members, GLI's Liver Cancers Council brings together committed stakeholders across the liver cancer community to share expertise and direction about programs and initiatives addressing all aspects of the liver cancer continuum. The council consists of international patient advocacy organizations, individual healthcare professionals, medical societies, and corporate partners.

#### The core focus and goals of the Liver Cancers Council are:



- Education and Support
- Policy and Advocacy
- International Involvement
- Screening and Early Detection





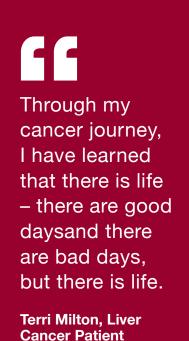


#### #Octoberls4Livers

# #Octoberis4Livers Campaign

Following the theme Driving Equity in Liver Cancers, the fifth annual #Octoberls4Livers campaign paved a path towards a more equitable future of liver health around the globe. Activities such as episodes of GLI LIVE focused on liver cancers, and versions of patient and provider resources in French, Mandarin, and Spanish were complemented by a suite of new activities including a cooking series (Fighting Liver Cancers with Food), and equity-focused roundtables with trailblazers in the Asian/Asian American, African/Black American, LatinX/Hispanic, and LGBTQIA+ liver cancer communities.





#### #Octoberls4Livers at a Glance

	3.5 B	PRESS RELEASE POTENTIAL REACH
•	1,841,11	4 IMPRESSIONS
	390,534	SOCIAL MEDIA REACH
P	3,209	ENGAGEMENTS
	4	HEALTH EQUITY ROUNDTABLES
9	6	COUNTRIES REACHED

The impact of the 2022 campaign was felt in communities across the globe, in large part due to valued partnerships. Open House events in Spain, Cameroon, and India increased knowledge amongst providers and patients and even led to the increased financial accessibility of HBV treatments in Cameroon.



Barcelona Liver Cancer Clinic, Spain



Limbe Regional Hospital, Cameroon



Kalinga Gastroenterology Foundation, India



# Fighting Liver Cancer with Food

The battle with liver cancers is often tough. Whether one needs rest or fuel, food can be a key tool in providing both nutrition and relief along the journey. In this three-part series, Donna R. Cryer and Chef Daniel Thomas share liver-healthy recipes, in a three part video series entitled Fighting Liver Cancer with Food, that could help someone at risk of or facing liver cancer: "Eating for Energy," "Eating for Comfort," and "Eating for Strength."

#### **Liver Central**

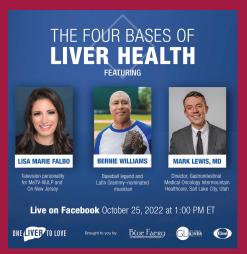
In partnership with TriSalus Life Sciences, GLI launched Liver Central, a comprehensive site for all things liver cancer. Liver Central provides patients, clinicians, and researchers a unique hub to find information on ongoing clinical trials, treatment options, and educational materials about the liver and liver cancers. Visit livercentral.org for more information.



#### **One Liver to Love**

Created in collaboration with Blue Faery and Eisai Inc., the One Liver to Love campaign raises awareness about liver cancer and the importance of adopting and maintaining healthy lifestyle choices to support liver health. With the support of spokesperson **Bernie Williams**, baseball legend and Grammy-nominated musician, the campaign features personal stories, critical information, educational resources, support services, and a sense of community for anyone impacted by liver cancer. For more information about the initiative, tips on navigating and living with liver cancer, as well as advocacy and support group information for patients and caregivers, please visit onelivertolove.com.

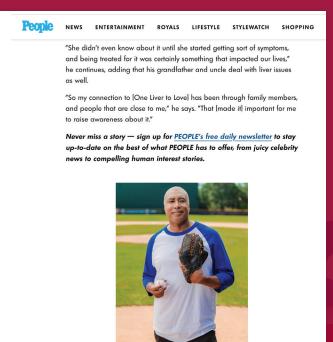






#### Media Features

One Liver to Love and Bernie Williams' personal connection to liver disease have caught the attention of the press, from the pages of *Cancer Health, The Healthy* and *People* magazine to the baseball-focused *Bronx Pinstripes* podcast. Bernie shared that when he was younger, his mother, uncle, and grandmother all dealt with liver disease – which has driven him to his involvement in the campaign and his promotion of a lifestyle that supports liver health.



Bernie Williams in People Magazine



### **Liver Cancers Program Impact**

Liver Cancers Lessons educational resources were made available in *French*, *Mandarin*, and *Spanish*.

