



Advocacy Organization Landscape Assessment: Liver Cancer Resources



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Introduction

Liver cancer is the third most deadly cancer in the world, accounting for 830,000 deaths in 2020.

¹ Fortunately in the past few years, the relative 5 year-survival rate of liver cancer has slightly increased due to increased awareness and research.² Although this increase in 5-year-survival rate is positive, there is still much work that needs to be done. The risk factors for liver cancer, which include infection with viral hepatitis B and/or C, obesity, diabetes, cirrhosis, and non-alcoholic fatty liver disease, are becoming increasingly prevalent, and account in part for the rise in liver cancer diagnoses and deaths.² The aim of this report is to examine the landscape of liver cancer resources available to both patients and healthcare professionals, and scientists.

Methodology

The Global Liver Institute (GLI) set out to gather information on the available liver cancer resources provided by cancer advocacy organizations and professional medical societies. The first landscape analysis was conducted in August 2017 from a list of liver cancer-focused advocacy organizations at the 2017 ASCO conference. Since then, the landscape analysis has been updated every two years in 2019 and currently this edition in 2021 in order to accurately portray the available resources currently offered. The number of organizations included in the first landscape analysis was 34 in 2017, and this year's update includes 47 organizations. An increase of 13 organizations shows the growth in organizations focused on providing resources for patients and/or healthcare professionals. As was done with the last update in March 2019, GLI staff collected information from each identified organization from the perspective of the average person searching for information on each organization's publicly available website.

Note: Because this data set is based only on information shown on an organization's website, it is possible that an organization may provide more resources than recorded in this report.

¹ "Cancer." *World Health Organization*. 3 March 2021

² "Cancer Facts & Figures 2021." *American Cancer Society*. 2021

Liver Cancer Resource Distribution: For Patients

	Disease Overview	Education Resources	Support Groups	Find-a-Doctor	Clinical Trial Matching	Liver Cancer News	Insurance Navigation/ \$ Assistance	Counseling/ Addtl. Support	Advocacy Info.
AACR	X	X*							X*
AASLD	X*	X*							X*
ACS	X	X	X			X	X*	X	X*
ACS-CAN									X*
ALF	X	X	X		X			X	X
ASCO	X	X			X	X			X*
ASCO: Conquer Cancer		X*							X*
ACCC	X	X				X			X*
Blue Faery	X	X	X		X	X			X
BLT	X	X				X		X	X
CLF	X	X						X	X
Cancer 101	X	X	X*		X*			X*	
CHN	X	X							X
CRI	X	X			X				
CSC	X	X	X	X	X		X		X*
CancerCare	X	X	X*				X	X	
Cholangio.	X	X	X			X		X	X
DICE	X	X			X	X			X
ELPA		X*							X*
FCF	X	X		X	X		X	X	
GLI	X	X				X		X	X
HBF	X	X*	X*		X*			X*	X*
HBF LCC	X	X		X					
ICC & ICCC		X*							X*
The II	X	X			X				
ILCA	X	X							
Latinas Contra Cancer	X*	X*	X*		X*				X*
LPI	X	X				X			X
NCI	X	X			X*	X			X*
NCCS	X*	X*							X*
NCCN	X	X				X			X*
NORD	X	X			X		X		X
ONS									X*
PCF	X	X	X		X			X	X
SIR	X	X		X					X*
SIRFoundati on	X	X		X					X*
Stupid Cancer	X*	X*	X*				X*	X*	X*

Triage Cancer	X*								X*
Ulman Fund		X*	X*	X*			X*	X*	

*These resources are not specific to liver cancer.

Liver Cancer Resource Distribution: For HCP/Scientists

	Events	Professional Development, CME	Publications	Clinical Trials	Medical Research	Funding, Grants	Liver Cancer News	Clinical Practice Guidelines
AACR	X	X*	X	X	X	X		
AASLD	X	X	X		X			X
ACS	X*	X*	X*		X*	X*		X*
ACS-CAN	X							
ALF			X		X	X		
ASCO	X*	X*	X*		X*	X*	X	X*
ASCO: Conquer Cancer	X*	X*					X*	X*
ACCC	X*	X	X		X			
Blue Faery				X	X			
BLT	X	X	X	X			X	X
CLF	X				X	X	X	X
Cancer 101								
CHN								
CRI		X*	X*		X*	X*		
CSC	X*	X*	X*					X*
CancerCare			X*		X*			
Cholangio.	X	X	X	X	X	X	X	
DICE	X		X		X		X	
ELPA	X		X*		X*	X*		
FCF				X	X	X	X	
GLI			X		X		X	
HBF		X*	X*	X*	X*	X*		
HBF LCC								
ICC & ICCC			X				X*	
The II								
ILCA	X	X	X	X	X			X
Latinas Contra Cancer								
LPI							X	
NCI	X	X	X	X	X	X	X	X*
NCCS	X*		X*				X*	
NCCN	X*	X*	X	X*	X*	X*	X	X
NORD	X	X	X			X	X	
ONS	X*	X	X					X*
PCF	X*					X*		
SIR	X*	X*	X*	X*				X*
SIRFoundation	X*	X*	X*	X*				X*

Stupid Cancer								
Triage Cancer	X*	X*						
Ulman Fund	X*	X*	X*		X*			X*

*These resources are not specific to liver cancer

American Association for Cancer Research (AACR)

Website	https://www.aacr.org/
Leadership	David A. Tuveson, MD, PhD, FAARC, President; Margaret Foti, PhD, MD (hc)
Founding Year	1907
Location	Philadelphia, PA
Revenue	\$124,747,357 (2019)
Mission	“To recognize and honor distinguished scientists whose major scientific contributions have propelled significant innovation and progress against cancer, and to leverage the expertise of the global brain trust of Fellows of the AACR Academy to advance the mission of the AACR to prevent and cure all cancers through research, education, communication, collaboration, science policy and advocacy, and funding for cancer research.”
Liver Cancer Resources for Patients	AACR does not appear to provide any educational materials that are directly liver cancer related. They do however provide broad cancer information such as: what is cancer, what is cancer research, cancer types, and cancer prevention. Patients can find broad cancer information here and this site can be especially informative in providing information for cancer treatment types and the importance of cancer research.
Liver Cancer Resources for HCP/Scientists	Under the tab ‘Cancer Researchers/Other Healthcare Professionals’ is information covering AACR events and conferences, AACR journal, and portal access for members to submit abstracts among other tasks.
Policy Involvement	Information on AACR’s policy initiatives can be found under the ‘Policy and Advocacy’ page on their website. Policy topics that they cover include but are not limited to: presidential administration’s agendas for cancer research, COVID-19 related initiatives, and a newsletter to keep up with current policy related events. There is also an <i>AACR Cancer Policy Monitor</i> , that is released on a monthly basis, providing links, articles, and other educational materials around policies surrounding federal cancer research to empower and educate advocates.

