

# Liver Cancers Council Individual Membership Letter of Invitation

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## Background

Liver Cancers, primarily hepatocellular carcinoma (HCC) and other rare liver cancers such as intrahepatic cholangiocarcinoma and fibrolamellar hepatocellular carcinoma, and secondary liver cancer, are among the few cancer types that are increasing in incidence and mortality, and accounted for more than 800,000 deaths worldwide in 2020 alone (ACS). The 5-year survival rate for HCC in the United States is only 20% for all stages and this drops to less than 3% when diagnosed at an advanced stage (ACS and SEER). Liver cancer patients suffer unnecessarily from late diagnosis, lack of liver cancers-specific education and navigation tools, and uneven access to proven best practices such as multidisciplinary tumor boards.

## Liver Cancers Council Membership as a Solution

Global Liver Institute's (GLI) Liver Cancers Council (LCC), launched May 2019 in Washington, DC, USA, seeks to bring liver and cancer advocacy organizations together to elevate the recognition of liver cancers' prevalence and impact.

Additionally, we are committed to promoting regular screening and early diagnosis, increasing the amount and quality of liver cancers-specific education, navigation, and policy, and providing training to liver cancers advocates to advance patient-centered research, care, support, and policy.

## Council Goals

Our vision is Increase the five-year survival rate for liver cancer to 36% by 2030. Through the Council, our goals are to:

- Increase the number of liver cancers patients diagnosed at early stages
- Support knowledge, choice, and access to appropriate treatment options
- Reduce disparities in screening, diagnosis, and treatment access
- Advance global policy and advocacy that supports research, access, and information for those impacted by liver cancers
- Elevate the global dialogue about liver cancers through scalable partnerships

In 2024:

- Address liver cancer disparities by proposing pilot screening initiatives in communities most disproportionately impacted in liver cancer incidence and mortality
- Increase liver cancer patient, survivor and caregiver engagement in all GLI activities including council engagement, the Liver Action Network, and the Advanced Advocacy Academy (A3)
- Disseminate Liver Cancer Lessons patient education program materials to patients, providers and advocacy with increased focus on disparate populations
- Grow annual international educational and open house events
- Enhance GLI interactive map with updated liver cancers statistics
- Advise NCI Liver SPOREs Projects at Mayo and MD Anderson
- Support NCCN's Patient Guidelines
- Host successful #OctoberIs4Liver liver cancer education and awareness campaign
- Create liver cancers resources specific to Veteran population 2
- Expand language translations for liver cancers resources
- Grow Health Equity Community Conversations liver cancers roundtable series to focus on immigrant, refugee, rural, aboriginal, and indigenous populations

## Achievements

Since the creation of the Liver Cancers Council, GLI has:

- Grown Liver Cancers Council to include more than 55 members representing patients, survivors, providers, and advocacy and corporate partners
- Established four focus areas for council involvement and input: Screening and Early Detection; Awareness, Education and Support; Policy; and International Materials & Resources Produced
- Liver Cancer Lessons, a suite of patient education materials and videos addressing liver cancers, now including Arabic, French, Mandarin, Somali, and Spanish languages
- Published Liver Cancer Advocacy Organization Landscape Assessment
- Sponsored NCCN's Patient Guidelines for Liver Cancer and Gallbladder and Bile Duct Cancers
- Collaborated with Cancer Support Community's Liver Cancer Frankly Speaking About Cancer resource

- Reviewer and contributor for JHEP Reports published journal, Volume 4, Issue 12, 100578; What to do about hepatocellular carcinoma: Recommendations for health authorities from the International Liver Cancer Association

#### Patient Focused Advocacy

- Implemented robust 2023 #OctoberIs4Livers Education & Awareness Campaign
- Trained Liver Cancers patients and caregivers through our A3
- Keynote speaker at International Society of Gastrointestinal Interventional Oncology
- Panelist at Barcelona Clinic Liver Cancer multidisciplinary liver conference
- Partnerships
- Partnered with ACCC on Multidisciplinary HCC Care Environmental Scan
- Founding Member of the GI Cancers Alliance
- Liver Cancer partner with Cancer Support Community's Cancer Experience Registry and Frankly Speaking series on Liver Cancers
- Deadliest Cancers Coalition
- Committee member for the Texas Collaborative Center for Hepatocellular Cancer (TeCH) multi-stakeholder group
- Patient advocacy reviewer and contributor for NCI Liver SPORes Transitional Research Program for Mayo Clinic, Rochester and University of Texas MD Anderson Cancer Center

#### Investment

Your involvement in the **Liver Cancers Council** will contribute to shaping policies, advancing clinical practices, promoting lifestyle support, and raising awareness about pediatric and rare liver diseases globally.

GLI invites you to become an individual member of the Liver Cancers Council, offering the following benefits:

- A minimum of two virtual LCC meetings/yr are virtually hosted
- Opportunity to suggest LCC Members
- Opportunity to suggest agenda topics
- Opportunity to speak and present in LCC meetings and specific patient/HCP webinars and programs
- Opportunity to provide updates on current liver cancer research projects or activities
- Opportunity to participate in focused workgroup calls and meetings
- Acknowledgment as a **Liver Cancers Council Individual Member**
- LCC members may create presentation and material featuring member names and logos

Your involvement in the Liver Cancers Council will contribute to shaping policies, advancing clinical practices, promoting lifestyle support, and raising awareness about Liver Cancers globally. By supporting the Liver Cancers Council, you align with a dedicated community working towards patient-centric standards of care, ultimately improving liver health outcomes for individuals worldwide.

## About Global Liver Institute

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