Sarah Manes, GLI's Director of Liver Cancer Programs, became a member of the Mayo Clinic Hepatobiliary NCI Specialized Programs of Research Excellence (SPORE) Advocacy Committee, a member of the MD Anderson Hepatobiliary NCI SPORE Advocacy Committee, and the the Chair of the Minnesota Cancer Alliance to assist in reducing the burden of cancer for all people living in Minnesota by working together to promote the goals of Cancer Plan MN.

Sarah Manes contributed the patient advocacy perspective in the *JHEP Reports* article "What to do about Hepatocellular Carcinoma (HCC): Recommendations for Health Authorities," an International Liver Cancer Association and European Liver Patients' Association advocacy document.



Liver Cancer resources now available in French, Mandarin, and Spanish



JHEP Reports



### **GLI Around the World**



### HCC-TAG

Park City, Utah

On February 12, Ivy Ahmed, GLI's former Director of Liver Cancer Programs, presented at the 3rd annual HCC-TAG conference in Park City, Utah. She spoke about the impact of our Liver Cancers Council, future plans and campaigns and mentioned our patient advocacy resources.



American Society of Clinical Oncology (ASCO)
Annual Meeting

Chicago, Illinois

Sarah Manes and Paula Boccalon attended the ASCO Annual Meeting in Chicago, Illinois, from June 3-7 and met with many key oncology leaders and experts in the liver cancers field to further broaden partnerships and build new collaborations.



Conference on Liver Disease in Africa by Africa HepatoPancreatoBiliary Cancer Consortium (AHPBCC) Cairo, Egypt

On August 27, Sarah Manes provided the opening remarks during the advocacy session on treatment options as part of the AHPBCC conference held in Cairo, Egypt.



Texas Collaborative Center for HCC: 3rd Annual Multi-Stakeholder Symposium

Houston, Texas

On September 17, Sarah Manes attended the 3rd Annual symposium in Houston, Texas, where she was appointed to represent the HCC patient voice.

The Barcelona Clinic Liver Cancer (BCLC) 2022 update Barcelona, Spain

On November 21, Sarah Manes was a virtual panelist during BCLC's event, Tackling the Complexity of Liver Cancer Management, in Barcelona, Spain. Her presentation entitled "The Multidisciplinary Board For an Optimal Patient Journey" focused on bringing the patient voice to the conversation.

# Pediatric and Rare Liver Diseases Programs

The Pediatric and Rare Liver diseases programs demonstrated significant growth and solidification in 2022. Working collaboratively with its council to maximize outreach efforts, our main goal remains to improve the health outcomes of rare liver disease patients through education, advocacy, and research.

# Pediatric and Rare Liver Diseases Council





collective of leaders within the pediatric and rare liver disease communities from around the world. In 2022, the Council continued to assemble to exchange knowledge, ideas, and best practices from patients and patient organizations, clinicians, policymakers, and partners in the pharmaceutical industry.

The Pediatric and Rare Liver Diseases Council is a multi-stakeholder

During 2022, the Council **doubled its size** reaching more than **42 members** spanning more than **8 countries**. Our work is organized into several programs, initiatives, and campaigns, that focuses on education, policy, and the International Classification of Diseases 10th Revision (ICD-10) within the pediatric and rare liver disease field.



# Rare Liver Diseases Month & #RareAware Campaign

To bring attention to rare liver diseases and increase global support for patients, GLI hosted its second annual Rare Liver Diseases Month throughout February 2022. The month-long #RareAware campaign to promoted awareness and educated the general public on the diverse range of rare liver diseases while also increasing opportunities for patients to connect and share experiences. Campaign activities included weekly GLI LIVE episodes with professionals in the field; GLI Living, a series of conversations on self-care with patients; Extraordinary Young People, weekly reading sessions and discussions with young patients; The Burden of Rare Pediatric Liver Diseases, a policy briefing; a webinar on Living with Rare Liver Diseases in Europe; and more.

#RareAware Key Metrics

700	189,723,513	PRESS RELEASE POTENTIAL REACH
•	1,532,647	SOCIAL MEDIA IMPRESSIONS
	292,183	SOCIAL MEDIA REACH
PQ	10,992	SOCIAL MEDIA ENGAGEMENTS
9	32	COUNTRIES REACHED

### **Pediatric and Rare Liver Diseases Programs Impact**

#### Expanded the team's reach

New memberships on committees and working groups through organizations like Global Genes, Rare Disease Diversity Coalition, and the Everyday Life Foundation expanded the reach of the pediatric and rare liver diseases team.