American Association for the Study of Liver Diseases (AASLD)

Website	www.aasld.org
Leadership	Raymond T. Chung, MD, FAASLD, President
Founding Year	1950
Location	Alexandria, VA, USA
Revenue	\$15,226,783 (2019)
Mission	“To advance and disseminate the science and practice of hepatology, and to promote liver health and quality patient care.”
Liver Cancer Resources for Patients	AASLD has no patient focused programs specific to liver cancer. A search of the AASLD website did yield several articles regarding aspects of liver cancer such as risk factors, statistics, relation to hepatitis, research, treatment, and prevention. The AASLD website has one page, “For Patients”, that has some resources for patients, although none are liver cancer-specific.
Liver Cancer Resources for HCP/Scientists	AASLD is geared toward clinicians and researchers, as it describes itself as “organization that advances you, your career, and the field of hepatology by providing the ultimate in liver research, training, and care of patients with liver disease.” As the largest hepatology medical society in the United States, AASLD holds events pertaining to professional development and continuing medical education for physicians such as The Liver Meeting. Medical research and AASLD’s own publications are featured on the website as well, and the AASLD Foundation provides funds for research fellowships. AASLD also has Clinical Practice Guidelines available to clinicians and are developed by a panel of experts.
Policy Involvement	Under the “About AASLD” tab there is a page titled “Public Policy.” AASLD operates through a Public and Clinical Policy Committee staffed by external consultants who make recommendations on topics of interest that are raised.

American Cancer Society (ACS)

Website	www.acs.org
Leadership	Gary Reedy, CEO
Founding Year	1913
Location	Atlanta, GA, USA
Revenue	\$720,131,846 (2019)
Mission	“To save lives, celebrate lives, and lead the fight for a world without cancer.”
Liver Cancer Resources for Patients	There is a page for liver cancer under the "Cancer A-Z" tab, which includes an overview of the disease, causes, risk factors, prevention, early detection, treatment, and the steps to take after treatment. ACS also has resources for all cancer patients, regardless of diagnosis, including online support groups, educational materials and glossaries, videos, and how to get involved in fundraising. In addition, there is a “News Search” function that compiles news stories and reports on liver cancer published by ACS and other organizations.
Liver Cancer Resources for HCP/Scientists	ACS has a page titled “For Healthcare Professionals” that includes information on prevention, early detection, survivorship care, and screening guidelines, although none are liver cancer-specific. The ACS website displays research programs, including additional information on the research conducted and funded, as well as information on available grants. Also available to clinicians are educational materials for their patients including fact sheets on cancer types, cancer side effects, and healthy living recommendations, except no liver-specific resources are listed.
Policy Involvement	ACS has a separate entity dedicated to policy: ACS CAN. See next page for information on ACS CAN.

American Cancer Society Cancer Action Network (ACS-CAN)

Website	www.fightcancer.org
Leadership	Lisa Lacasse, President
Founding Year	2001
Location	Washington, DC, USA
Revenue	\$37,948,021 (2018)
Mission	“To defeat cancer by helping to protect and increase public investment in groundbreaking medical research, and by improving access nationwide to the latest prevention and early detection measures, treatments, and follow-up care that are proven to save lives.”
Liver Cancer Resources for Patients	There are no programs specific to liver cancer listed, but ACS CAN is committed to policy and legislative solutions to fighting and curing cancer as opposed to other medical or disease specific organizations. Also available are quality of life resources that can pertain to all cancer patients, including liver cancer.
Liver Cancer Resources for HCP/Scientists	This organization has no liver cancer-specific resources for HCP or scientists, but it does have a multitude of other resources specifically for HCP and scientists. The material provided may be geared towards the individual determined to advocate for policy and legislative changes. HCP and researchers can learn valuable information regarding cancer research funding, patient quality of life, health care access, and cancer prevention.
Policy Involvement	The majority of everything ACS CAN does is policy oriented. ACS CAN is involved in policy and legislation on the local, state, federal, and hospital levels. ACS CAN participates in work related to health care access, insurance, cancer prevention, cancer research funding, and quality of life measures.

American Liver Foundation (ALF)

Website	www.liverfoundation.org
Leadership	Lorraine Stiehl, CEO
Founding Year	1976
Location	New York, NY, USA
Revenue	\$8,851,289 (2019)
Mission	“ALF’s mission is to promote education, advocacy, support services and research for the prevention, treatment and cure of liver disease.”
Liver Cancer Resources for Patients	ALF provides a “Liver Cancer” page that includes general liver information, liver cancer basics, risk factors, information for newly diagnosed patients, common questions to ask HCP, support groups, patient stories, access to ALF’s video bank, and blog posts. There is an ALF sponsored liver cancer support group that is run through Facebook. Also available to patients is a Clinical Trials matching service.
Liver Cancer Resources for HCP/Scientists	ALF provides liver cancer brochures for HCP to give to patients. It also offers the ALF Research Awards Program that provides funding opportunities for liver cancer research. The “Professional Development” page provides HCP and scientists opportunities for obtaining CME credits, although none of the current modules are liver cancer oriented. Oncologists also have the opportunity to serve on ALF’s national medical advisory board.
Policy Involvement	The “Advocacy” page on ALF’s website includes legislation that ALF has supported. ALF provides advocates with direct links to policies and means to sign on to letters of support and opposition. Also on this page is information on advocacy events, one of which is ALF’s upcoming Virtual Advocacy Week that will train advocates and have them virtually meet with Congressional Staffers to advocate for liver diseases and cancer on Capitol Hill.

American Society of Clinical Oncology (ASCO)

Website	www.asco.org
Leadership	Clifford A. Hudis, MD, FACP, FASCO, CEO
Founding Year	1964
Location	Alexandria, VA, USA
Revenue	\$162,711,421 (2019)
Mission	"Conquering cancer through research, education, and promotion of the highest quality patient care."
Liver Cancer Resources for Patients	ASCO’s “Resources for Patients” link redirects to Cancer.Net, which is branded as “Doctor-Approved Information for Patients from ASCO.” Cancer.Net has a multitude of liver cancer resources for patients, including liver cancer basics, risk factors, diagnostic tests, types of treatments, clinical trial information, follow-up care, latest research, survivorship, and more.
Liver Cancer Resources for HCP/Scientists	This organization has no liver cancer-specific resources for HCP or scientists outside of abstracts, meeting videos, conferences, and publications related to liver cancer. According to their website, “ASCO promotes and provides for: lifelong learning for oncology professionals, cancer research, an improved environment for oncology practice, access to quality cancer care, a global network of oncology expertise, and educated and informed patients with cancer.” Over 40,000 oncology professionals belong to ASCO and utilize its programs and resources. Some of the HCP resources include annual meetings (at which liver cancer is represented), practice guidelines, research, training, education, and international programs.
Policy Involvement	The "Policy Issues & Statements" (within the Practice & Policy tab) page includes information on: cancer prevention, access to and quality of cancer care, adequate reimbursement and coverage, and access and support for evidence-based research. ASCO also has an advocacy center that provides its own Advocacy Toolkit and information on the ACT Network, state advocacy, the AMA House of Delegates, and on ASCO’s Health Policy Fellowship program. In addition, Cancer.Net, “Doctor-Approved Information for Patients from ASCO,” provides patient and caregiver advocacy and policy resources, including cancer research, public policy advocacy, drug discovery and more.

The ASCO Foundation: Conquer Cancer

Website	www.conquer.org
Leadership	Nancy Daly, MS, MPH, Executive Vice President and Chief Philanthropic Officer
Founding Year	1964
Location	Alexandria, VA, USA
Revenue	\$30,450,646 (2019)
Mission	"Conquering cancer worldwide by funding breakthrough research and sharing cutting-edge knowledge."
Liver Cancer Resources for Patients	Conquer Cancer has no liver cancer-specific resources for patients and redirects users to ASCO’s Cancer.net site.
Liver Cancer Resources for HCP/Scientists	This organization has no liver cancer-specific resources for HCP or scientists, but it does have a multitude of HCP and scientist resources for generic cancers and for specific cancers (liver cancer not included). Conquer Cancer provides online medical education, meetings, symposia, workshops, and information on its research opportunities and research results. Conquer Cancer’s Quality Oncology Practice Initiative (“an oncologist-led, practice-based quality improvement program”) for HCP is also featured on the website.
Policy Involvement	Conquer Cancer is affiliated with ASCO, an organization involved with policy and advocacy in the following ways: The "Advocacy & Policy" page includes policies, positions, and guidance, advocacy news and analysis, state affiliates, and cancer care initiatives. ASCO also has an advocacy center that provides its own Advocacy Toolkit and information on the ACT Network, state advocacy, the AMA House of Delegates, and on ASCO’s Health Policy Fellowship program. In addition, Cancer.Net, “Doctor-Approved Information for Patients from ASCO,” provides patient and caregiver advocacy and policy resources, including cancer research, public policy advocacy, drug discovery and development, and more.