#### Conquering Cholestatic Pruritus

Global Liver Institute partnered with experts to conduct a three-part webinar entitled Conquering Cholestatic Pruritus on December 9, which aimed to raise awareness about pruritus in cholestatic liver diseases. The webinar focused on educating the audience about the burden of intractable itch, exploring management strategies and innovations, and addressing the lack of therapy opportunities for patients.



#### PBC EL-PFDD Report

In November, GLI launched the PBC EL-PFDD Meeting outcome final report. The report provided an overview and key takeaways from the GLI-led EL PFDD meeting on PBC on February 4 that provided a channel for rare disease patients to share their stories and voice their perspective in the drug development process. View the report here.





#### **GLI Around the World**



#### Living with Rare Liver Diseases in Europe

On February 18, GLI hosted a webinar dedicated to pediatric and rare liver diseases focusing on the complexities in this field: diagnosis, treatment, care pathways, impacts upon the family, transition to adulthood. The event was co-hosted with EASL and endorsed by the European Reference Network for Hereditary Metabolic Diseases (MetabERN), Liver Patients International (LPI) and the PBC Foundation.



# Global Genes Patient Advocacy Summit San Diego, California

The Pediatric and Rare team attended the 2022 Rare Patient Advocacy Summit hosted by Global Genes in San Diego. In addition to engaging with patients, caregivers, advocates, health professionals, researchers, partners, and allies, we were also able to share findings on the PBC patient experience from the EL-PFDD with a poster presentation.



### Alagille Conference

Colorado Springs, Colorado

Members of the pediatric and rare team attended the 2022 Alagille Syndrome Symposium held on July 14-17. The event featured presentations from leading experts in the field, breakout sessions for families and patients, and opportunities for networking and connecting with others in the Alagille community.

# Communications

During 2022, GLI built a new communications team, which resulted in the creation of new strategies, an uplifted brand image, and an enhanced and cohesive message. With the many programs and campaigns that we host and support, building a consistent unified voice was a key step in this process.

The communications team amplifies the impact of GLI's programs and facilitates the flow of information between GLI and the public through our websites, social media channels, campaigns, press releases, and more. The department maintains relationships with physicians, partners, media outlets, journalists, and professionals in the field to raise liver health to its rightful place on the global public health agenda.

#### **Achievements**



#### New Global Liver Institute Website

In an effort to make the information that we produce more digestible, accessible and user friendly to the patients and caregivers that we serve, GLI's website underwent a full makeover. A new, more modern design, simplified language, and new tools that will help patients, caregivers, and partners navigate the website.

External Media Appearances







32 Articles 🖲 17 Podcasts 📸 6 Broadcasts

### **Selected Media Placements**



#### The Guardian



#### **WJLA**



#### Runner's World



Rare Revolution Magazine



#### The Hill



#### El Tiempo Latino



#### **Bloomberg Radio**



**NCQA Podcast** 



#### **Politico**



#### WUSA9



Take the Lead

### **Logo Design**



#### #RareAware logo

Since the zebra is the official symbol of rare diseases in the United States, the #RareAware campaign logo includes zebra stripes shaped into a liver symbolizing the realm of rare liver diseases that the campaign focuses on.



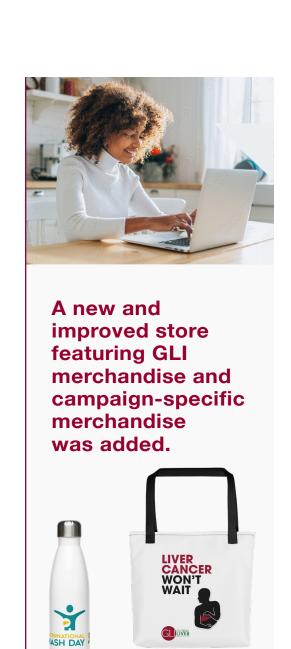
#### #Octoberls4Livers logo

The #OctoberIs4Livers campaign focuses on liver cancers. Using the ribbon motif that is commonly used for many cancer-related diseases as an inspiration, the burgundy liver is placed at the center surrounded by the lighter pink ribbon which represents a gentle, nurturing presence around the liver.

#### Liver Health is Public Health logo

To reflect the universal nature of the initiative, the liver is the central focus of the icon and is populated by icons that reflect the core areas of public health. The figure of a person lifting this liver represents the core mission of the LHPH initiative: to elevate liver health to its rightful place.