Association of Community Cancer Centers (ACCC)

Website	www.accc-cancer.org
Leadership	Krista Nelson, MSW, LCSW, OSW-C, FAOSW, President
Founding Year	1974
Location	Rockville, MD, USA
Revenue	\$12,701,280 (2019)
Mission	“To be the leading education and advocacy organization for the multidisciplinary cancer team.”
Liver Cancer Resources for Patients	Under the “Learn” tab, liver cancer is listed as one of the cancer types with resources available. ACCC established the Multidisciplinary Hepatocellular Carcinoma Care, which has identified effective practices within multidisciplinary care and has those resources listed on the ‘Liver Cancers’ page. Topics covered include basic liver cancer information and sources, ACCC publications in “Oncology Issues,” and information on ACCC’s Multidisciplinary Hepatocellular Carcinoma Care Education Program. All of ACCC’s liver cancer resources are available to both patients and HCP/scientists. Resources dedicated for patients are available on ACCC’s site and include links to partnered community cancer organizations, and GLI’s Liver Cancer Glossary is showcased among others as a trusted resource on their website.
Liver Cancer Resources for HCP/Scientists	In 2018, ACCC launched the Less Common Cancer Education Project. Shortly after, ACCC published the Multidisciplinary Hepatocellular Carcinoma Care Environmental Scan, which is available on the ACCC website. In an effort to better understand access to care barriers for liver cancer treatment, ACCC published a Liver Cancer Heatmap to better understand incidence rates of liver cancer around the United States and what geographic areas are most in need. ACCC also has resources that cover multidisciplinary HCC care effective practices in care coordination, which can serve as guidelines to HCPs.
Policy Involvement	The "Advocate" section of the website has links to the Oncology Care Model Collaborative; the ACCC Legislative Action Center; and a page addressing access, payment, and reimbursement reform.

Blue Faery

Website	www.bluefaery.org
Leadership	Andrea Wilson, Executive Director
Founding Year	2002
Location	Birmingham, AL, USA
Revenue	\$214,969 (2019)
Mission	“Blue Faery’s mission is to prevent, treat and cure primary liver cancer, specifically Hepatocellular Carcinoma, through research, education and advocacy.” The organization was founded by Andrea Wilson to honor her sister, Adrienne Wilson, who succumbed to liver cancer after a 147-day battle with HCC.”
Liver Cancer Resources for Patients	Blue Faery is a liver cancer (mostly HCC) dedicated organization, and provides resources related to liver cancer in the field of research, patient and family education, advocacy, treatment centers, clinical trials and clinical trial matching, statistics, treatment options, glossary of liver cancer terms, liver cancer news, podcasts, and external resources.
Liver Cancer Resources for HCP/Scientists	Under the "For Doctors" tab, there is information on how to list clinical trials, how to get involved in the Blue Faery Advisory Board and Medical Research Committee, and the Blue Faery Award for Excellence in Liver Cancer Research.
Policy Involvement	Blue Faery is involved in policy and legislation for liver cancer patients and care as Andrea Wilson sits on the NCI Hepatobiliary Task Force. Andrea Wilson also participates in other policy activity and documents her work on the Blue Faery website. In addition, some of the editions of Liver Cancer News do state changes made to policies and legislation that may affect liver cancer patients.

British Liver Trust

Website	www.britishlivertrust.org.uk
Leadership	Pamela Healy OBE, Chief Executive
Founding Year	1988
Location	Bournemouth, UK
Revenue	\$1,080,145 (2019) (converted from pounds to dollars)
Mission	“We are here for everyone affected by liver disease, whatever the cause and wherever they live... We support patients and families so you don’t have to face liver disease alone. We campaign to improve awareness so more people are aware of the risks to the liver. We lobby for improved services for patients. We fund research to find the causes and treatments of liver disease.”
Liver Cancer Resources for Patients	The British Liver Trust has a page dedicated to information about liver cancer, including but not limited to causes, types, symptoms, diagnostic tests, online liver health screeners, and treatment options. A helpline center is available for support and is operated by The British Liver Trust and is staffed by qualified nurses. The page also lists several external sites that offer support to cancer patients as well as a brochure for liver cancer patients.
Liver Cancer Resources for HCP/Scientists	The British Liver Trust lists several liver cancer research articles and provides information on these projects for HCP. On the “Professionals” page, there are opportunities for HCPs to get involved with the organization’s Clinical Advisory Group. There are also resources available including but not limited to liver function guidelines, patient factsheets for distribution, and a liver disease toolkit.
Policy Involvement	The British Liver Trust has some information and news articles about policy regarding liver health upon a “policy” search of the website. Efforts on behalf of The British Liver Trust include advocating for better cancer treatments and organ donation, among other critical policy topics.

Canadian Liver Foundation (CLF)

Website	www.liver.ca
Leadership	Jennifer Nebesky, President & CEO
Founding Year	1969
Location	Ontario, Canada
Revenue	\$6,900,000 (2019)
Mission	“Through research, we are able to improve prevention, screening, diagnostics, and treatments in order to reduce the incidence and impact of liver disease. Research is the key to minimizing the impact on people affected by liver diseases, but it’s only as good as its practical application. Through our advocacy, education, and patient support efforts, we share the knowledge gained through research to improve the lives of liver disease patients and protect others who are at risk. At the same time, we seek to eliminate the barriers that may limit patients’ access to research breakthroughs”
Liver Cancer Resources for Patients	CLF has an entire liver cancer page with information on the causes, classifications, statistics, transplants, prevention, and future of the disease. There is also a “Patients & Caregivers” tab that includes the Canadian National Help Line, “Living with Liver Disease Programs,” the LIVERight Health Forum, and a Peer Support Network. There do not appear to be any liver cancer dedicated resources that cover the cancer progression.
Liver Cancer Resources for HCP/Scientists	CLF has a multitude of resources for HCP, including clinical practice guidelines, diagnostic tools and calculators, educational videos and slides, information on meetings and conferences, and disease specific resource centers, and information on research and grant opportunities.
Policy Involvement	CLF has an advocacy page that details the policy and advocacy involvement the organization has had in the past. CLF also offers advice for patients, family members, physicians, nurses, and allied health professionals on how to advocate for patients and liver health.

Cancer 101

Website	www.cancer101.org
Leadership	Sarah Krug, Executive Director
Founding Year	2002
Location	New York, NY, USA
Revenue	\$127,238 (2018)
Mission	“To empower, inform and engage patients and their caregivers to take control over their diagnoses, navigate the cancer journey, and partner with their healthcare team to make informed decisions.”
Liver Cancer Resources for Patients	Cancer 101 has a liver cancer page for patients that has statistics and symptoms. However, the page has a disclaimer that states “You will be redirected to information provided by the National Cancer Institute.” The different topics lead to the corresponding NCI page that opens up on a different page. Topics covered by the NCI pages include cause and prevention, screening, treatment, coping with cancer, and others. The American Liver Foundation and Global Liver Institute are listed as additional resources for patients.
Liver Cancer Resources for HCP/Scientists	Cancer 101 is a patient support organization and does not have resources for HCP or scientists.
Policy Involvement	Cancer 101 is a patient support organization and is not involved in policy.