### GLI Conference Booth Branding



After joining virtual conferences for a few years due to COVID-19, GLI's booth at The Liver Meeting® was all about re-introducing the brand, showcasing our uplifted branding (through new banners, educational material, merchandise, and more) and focusing on our newly launched Liver Health is Public Health initiative. Through an interactive activity, the What does Liver Health mean to you? banner served as a marketing technique that raised curiosity, grabbed the attendees' attention, led them to come into our booth to find out more, share their answers and learn more about the initiative and how to get involved.



Sanitizer booths were placed in the meeting space to bring attention wto the newly-launched Liver Health is Public Health initiative.





#### Media

#### **Press Releases**

Throughout 2022, GLI released 7 press releases on the newswire, reaching millions of readers in the US, Canada, and around the world. These press releases were picked up by many outlets, including *Yahoo Finance*, *Yahoo News*, *National Post*, *Globe Newswire*, and *AP News*.

#### **Email Marketing**

The 2022 email marketing strategy included a mixture of newsletters, e-blasts, and fundraising emails. Following a new format, our Liver Health Policy Updates and NASH News continued to be sent out at a reduced frequency. Three new newsletters were introduced: Liver Cancer News, Pediatric and Rare Liver Diseases News, and The Latest at GLI, a quarterly newsletter that compiles GLI achievements across all departments that have occurred.







#### Social Media

Throughout 2022, GLI's communications team supported multiple internal and external campaigns. The team **created**, **strategized**, **designed**, **executed**, and **monitored** GLI's main internal campaigns.

#### Top Posts



Pediatric and Rare Liver Diseases' #RareAware campaign, throughout the month of February



International NASH Day on June 9



Liver Cancers #Octoberls4Livers campaign, throughout the month of October



- O Contributed to robust global conversations with key stakeholders
- Hosted live streams and engaged strong audience on Facebook Increased our in LinkedIn activity and presence
- O Expanded our **Instagram**presence by introducing
  infographics and short video content
- O Continued to grow our repository of liver health educational content on our **YouTube** channel, creating more organized playlists



Over a billion and a half people around the world are currently living with liver disease – and that number continues to rise each day. Liver disease poses a big global threat, which means there are big conversations to be had. Every Wednesday, we sit down with experts from policymakers and patient advocates to clinicians and research executives and more to have high-level conversations about the policies, people, and global forces that affect the patients with liver disease and their families.

2022 was a year for milestones for GLI LIVE! Episodes highlighted inspirational patient advocates, partners in liver health from around the world, influential female leaders in healthcare, and experts in rare liver diseases, liver cancers, and NASH during major campaigns. We reached a triple-digit number of episodes.

#### GLI LIVE in numbers

Celebrated our 100th episode in November

Aired 29 new episodes throughout 2022

Featured 44 guests from around the world

Released 30 podcast episodes

>Received over 1000 unique downloads of podcast episodes



GLI LIVE: The Podcast

In June, *GLI LIVE: The Podcast* was launched. An audio-only version featuring GLI LIVE episodes, new and from the vault, to reach an audience on the go. *GLI LIVE: The Podcast* (available on major podcast platforms including Spotify, iHeartRadio, and Audible) is a new way for the important conversations we're having to reach the people who need to hear.

### Check out a few key moments from the year







Physical Activity, Nutrition, and NASH



Past & Present: History of Barcelona Clinic Liver Cancer #Octoberls4Livers



Racial Disparities in Rare Liver Disease Research #RareAware

#### Jonathan Stine, MD, MSc

Associate Professor, Department of Medicine, Division of Gastroenterology and Hepatology, Penn State Health

#### Amy Goss, PhD, RDN

Professor of Nutrition Sciences at UAB, Registered Dietician Jordi Bruix, MD, PhD Co-Founder. BCLC

Concepció Brú Saumell, MD, PhD Co-Founder, BCLC

Maria Reig, MD, PhD Head, BCLC Teneasha Washington, PhD, MPH, MBA Rare Disease Researcher & Professor

#### Veronica Williams, MS

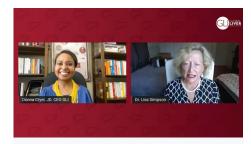
Board Member, Autoimmune Hepatitis Association and AIH Patient



Spotlight on Minority Health



Running on Hope



Influential Women in HealthCare Series

Darrell Gray, II, MD, MPH, FACG Board Member and Co-Founder, Association of Black Gastroenterologists and Hepatologists **Phil Shin**Marathoner and Liver Transplant
Recipient