Cancer Hope Network

Website	www.cancerhopenetwork.org
Leadership	Jesus Repetto, CEO
Founding Year	1981
Location	Chester, NJ, USA
Revenue	\$442,497 (2018)
Mission	“To provide free one-on-one confidential support to all people (patients, family or friends) impacted by cancer, along the entire continuum from diagnosis through survivorship. We provide support by training volunteers who faced similar experiences who are matched to those needing our services. Through this process we strive to instill hope and make a positive difference in the lives of people touched by cancer.”
Liver Cancer Resources for Patients	Cancer Hope Network provides a list of external resources, but does not have any of their own liver cancer resources.
Liver Cancer Resources for HCP/Scientists	Cancer Hope Network is a patient support organization and does not have resources for HCP or scientists.
Policy Involvement	Cancer Hope Network is a patient support organization and is not involved in policy.

Cancer Research Institute (CRI)

Website	www.cancerresearch.org
Leadership	Jill O’Donnell-Tormey, CEO, Director of Scientific Affairs
Founding Year	1953
Location	New York, NY, USA
Revenue	\$37,223,458 (2020)
Mission	“Save more lives by fueling the discovery and development of powerful immunotherapies for All Types of Cancer.”
Liver Cancer Resources for Patients	CRI has a liver cancer page with information on how immunotherapy can help treat liver cancer and information on how to find clinical trials specific to liver cancer. The general “Patient” portal allows patients to explore immunotherapy in depth, has clinical trial information, provides resources (printable resources, helpful links, glossary of terms, and cancer information), and allows patients to stay up to date on what is new in the field of immunotherapy. CRI also has an “ImmunoCommunity” that allows patients to “Read real stories of inspiration and lessons learned, or connect with our ImmunoAdvocates directly about their experiences with immunotherapy treatment”. However, there are no liver cancer-specific stories within the ImmunoCommunity.
Liver Cancer Resources for HCP/Scientists	CRI has no liver cancer-specific resources for HCP or scientists, but it does have a multitude of other HCP and scientist resources. CRI provides information on scientific leadership, fellowships and grants, clinical development, the science on immunotherapy, and events and other resources for scientists.
Policy Involvement	CRI does not have any obvious policy involvement.

Cancer Support Community (CSC)

Website	www.cancersupportcommunity.org
Leadership	Elisabeth Franklin, PhD, MSW, President
Founding Year	1982
Location	Washington, DC, USA
Revenue	\$8,624,191 (2017)
Mission	“As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC) is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.”
Liver Cancer Resources for Patients	CSC has a liver cancer devoted booklet called “Frankly Speaking About Cancer: Liver Cancer” with detailed information about cancer, how it is diagnosed, currently available treatments, and advice for combating the emotional toll a cancer diagnosis can place on the patients and caregivers alike. On CSC’s webpage there is additional information such as a "Find a Treatment Center" function, clinical trial information, how to navigate insurance, and quality of life information. CSC also has the Cancer Experience Registry and unique resources such as blogs, radio shows, and a list of support opportunities that liver cancer patients can utilize. The discussion board blog posts act as a platform for connecting cancer patients. CSC also operates a Cancer Support Hotline for patients.
Liver Cancer Resources for HCP/Scientists	CSC has no liver cancer-specific resources for HCP or scientists, but it does have a multitude of other HCP and scientist resources. The Research and Training Institute combines the different types of cancer experiences (psychosocial, behavioral, physical, survivorship, etc.) to create streamlined program delivery. CSC also provides publications and presentations that relate to evidence-based interventions used to improve patient experience.
Policy Involvement	Under the “Our Institutes” page is information about CSC’s Cancer Policy Institute (CPI), which brings together patient advocates and policy experts to ensure that the voices of cancer patients and their loved ones play a central role in federal and state legislative, regulatory, and executive policy making.” CPI believes in “access to care for all patients, quality as a central theme, and research as a critical priority.” CSC also has a compilation of policy webinars and videos, advocacy toolkits, and fact sheets.

CancerCare

Website	www.cancercare.org
Leadership	Patricia Goldsmith, CEO
Founding Year	1944
Location	New York, NY, USA
Revenue	\$20,413,573 (2019)
Mission	“CancerCare® is the leading national organization dedicated to providing free, professional support services including case management, counseling, support groups, educational workshops, publications and financial assistance to anyone affected by cancer. All CancerCare services are provided by oncology social workers and world-leading cancer experts.”
Liver Cancer Resources for Patients	CancerCare has a liver cancer page under the “Help by Diagnosis” tab that has with educational resources, publications, and ways to get added support and care, as well as a very well rounded patient resource page with links to community programs, financial assistance, publications, connect education workshops, support groups, and counseling. There are no dedicated support groups for liver cancer, but patients are encouraged to join a general support group. CancerCare also operates a “Hopeline” which is how patients can be in contact with a social worker.
Liver Cancer Resources for HCP/Scientists	CancerCare has no liver cancer-specific resources for HCP or scientists, but it does have a multitude of other HCP and scientist resources. "For Health Care Professionals" portal that allows HCP to connect their patients to the resources on the site, refer patients to speak with a counselor, order publications, and register for webcasts. There is also the CancerCare + Patient Access and Engagement Report that details CancerCare’s latest research.
Policy Involvement	CancerCare advocates for the cancer patient with press releases, blog posts, and articles about health policy and its effects on cancer patients. CancerCare also attends political events such as congressional briefings and roundtable discussions.

Cholangiocarcinoma Foundation

Website	www.cholangiocarcinoma.org
Leadership	Stacie Lindsey, Founder & CEO
Founding Year	2006
Location	Herriman, UT, USA
Revenue	\$1,527,321 (2017)
Mission	“To find a cure and improve the quality of life for those affected by cholangiocarcinoma.”
Liver Cancer Resources for Patients	The Cholangiocarcinoma Foundation website provides key information on the disease (overview, symptoms, staging, risk factors, treatment options, key statistics). There is a tab for patients, which provides support for those who are newly diagnosed, research opportunities, clinical trials, patient registries, educational materials, external resources, a glossary of terms, webinars, and discussion boards. There is also a tab for ‘Newly Diagnosed/New to CCF’ and provides the first steps that should be followed by someone who has just been diagnosed with cholangiocarcinoma. All resources provided to patients and caregivers are very comprehensive and cover all aspects of the cancer journey.
Liver Cancer Resources for HCP/Scientists	The Cholangiocarcinoma Foundation hosts an annual conference for HCP and scientists in the field. Patients are also welcome to join the webinar. There is also a tab for professionals on the organization’s site, which includes information on the foundation’s advisory board, clinical trials, research grants, genetic studies, international research network, educational materials, webinars, and major cancer center application forms.
Policy Involvement	The Cholangiocarcinoma Foundation’s policy involvement can be found by searching “Policy” on their website. The search reveals a 2015 post titled “Advocacy, Public Policy and the Cholangiocarcinoma Foundation.” This piece states the importance of health care legislation and how the Cholangiocarcinoma Foundation sees advocates of rare disease as important players in the changing of legislation.

Digestive Cancers Europe (DiCE)

Website	www.digestivecancers.eu
Leadership	Dora Constantinides, Chair; Zorana Maravic, Acting CEO; Jolanta Gore-Booth, Executive Director, Co-Founder
Founding Year	2018
Location	Brussels, Belgium
Revenue	\$376,289 (2018)
Mission	“Our mission is to contribute to early diagnosis and decreased mortality from digestive cancers and to increase overall survival and quality of life.”
Liver Cancer Resources for Patients	The DiCE website features a specific page for patients. This section includes sections on: finding local patient organizations, finding clinical trials, information on digestive cancers, a “Colorectal Cancers Navigator” (answers the question: “I have been diagnosed with colorectal cancer. What do I do now?”), patient voices/advocacy, patient rights, and resources for caretakers.
Liver Cancer Resources for HCP/Scientists	DiCE includes a page for the latest news on digestive cancers, which includes news about DiCE, member news, and medical news. This could be utilized by scientists to find recent articles. Additionally, there is a page on recent publications. DiCE hosts several events and webinars, including their Masterclass Series of 2021 and a Pan European Campaign for Oesophageal Cancer Awareness Month in April of 2021.
Policy Involvement	DiCE’s policy involvement can be seen on their website under “About Us” and “What We Do”, on the page “Working Together for Policy Change.” There are numerous policy projects detailed on this page.

European Liver Patients’ Association (ELPA)

Website	www.elpa.eu
Leadership	Marko Korenjak, President
Founding Year	2005
Location	Brussels, Belgium
Revenue	N/A
Mission	“ELPA’s aim is to promote the interests of people with liver disease and in particular: to highlight the size of the problem; to promote awareness and prevention; to address the low profile of liver disease as compared to other areas of medicine such as heart disease; to share experience of successful initiatives; to work with professional bodies such as EASL and with the EU to ensure that treatment and care are harmonised across Europe to the highest standards.”
Liver Cancer Resources for Patients	There is a page dedicated to information on HCC, which is listed under “Liver Diseases”. There are no programs specific to liver cancer for patients. There are also events that liver cancer patients and caregivers can support and participate in, including Liver Cancer Awareness Month, as well as research opportunities for patients.
Liver Cancer Resources for HCP/Scientists	ELPA has a page dedicated to information on HCC, which is listed under “Liver Diseases”. ELPA has numerous meetings, events, and symposiums that may feature liver cancer.
Policy Involvement	ELPA has several programs involved in policy. The first is the Hep-CORE study, which attempts to shed light on national policies regarding HVB/C and how patients are affected by the implementation of policy recommendations across the continent. ELPA also has ELPA University, “a year-long capacity building programme on liver health and advocacy.” The development of patient advocates and liver health advocates is important in the further progression of policy making affecting these populations.

Fibrolamellar Cancer Foundation (FCF)

Website	www.fibrofoundation.org
Leadership	Marna O. Davis, Co-Chairmen, Board of Directors; John Hopper, President/Executive Director
Founding Year	2008
Location	Greenwich, CT, USA
Revenue	\$453,220 (2019)
Mission	“Find a cure and treatment options, raise awareness of this disease, and connect and support the fibrolamellar community of patients and their families.”
Liver Cancer Resources for Patients	FCF is dedicated to fibrolamellar carcinoma, a rare liver cancer, and provides background information on the disease, treatment options, research, patient resources, and clinical trial information. Patient resources include information on how to connect with fellow fibrolamellar patients, find a doctor, and how to locate resources (transportation, housing, financial support, medical communication, reading, films, etc.). Additionally, FCF has a page dedicated to relevant events for patients. Their website features a glossary of terms related to liver cancer.
Liver Cancer Resources for HCP/Scientists	FCF provides information on current research projects, news related to relevant press releases and media coverage, available grants, and tissue banks.
Policy Involvement	FCF does not have any obvious policy involvement.

GI Cancers Alliance

Website	https://www.gicancersalliance.org/
Leadership	N/A
Founding Year	N/A
Location	Central Square, NY
Revenue	N/A
Mission	“To raise awareness, provide education and advocate to prevent, treat and cure gastrointestinal cancers through a collaboration between advocacy groups, industry and institutional partners.”
Liver Cancer Resources for Patients	Dedicated to convening GI cancer partners, the GI Cancers Alliance is made up of fellow advocacy partners, industry members, and clinicians from top academic centers. They provide liver cancer specific information covering risk factors, diagnosis, treatment, and prevention. They reference fellow liver cancer focused information offering patient resources, and GLI is listed.
Liver Cancer Resources for HCP/Scientists	GI Cancers Alliance does not appear to provide any resources for HCP/scientists.
Policy Involvement	GI Cancers Alliance does not have any obvious policy involvement on their website, but they advocate for increased research funding for GI cancer types as well as increasing clinical trial enrollment.



Global Liver Institute (GLI)

Website	https://www.globalliver.org/
Leadership	Donna R. Cryer, JD, President & CEO
Founding Year	2013
Location	Washington, DC, USA
Revenue	\$848,809 (2019)
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.”
Liver Cancer Resources for Patients	Within the ‘Liver Cancers’ tab on the GLI website, there are many patient educational materials available that cover all aspects of the cancer journey such as types of liver cancer, risk, screening and risk reduction, symptoms and detection. Most notably is the educational suite of patient materials called <i>Liver Cancer Lessons</i> which provides vital information on liver cancer types, risk, types of screening and reduction practices, as well as information on how to cope with the diagnosis of liver cancer. Additionally, there are also many videos that are available for watching from experts in the liver cancer space that give trusted insights into making the best of the liver cancer experience. Also a large priority for GLI is their #OctobersIs4Livers campaign that is held every October to promote liver cancer awareness and patients & survivors are strongly encouraged to get involved as advocates in this effort. Advocates assist GLI in raising awareness of the risk factors for liver cancer & providing support to those already diagnosed.
Liver Cancer Resources for HCP/Scientists	Also found under the ‘Liver Cancers’ page on the GLI website, information is available on the Liver Cancers Council which is described as a group of stakeholders that come together to improve the live cancer experience. The council is comprised of advocacy partners, healthcare professionals, patients, survivors, partners, and advocates. The goals of the council are listed under this page and have relevant and lofty, yet attainable goals.
Policy Involvement	GLI policy initiatives span from liver health to liver cancer, and all other areas in between. Strong emphasis and focus is placed on policy actions that have the possibility to be implemented at the federal level. Advocates are a critical piece of GLI’s policy efforts and play a large role in advocating for issues such as liver cancer program

	appropriations, clinical trial inclusion efforts, and treatment options advancements on Capitol Hill.
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Hepatitis B Foundation (HBF)

Website	www.hepb.org
Leadership	Timothy Block, Co-Founder/President; Louis P. Kasssa, III, Executive Vice President/Chief Operating Officer
Founding Year	1991
Location	Doylestown, PA, USA
Revenue	\$1,945,843 (2019)
Mission	“The Hepatitis B Foundation is a national nonprofit organization dedicated to finding a cure and improving the quality of life for those affected by Hepatitis B worldwide. Our commitment includes funding focused research, promoting disease awareness, supporting immunization and treatment initiatives, and serving as the primary source of information for patients and their families, the medical and scientific community, and the general public.”
Liver Cancer Resources for Patients	HBF is mainly focused on efforts around viral hepatitis, but there are also some resources available for liver cancer patients as part of their Liver Cancer Connect Program. Once on the program’s page, the many available resources within this program are accessible and include liver cancer information for newly diagnosed patients. Also listed is information on risk factors, prevention, screening, symptoms, diagnosis, staging, treatment, and follow up care. The page provides useful patient resources on talking to a healthcare team, liver cancer centers, drug watch, a glossary of terms. HBF also provides information on online support groups and the importance of educating about the relationship between liver cancer and hepatitis B.
Liver Cancer Resources for HCP/Scientists	This organization has a page dedicated to guidelines for health care professionals in treatment of liver cancers. There are no other liver cancer-specific resources for HCP or scientists, however, it does have a multitude of other HCP and scientist resources. Under the "Research & Programs" tab there is a list of programs geared toward the scientists and HCP. This includes information on education and training, public health and international programs, and HBF’s research institute, the Baruch S. Blumberg Institute.