**Lisa Simpson, MB, BCh, BAO, MPH** President & CEO, Academy Health

Check out the 2022 GLI LIVE episode directory on page 74

# Thought Leadership & Speaking Engagements

### **Health Equity**

4/4	National Academies of Sciences, Engineering, and Medicine, Public Workshop Use of Race, Ethnicity, and Ancestry as Population Descriptors
4/19	Got Health Data? Moving Toward a Justice-Based Model of Health Data Use Conference, University of California Health, Presentation Fit for Purpose: Aligning Health Data Governance and Use with the Public Good
4/28	Bloomberg Black Business Beat Podcast
6/24	Aspen Ideas Festival: Health Track, Aspen, CO Pfizer Presents: Inclusive Research, More Equitable Medicine





9/30

9/21	Research!America National Health Research Forum Reception,
	Washington, DC

2022 Gastroenterology & Hepatology Advanced Practice Providers National Conference, Workshop Session, Nashville, TN Health Disparities in Liver Disease





10/11	I've been Thinking Podcast Leadership, Innovation and Racial Equity in Liver Health
10/12	North Carolina Biosciences Organization Annual Meeting, Panel, Durham, NC Health Equity and Disparity
11/5	AASLD's The Liver Meeting®, Patient Keynote Address, Washington, DC

11/5

AASLD's The Liver Meeting®, Patient Keynote Address, Washington, DC
Liver Health Equity: Overcoming Stigma, Access, and Policy

The Personalized Medicine Coalition Summit: Personalized Medicine and the Patient, Panel, Boston, MA
Diversity, Equity, and Inclusion in Personalized Medicine: A Panel Discussion on How Personalized Medicine Can Improve Care for Diverse Patient Populations



12/13

12/6 Milken Future of Health Summit, Panel, Washington, DC Improving Health Equity in Rare Diseases Research

Partnership to Improve Patient Care Annual Forum 2022, Panel, Washington, DC

#### **NAFLD & NASH**





S3E12: Non-Hispanic Black Americans & NASH

4/20 NASH Tsunami Podcast

S3E21: Naim Alkhouri and Donna Cryer Bring News to Surfing

the NASH Tsunami

5/4 touchENDOCRINOLOGY, Video Interview

Donna Cryer, GLI 2022: International NASH Day

5/6 Innovations in NAFLD Care Workshop 2022, Barcelona, Spain

Roundtable Discussion: The NAFLD Continuum of Care

5/23 Digestive Diseases Week 2022, AASLD-sponsored Research

Forum Session, San Diego, CA

NAFLD/NASH – Sounding the Alarm on a Global Public

Health challenge

7/08 AASLD/EASL NAFLD Nomenclature Consensus Conference,

Chicago, IL

Nomenclatures under Consideration: Benefits and Limitations

7/20 Inside Health Care: A Podcast by NCQA

#84: Donna Cryer & the Wake-up Call for Liver Disease Treatment

10/26 PrimaryCareNOW, Industry Webcast

NAFLD 2022 Guidelines: New opportunities to improve care

in Obesity and Type II Diabetes

11/6 AASLD's The Liver Meeting®, Presentation, Washington, DC

Pan-Society Presentation of NAFLD Nomenclature

Consensus Process





### Policy & Governance

AASLD Patient Advocacy Webinar Building Upon the Positive Momentum in Patient & Physician Liver Advocacy
AcademyHealth's National Health Policy Conference (Health Datapalooza), Washington, DC Drug Pricing Regulation Trade-offs: Real or Imagined?
Council of Medical Specialty Societies 2022 Spring Meeting, Panel, Chicago, IL
Association of Health Care Journalists' Health Journalism Austin, TX Help your readers understand the "information blocking" rule and how it relates to patient safety
The Future of Health Data Summit 2022 hosted by Datavant, Washington, DC The Future of Patient Centered Research

# Liver Health is Public Health & General Liver Health



4/19 Washington ABC7, Washington, DC

Liver Disease Awareness

4/25

WUSA9 Great Day Washington with Ellen Bryan,

Washington, DC

Prevent and Recognize Liver Disease



5/27 Washington Informer with Shevry Lassiter, Washington, DC

Season 3, Episode 7



6/6 Ebony Black Power Moves Podcast

Promoting Universal Liver Health Awareness with Donna Cryer, Founder, President & Chief Executive Officer of Global

Liver Institute

10/07 Sanofi's 3rd Global Liver Health Forum

Global Liver Institute's Annual Report



10/20 Sanofi's Shout-Out for Liver Care

Living Out Loud: Creating the Next Level of Patient

Advocacy for Liver Health

11/9 The Ellevate Podcast: Conversations with Women Changing

the Face of Business

Leading the Charge, with Donna R. Cryer



### Patient Advocacy & the GLI Story



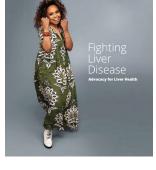
7/12

7/13

10/04

11/9

4/19 Got Health Data? Moving Toward a Justice-Based Model of Health Data Use Conference, University of California Health, Panel Incorporating the patient Person's Voice into Decisions Around Data Use



GlympseBio Speaker Series

The Scope with Dr. K, a SonarMD Podcast Attorney and Patient Advocate Donna Cryer



August The Taft Bulletin Fighting Liver Disease: Advocacy for Liver Health

> Our Global Patients in Focus Week Pfizer Patients in Focus Fireside Chat

11/5 AASLD's The Liver Meeting®, Presentation, Washington, DC Meet The Experts dX 8: Using patient advocacy to advance research in chronic liver diseases



Pfizer's Global Pan-Therapeutic Patient Centricity, Advisory Board, New York, NY

12/26 Her Success Story Podcast Transcending a Culture for Team Patient

# **External Audit Results**

### **Independent Auditor's Report**

To the Board of Directors of Global Liver Institute, Inc. Washington, D.C.

#### **Opinion**

We have audited the accompanying financial statements of Global Liver Institute (a nonprofit organization), which comprise the statement of financial position as of December 31, 2021, and the related statements of activities, functional expense, and cash flows for the year then ended, and the related notes to the financial statements.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Global Liver Institute as of December 31, 2021, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the Unted States of America.

#### **Basis for Opinion**

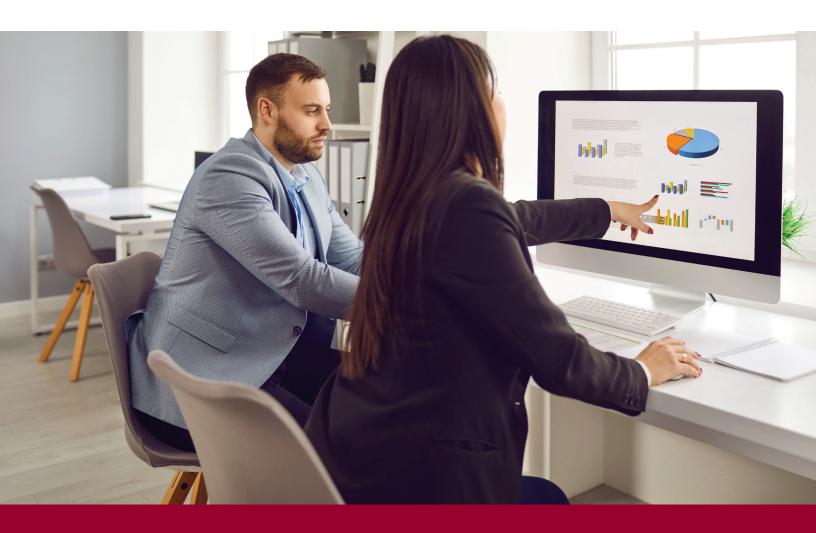
We conducted our audit in accordance with auditing standards generally accepted in the Unted States of America. Our responsibilities under those standards are further described in the Aditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of Global Liver Institute and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audit. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.



#### Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whehter due to fraud or error.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substancial doubt about Global Liver Institute's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.



## Auditor's Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not guarantee that an audit conducted in accordance with generally accepted auditing standards will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as internal control. Misstatements, including omissions, are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgement made by a reasonable user based on the financial statements.

## In performing an audit in accordance with generally accepted auditing standards, we:

- Excercise professional judgement and maintain professional skepticism throughout the audit.
- Indentify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of Global Liver Institute's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judegment, there are conditions or events, considered in the aggregate, that raise substantial doubt about Global Liver Institute's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control related matters that we identified during the audit.