Policy Involvement	HBF does quite a bit of work with policy and advocacy efforts on behalf of hepatitis patients, but there don't seem to be any efforts solely dedicated to liver cancer. HBF's goal is to double federal funding for hepatitis B efforts and to decrease discrimination against hepatitis patients. Although not all the work done in the policy and advocacy field is directly related to liver cancer, there is an established connection between hepatitis and liver cancer, so efforts by HBF have the potential to minimize liver cancer cases.
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Hepatitis B Foundation: Liver Cancer Connect

Website	www.hepb.org/research-and-programs/liver/
Leadership	Joan Block, Executive Director
Founding Year	2012
Location	Doylestown, PA, USA
Revenue	<i>Liver Cancer Connect</i> is a program of the Hepatitis B Foundation and no specific financial information was found on this sole program.
Mission	“Liver Cancer Connect is a dedicated program of the Hepatitis B Foundation that was created to provide individuals and families with the information and support they need when facing the challenge of primary liver cancer. Although this is a serious diagnosis, there is good reason to have hope because of the many advances made in the early detection, management and treatment of liver cancer.”
Liver Cancer Resources for Patients	The navigation for Liver Cancer Connect reveals the resources available, which span from information for newly diagnosed patients (what liver cancer is and its, risk factors, prevention methods, symptoms, screening options) to diagnostics, health care provider interaction, cancer centers available, treatment options, follow up care, external resources, and a glossary of terms related to liver cancer.
Liver Cancer Resources for HCP/Scientists	Liver Cancer Connect is mostly dedicated to the patient perspective and geared to those who have been diagnosed with liver cancer or have had a close one diagnosed. The overarching organization, the Hepatitis B Foundation, does have resources for HCP and researchers and provides research through the Baruch S. Blumberg Institute.
Policy Involvement	There are no policy programs available on the Liver Cancer Connect website. The overarching organization, the Hepatitis B Foundation, does quite a bit of work with policy and advocacy efforts on behalf of hepatitis patients. HBF’s efforts to double federal funding for liver cancer and hepatitis B and to decrease discrimination against hepatitis patients. Although not all the work done in the policy and advocacy field is directly related to liver cancer, there is a physiological correlation between hepatitis and liver cancer, so efforts by HBF have the potential to reach liver cancer patients.

The Intercultural Cancer Council (ICC) and Caucus (ICCC)

Website	www.interculturalcouncil.org
Leadership	Pamela M. Jackson, MS, Executive Director, ICC; Patricia Matthews-Juarez, PhD, Chair, ICC
Founding Year	1995
Location	Nashville, TN, USA
Revenue	\$176,023 (2019)
Mission	“The Intercultural Cancer Council promotes policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States and its associated territories.”
Liver Cancer Resources for Patients	The Intercultural Cancer Council has no liver cancer-specific resources, but they have a “Cancer Resources” page under “Updates & New Info,” which provides several websites for information on various cancer types and patient resources. They also have a multitude of resources that are organized in the ICC Library. The resources available include fact sheets, publications, and an edict titled “Eliminating Disparities in Clinical Trials.”
Liver Cancer Resources for HCP/Scientists	The resources available on the ICC and ICCC website are not advertised to HCP or scientists, although many of the available resources could be useful for HCP and scientists.
Policy Involvement	The ICCC is the entity focused on policy, and according to the ICCC president, “Mostly as a member of OVAC (One Voice Against Cancer) we lobby for increases on a yearly basis for NIH, NCI, and CDC. Our goal is to ensure that these provide funding that further our efforts to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States and its associated territories. We have been very successful in our increases and meet by phone once a month to get these increases--In December of 2015 we saw the passing of One Degree Legislation and it passed the largest increase for cancer research in over ten years. This new funding will play a pivotal role in our ability to discover new cures and find new ways to prevent and cure cancer and will continue to increase in years to come.”

The Interventional Initiative (II)

Website	www.theii.org
Leadership	Susan Jackson, MBA, CEO; Isabel Newton, MD, PhD, Chairperson of the Board
Founding Year	2015
Location	Oakland, CA, USA
Revenue	\$71,065 (2018)
Mission	“The Interventional Initiative is a not-for-profit 501c3 organization with a public service mission to educate and engage the public about the value of minimally invasive, image-guided procedures (MIIPs). Our mission is achieved through several public-centric multimedia production and social media initiatives.”
Liver Cancer Resources for Patients	There is a liver cancer page under the "What are MIIPs?" and “Procedures” tab that provides basic information on the liver and liver cancer statistics, diagnoses, treatments, and additional resources. They also have a video on their website about liver cancer.
Liver Cancer Resources for HCP/Scientists	Most of the information provided is geared to the patient perspective for understanding, prepping for, and dealing with MIIPs.
Policy Involvement	The only mention of policy is that policy makers are unaware of all of the treatment options available to patients. They focus on promoting awareness for MIIPs through their various programs, including their National Without a Scalpel Day.

International Liver Cancer Association (ILCA)

Website	https://ilca-online.org/
Leadership	Bruno Sangro, MD, PhD, President
Founding Year	2006
Location	Brussels, Belgium
Revenue	N/A
Mission	“To lead a global Community of physicians, scientists and allied professionals through education and research with the goal to better prevent and treat liver cancer.”
Liver Cancer Resources for Patients	There are a few resources listed for patients covering topics such as liver cancer basics, types of liver cancer, risk factors, diagnosis, treatment options, and information for caregivers. There are no other resources listed for patients other than the general information topics.
Liver Cancer Resources for HCP/Scientists	ILCA gathers together multidisciplinary experts in the liver cancer field and provides impactful resources for members as well as all that wish to be a part of the work. ILCA holds a highly regarded annual conference in which experts in the field present on the latest research in liver cancer. Another important program is the ILCA School of Liver Cancer which is held annually. The 2021 program will cover groundbreaking new innovations in the knowledge of pathogenesis and clinical management of different types of liver cancer.
Policy Involvement	ILCA has no apparent involvement in policy initiatives.

Latinas Contra Cancer (LCC)

Website	www.latinascontracancer.org
Leadership	Darcie Green, CEO, Executive Director; Sandra Madrigal, Board Chair
Founding Year	2003
Location	San Jose, CA, USA
Revenue	\$269,893 (2018)
Mission	“To create an inclusive health care system that provides services to the underserved Latino population around issues of breast and other cancers.”
Liver Cancer Resources for Patients	Latinas Contra Cancer does not have any liver cancer-specific resources for patients. Their website includes resources for all types of cancer patients, including information on research, clinical trials, patient support, detection and screening, prevention, capacity building, and education and resource materials.
Liver Cancer Resources for HCP/Scientists	Latinas Contra Cancer is a patient focused organization and does not have resources for HCP or scientists.
Policy Involvement	Latinas Contra Cancer has some involvement in policy, participating in the National Latino Cancer Summit.