# Financials 2022

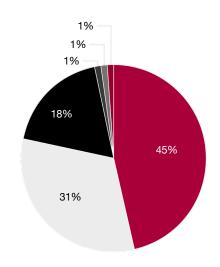
Assets	
Cash and Cash Equivalents	
Accounts Receivable	911,631
Other Current Assets	36,566
Fixed Assets-Net	15,231
Total Assets	\$963,428
Liabilities and Net Assets	
A/P and accrued expenses	224,531
Deferred Revenue	975,014
Loan Payable - Ioan	14,957
Total Liabilities	1,214,502
Net Assets Total	(251,074)
Liabilities and Net Assets	\$963,428
Revenue	
Memberships	1,248,054
Contributions-Unrestricted	530,551
Contributions-Restricted	25,000
Sponsorships	872,972
Other Revenues	75,876
Total Revenue	\$2,752,453
Total Neverlue	
Expenses	. ,
	2,095,361
Expenses	
Expenses Programs and Grants	2,095,361

Change in Net Assts
Net Assets, *Beginning of Year*Net Assets, *End of Year* 

\$ 173,533 \$ 436,480 \$ 610,013

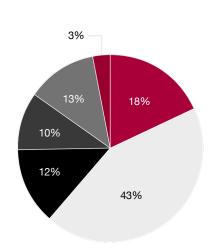
## **GLI Revenue Types**

•	Membership Dues	45%
	Sponsorships	31%
•	Grants	18%
•	Individual Contributions	1%
•	Program Service Fee	1%
•	Restricted Funds	1%



## **Expenses by Program**

•	Liver Cancers	18%
	NASH	3%
•	Policy	13%
•	Pediatric and Rare Liver Diseases	10%
•	Patient Engagement	12%
•	Administrative	3%



# **Appendix**

### GLI LIVE Episodes and Guests

#### Picking Up Where We Left Off

Katy Smali, MPA, MPH, PMP

Project Manager, Integrated Care, Montefiore Care Management

#### Experience of Hispanic Patients with Liver Diseases

Julio Gutierrez, MD

Hepatologist at Scripps Health

VP Research & Clinical Science at ProSciento

#### Collaborating on a Mutual Mission: Advancing Liver Health

Laurie Deleve, MD, PhD, FAASLD

President, Governing Board, American Association for the Study of Liver Diseases (AASLD)

#### LAN Member Community Spotlight - Liver Wellness Foundation

Farrah Douglas

President & CEO, Liver Wellness Foundation

Kristina Clark

Human Resource Professional

Liver Health Foundation Board Member

#### Learn More about Rare Liver Cancers #RareAware

Sanford Simon PhD

Fibrolamellar Carcinoma researcher & parent

Lisa Craine

Cholangiocarcinoma patient & mentor

#### Racial Disparities in Rare Liver Disease Research #RareAware

Teneasha Washington, PhD, MPH

Director/Founder, The Washington Group

Veronica Williams, MS

Autoimmune Hepatitis (AIH) patient

Board member at AIH Association

#### Pediatric Rare Liver Diseases #RareAware

William Balistreri, MD

Cincinnati Children's Hospital Medical Center

Samantha Melaney

Author of "LiveReal"

Organ donation advocate

#### Newborn Screening Policy & Advocacy in Rare Liver Diseases #RareAware

Dylan Simon, MS

Associate Director of Policy, EveryLife Foundation

Melissa Gamble

Executive Director & Co-Founder, The Global Foundation for Peroxisomal Disorders

#### Influential Women in HealthCare Series - Academy Health

Lisa Simpson, MB, BCh, MPH, FAAP

President & CEO, Academy Health

#### Influential Women in HealthCare Series - Research!America

Mary Woolley

President & CEO, Research!America

#### Influential Women in HealthCare Series - NCQA

Margaret O'Kane

President, National Committee for Quality Assurance (NCQA)

#### Influential Women in HealthCare Series - CMSS

Helen Burstin, MD, MPH, MACP

Executive Vice President & CEO, Council of Medical Specialty Societies

#### LAN Member Spotlight - Northeast Ohio Liver Alliance

Mousab Tabbaa, MD

Treasurer, Northeast Ohio Liver Alliance

President/CEO, NorthShore Gastroenterology & Endoscopy Centers

Elaine Turley

Board Member, Northeast Ohio Liver Alliance

Co-Founder & Executive Director, Transplant House of Cleveland

#### Spotlight on Minority Health - Association of Black Gastroenterologists & Hepatologists

Darrell Gray, II, MD, MPH, FACG

Board Member and Co-Founder of the Association of Black Gastroenterologists & Hepatologists