Liver Patients International (LPI)

Website	www.liverpatientsinternational.org
Leadership	George Kalamitsis, Chair
Founding Year	2019
Location	Brussels, Belgium
Revenue	N/A
Mission	“LPI will keep patients at the center of all that it does. We work in a progressive and collaborative way, ensuring meaningful engagement and partnerships with other stakeholders. We represent and advocate for all patients affected by liver disease in both policy and operational contexts and promote equal access to effective areas of liver healthcare.”
Liver Cancer Resources for Patients	The website has a page with information on the different types of liver conditions, including causes, symptoms and signs, diagnosis, and treatment. LPI’s website also includes a section for “News,” which provides information on recent research and articles on liver conditions.
Liver Cancer Resources for HCP/Scientists	LPI does not currently have any resources specific to HCPs or scientists, however, they have a page on recent news articles.
Policy Involvement	The LPI does not have any current involvement in policy, however, the “What We Do” page outlines their goals, including policy and advocacy work on behalf of liver patients as well as information and awareness campaigns.

LiveStrong

Website	https://www.livestrong.org/what-we-do
Leadership	Greg Lee, President & CEO
Founding Year	1997
Location	Austin, TX
Revenue	
Mission	“We ask survivors and caregivers what they need, we ask the system how it can be more person-centered, we ask innovators how we can bring impossible ideas to life”
Liver Cancer Resources for Patients	Although not liver cancer specific, Livestrong is a survivorship focused organization that offers a myriad of resources to patients who are in all stages of their cancer diagnosis- including just diagnosed all the way to end of life care management. They list common concerns of cancer patients including social & emotional support, fertility, and everyday needs- just to name a few. Subsequent resources address all the listed concerns and provide many different types of support from different angles. Additional tools for patients include a Living After Cancer Treatment brochure and a prescription discount card.
Liver Cancer Resources for HCP/Scientists	Livestrong is a patient centered organization and does not provide any resources to HPC/scientists.
Policy Involvement	Livestrong does not have any policy involvement.

National Cancer Institute (NCI)

Website	www.cancer.gov
Leadership	Norman Sharpless, MD, Director; Douglas R. Lowy, MD, Principal Deputy Director
Founding Year	1937
Location	Bethesda, MD, USA
Revenue	\$6,327,000,000 (2020)
Mission	“NCI leads, conducts, and supports cancer research across the nation to advance scientific knowledge and help all people live longer, healthier lives.”
Liver Cancer Resources for Patients	NCI has a page dedicated to liver and bile duct cancer, which includes an overview of the disease, treatment, causes and prevention, screening, research, coping resources, and statistics. NCI also provides a variety of general cancer resources for patients, including cancer basics, information for newly diagnosed patients, a dictionary of cancer terms, and more. The NCI has a Center for Cancer Research (CCR) Liver Cancer Program, which provides resources for patients including information about liver cancer, contacting NCI’s clinical team, finding a clinical trial, and additional educational resources.
Liver Cancer Resources for HCP/Scientists	NCI has a version of the same liver cancer page geared toward an audience of HCP and oncology professionals. NCI funds grants in cancer research and provides training for professionals. The website also details the events that are available to professionals and researchers. NCI established the Center for Cancer Research (CCR) Liver Cancer Program, “A multidisciplinary network of researchers and clinicians dedicated to improving early detection, diagnosis, and treatment of liver cancer.” The website for this program includes HCP specific resources, including patient referral information and clinical training opportunities. There is also a section specific to researchers that includes information on focus areas and collaborations of NCI’s science, the NCI CLARITY study, publications, and contact points for the program. The CCR Liver Cancers Program also includes a section for relevant news and events for liver cancer professionals and patients.
Policy Involvement	NCI has a page detailing the legislative activities it is involved in, such as hearings, testimonies, and legislation. There is information on the history of cancer legislation and policy, as well as external resources for legislation and legislative terms. Advocates can stay up

	to date on recent public law pertaining to cancer research, treatment, clinical trials, and more at this site as well.
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National Coalition for Cancer Survivorship (NCCS)

Website	www.canceradvocacy.org
Leadership	Shelley Fuld Nasso, MPP, CEO; Samira K. Beckwith, Acting Board Chair
Founding Year	1986
Location	Silver Spring, MD, USA
Revenue	\$1,952,609 (2019)
Mission	“To advocate for quality cancer care for all people touched by cancer. Founded by and for cancer survivors, NCCS created the widely accepted definition of survivorship and defines someone as a cancer survivor from the time of diagnosis and for the balance of life.”
Liver Cancer Resources for Patients	NCCS does not have any liver cancer specific resources, however, provides many general resources for cancer patients, including COVID-19 resources for cancer survivors, a survivorship checklist, a cancer survival toolbox, and a telehealth project. The NCCS also provides publications on numerous topics, including talking with a doctor, self advocacy, employment rights, and remaining hopeful.
Liver Cancer Resources for HCP/Scientists	There are no liver cancer specific resources for HCP and scientists, however there are general resources including news, events, webinars, and a page on tools for care providers, including first steps for patients and planning patient care.
Policy Involvement	NCCS is heavily involved in policy, and in addition to government action, NCCS advocates with NGOs whose decisions and policies affect the care that cancer patients receive. NCCS aims to represent the perspective of cancer survivors in public policy discussions. Their policy involvements include focuses on quality cancer care, access to care, health equity, redefining functional status (RFS), and a State of Cancer Survivorship Study. The NCCS also holds a Cancer Policy Roundtable. NCCS also has the Cancer Policy & Advocacy Team program, for survivors and caregivers to learn about policy issues, and holds a CPAT Symposium each year.

National Comprehensive Cancer Network (NCCN) and NCCN Foundation

Website	www.nccn.org
Leadership	Robert W. Carlson, MD, CEO; Ronald S. Walters, MD, MBA, MHA, MS, Chair of Board
Founding Year	1995
Location	Plymouth Meeting, PA, USA
Revenue	\$39,212,689 (2019)
Mission	“To improve the quality, effectiveness, and efficiency of cancer care so that patients can live better lives.”
Liver Cancer Resources for Patients	NCCN published its first version of NCCN Guidelines for Patients: Hepatobiliary Cancers. These guidelines include general hepatobiliary cancers information and additional information on testing, cancer treatments, treatment decision making, and more. There is also a NCCN Patient Site which has valuable information that is pertinent to all cancer patients, such as guidelines, patient webinars, support for patients and caregivers, news, and events.
Liver Cancer Resources for HCP/Scientists	NCCN has Clinical Practice Guidelines available to physicians that cover standard procedures for treatment of liver cancers, supportive care, and specific populations. NCCN also provides educational events and programs, as well as a multitude of clinician and business resources. These include but are not limited to: member institutions, research programs, analytics, research, consulting, and access to publications and subscriptions.
Policy Involvement	The NCCN Policy and Advocacy Program works to advance patient access to cancer care through engagement with policy makers, regulatory agencies, and private and public payers. This program allows stakeholders in the field of oncology to discuss the challenges they face in health policy and develop educational programming on relevant policy issues. The NCCN has a Policy Fellows Program, which aims to provide exposure to oncology policy for early-career health policy professionals. The NCCN also convenes Policy Summits, that address a wide range of health policy concerns that oncology professionals wish to discuss and change, and webinars on cancer equity. The NCCN has a variety of white papers dedicated to cancer care quality, pain management, and access to cancer centers.