#### LAN Member Spotlight - Fatty Liver Alliance

Mike Betel

President & Founder, Fatty Liver Alliance

Supriya Joshi, MD

Chair of the Medical Advisory Board, Fatty Liver Alliance

Certified Gastroenterologist and Hepatologist

#### The Caregiver's Perspective

#### Wayne Eskridge

Patient

Co-Founder, Fatty Liver Foundation

#### Rosemary Wickowski

Caregiver

Co-Founder, Fatty Liver Foundation

#### Tony Villiotti

Patient

Co-Founder, NASH kNOWledge

#### Betsy Villiotti

Caregiver

Co-Founder, NASH kNOWledge

#### Running on Hope w/ Marathoner and Liver Transplant Recipient Phil Shin

Phil Shin

Marathoner, Cancer Fighter, Liver Transplant Recipient

#### Telemedicine, Equitable Care, and More

Reed Tuckson, MD, FACP

Managing Director, Tuckson Health Connections, LLC

#### Physical Activity, Nutrition, and NASH

Jonathan Stine, MD, MSc, FACP

Director Research, Penn State Health Liver Center

Amy Goss, PhD

Assistant Professor of Nutrition Sciences, University of Alabama, Birmingham

#### Meet #NASHday Global Partners

#### Michael Ochieng Nyawino

Executive Director, Christian Community Healthcare Foundation (COHECF)

#### Jackie Maalouf, PhD

President & Founder, DiaLeb - The National Diabetes Organization

#### Partha Sarathi Mukherjee, MSc, PhD

Secretary, Liver Foundation West Bengal

#### Scott Suckow

GLI's LAN Chairperson

Executive Director, Liver Coalition of San Diego

#### Tatiana Reic, MSCi

President, Croatian Society for the Liver Diseases "Hepatos"

#### LAN Member Community Spotlight - NASH kNOWledge

#### Gina Villiotti Madison

Executive Director, NASH kNOWledge

#### Rohit Kohli, MD

Chief, Division of Gastroenterology, Hepatology & Nutrition, Children's Hospital Los Angeles Professor of Pediatrics USC Keck School of Medicine Board Member, NASH kNOWledge

#### 6/29: Podcast Launch

Donna R. Cryer, JD President & CEO of GLI GLI LIVE Host

## #Octoberls4Livers: Moving from Science to Policy to Eliminate HCC & Hepatitis John Ward, MD

Director, Coalition for Global Hepatitis Elimination, Task Force for Global Health

#### #OctoberIs4Livers: Liver Cancers SPORE

#### Ahmed Kaseb, MD, CMQ

Professor & Program Director of HCC, Department of Gastrointestinal Medical Oncology, University of Texas MD Anderson Cancer Center

#### #OctoberIs4Livers: Past & Present: History of Barcelona Clinic Liver Cancer

Maria Reig, MD, PhD

Head of Barcelona Clinic Liver Cancer (BCLC)

Jordi Bruix, MD, PhD

BCLC Group Founder, Liver Unit at the Hospital Clinic of Barcelona University

Concepció Brú Saumell, MD, PhD

BCLC Group Founder

#OctoberIs4Livers: Financial Toxicity: The Cost of Cancer Care

Jada Desmarais, MBA

Senior Manager, Baker Newman Noyes

#### Navigating the LIVER MEETING as a Patient or Patient Advocate

Donna R. Cryer, JD
President & CEO of GLI
GLI LIVE host

Jeff McIntyre

Vice President, Liver Health Programs, Global Liver Institute

#### References

- 1. Moon AM, Singal AG, Tapper EB. Contemporary Epidemiology of Chronic Liver Disease and *Cirrhosis. Clin Gastroenterol Hepatol.* 2020;18(12):2650-2666. doi:10.1016/j.cgh.2019.07.060
- 2. Younossi ZM, Koenig AB, Abdelatif D, Fazel Y, Henry L, Wymer M. Global epidemiology of nonalcoholic fatty liver disease-Meta-analytic assessment of prevalence, incidence, and outcomes. *Hepatology*. 2016;64(1):73-84. doi:10.1002/hep.28431
- 3. The Global Cancer Observatory. Liver. World Health Organization; 2020.
- 4. American Cancer Society. Cancer Facts & Figures 2022. Atlanta: American Cancer Society; 2022.





Global Liver Institute (GLI) is a patient-driven 501(c)(3) nonprofit organization headquartered in Washington, DC, with offices in the EU and UK, 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 disease and the importance of liver health to well-being. GLI promotes innovation, encourages collaboration, and supports the scaling of optimal approaches to improve research, care, and policy. By bringing together more than 200 community-based, national, and international organizations across its Councils, Campaigns, and events, GLI equips advocates to identify and solve the problems that matter to liver patients. Follow GLI on Twitter, Facebook, Instagram, LinkedIn, and YouTube.

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## We put your contribution to work







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