National Organization for Rare Disorders (NORD)

Website	https://rarediseases.org/
Leadership	Peter L/ Saltonstall, President and CEO
Founding Year	1983
Location	Danbury, CT, USA
Revenue	\$52,413,377 (2019)
Mission	“NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.”
Liver Cancer Resources for Patients	In addition to providing very comprehensive information for hundreds of rare diseases, NORD provides educational videos, webinar series, clinical trials and downloadable resources, just to highlight some resources provided. There is also a Patient and Caregiver Resource Center complete with in depth information to help guide patients and caregivers through their journey with a rare disease. There is information on some rare pediatric & liver cancers listed on NORD’s website.
Liver Cancer Resources for HCP/Scientists	Under the ‘For Clinicians and Researchers’ tab on NORD’s website is information for resources, research opportunities, and events to connect with fellow colleagues. NORD appears to promote research and innovation and therefore has many opportunities for grants and other research funding.
Policy Involvement	As listed on the website, NORD advocates for policy changes at the federal and state level that impact all Americans. NORD appears to have articles for featured policy issues: appropriations, research, access to affordable and adequate coverage, access to affordable medicines, access to diagnostics, access to innovative medicines and therapies, among many others.

Oncology Nursing Society (ONS)

Website	www.ons.org
Leadership	Nancy Houlihan, MA, RN, AOCN, President
Founding Year	1973
Location	Pittsburgh, PA, USA
Revenue	\$3,857,894 (2019)
Mission	“The mission of the Oncology Nursing Society is to promote excellence in oncology nursing and quality cancer care.”
Liver Cancer Resources for Patients	ONS is an organization for nurses and has no resources for patients.
Liver Cancer Resources for HCP/Scientists	ONS has a “Site-Specific Cancer Series” that includes a section on pancreatic and hepatobiliary cancers. ONS also has a variety of resources available on their website that are not liver cancer-specific. These resources include information on business development, conferences, awards, continuing nursing education, continuing practice resources, nursing journals, quality guidelines, and standards and reports.
Policy Involvement	The ONS website has a tab titled “Advocacy and Health Policy” under “Making a Difference” that includes the subheadings Policy Priorities, Position Statements, Advocacy Webinars and Podcasts, Join the ONS Capitol Gang, Health Policy Resources, Health Policy Coalitions, and Public Health Issues, and Advocacy and Health Policy Events. The ONS Center for Advocacy and Health Policy Events include Health Policy Summits and Capitol Hill Days. ONS’s advocacy and policy agenda calls for “improving cancer symptom management and palliative care; advancing and ensuring access to quality cancer prevention and care and; strengthening nursing workforce contributions to safeguard public health.”

Prevent Cancer Foundation

Website	www.preventcancer.org
Leadership	Carolyn “Bo” Aldigé, Founder, CEO
Founding Year	1985
Location	Alexandria, VA, USA
Revenue	\$6,560,753 (2019)
Mission	“The mission of the Prevent Cancer Foundation is saving lives across all populations through cancer prevention and early detection”
Liver Cancer Resources for Patients	There is a liver cancer page with information such as risk factors, symptoms, prevention, and a section for additional resources. Prevent Cancer Foundation also provides patients with additional information non-specific to liver cancer, which includes information on preventing cancer, at risk groups, clinical trials, screening, and research. Prevent Cancer holds numerous campaigns, conferences, and fundraisers for cancer prevention.
Liver Cancer Resources for HCP/Scientists	This organization has no liver cancer-specific resources for HCP or scientists, but it does have a multitude of other resources for HCP and scientists. Prevent Cancer Foundation provides opportunities for research grants and fellowships for early detection and prevention. Prevent Cancer Foundation also has information on their global reach, cancer technology, and events that they participate in that may be of interest to oncology professionals.
Policy Involvement	Prevent Cancer Foundation has an “Advocate” page under “Get Involved” that educates patients, caregivers, oncology professionals, and others involved in health care and public health on how to advocate for cancer legislation and policy. There is information on the areas of focus, advocacy strategies, and coalitions that the Foundation is involved in. In addition, there are sections for news and events, advocacy resources, letters, an advocacy toolkit, and information on how to take action. Prevent Cancer Foundation also participates in the “Think About the Link” Campaign that focuses on virally caused cancers, and they attend congressional briefings and participate in grassroots outreach.

Patient Advocate Foundation

Website	https://www.patientadvocate.org/
Leadership	Alan Blach, PhD, CEO
Founding Year	1996
Location	Hampton, VA
Revenue	\$39,538,138
Mission	“Provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses.”
Liver Cancer Resources for Patients	Patient Advocate Foundation’s main focus is providing case management services, co-pay relief programs, and financial aid to patients with any type of life threatening disease. They also provide informational resources on insurance and paying bills.
Liver Cancer Resources for HCP/Scientists	They do not appear to have any resources for HCP/scientists.
Policy Involvement	They do not appear to have any obvious policy involvement.

Society of Interventional Radiology (SIR)

Website	www.sirweb.org
Leadership	Matthew S. Johnson, MD, FSIR, President
Founding Year	1973 as Society of Cardiovascular Radiology, 2002 as Society of Interventional Radiology
Location	Fairfax, VA, USA
Revenue	\$10,942,815 (2018)
Mission	“The mission of the Society of Interventional Radiology is to improve patient care through image-guided therapy.”
Liver Cancer Resources for Patients	A patient information brochure on liver cancer is available through a website search. There is a patient center on the website that allows patients to gain a better understanding of what interventional radiology is and how it may be beneficial to the patient. There is also a “Find a Doctor” feature on the website.
Liver Cancer Resources for HCP/Scientists	SIR has a “Member Central” that includes information for HCP and researchers, including clinical practice guidelines, quality improvement measures, meeting and education information, and publications. There is also liver cancer content available at meetings for HCP and scientists.
Policy Involvement	SIR has an “Advocacy” page that includes sections for advocacy and outreach, voices for IR, an advocacy toolkit, and SIRPAC. The advocacy page provides information on how to advocate before Congress, regulatory and federal agencies, and the White House. It also provides “latest actions” involving SIR, upcoming events, and further information on physician reimbursement and COVID-19 advocacy.

SIRFoundation

Website	www.sirfoundation.org
Leadership	Carolyn Strain, MA, MS, Executive Director; Katharine L. Krol, MD, FSIR, Chair of Board
Founding Year	1993
Location	Fairfax, VA, USA
Revenue	\$1,234,211 (2019)
Mission	“SIR Foundation is a scientific foundation dedicated to fostering research in interventional radiology for the purposes of advancing scientific knowledge, increasing the number of skilled investigators, and developing innovative therapies that lead to improved patient care and quality of life. The foundation is committed to fostering the development and enhancement of innovative, minimally invasive, image-guided therapies from inception to mature clinical application and to conduct educational programs in the service of its mission.”
Liver Cancer Resources for Patients	The SIRFoundation provides the same liver cancer patient information brochure as the one on the SIR website. It can be accessed through the website by searching key terms such as ‘liver cancer’ and ‘liver diseases’. There is also a section on the website dedicated to clinical trials, non-specific to liver cancer.
Liver Cancer Resources for HCP/Scientists	SIRFoundation has articles and press releases pertaining to liver cancer and interventional radiology research, treatment, clinical trials, and news. SIRFoundation also provides general information on clinical research, research consensus panels, prospective trials, clinical registries. It also allows HCP and scientists to submit individual research or registry ideas. In addition, there are numerous standardized reports for treatments of liver cancer, including biopsy, TACE, ablation, and more, which could be useful to HCP. Finally, they do have information on liver diseases, which are precursors to liver cancer.

Policy Involvement	SIRFoundation does not appear to have a section detailing policy involvement. Upon a search of the website, an ‘Advocacy and Policy’ page pops up that links back to SIR and leads to information on the advocacy and policy involvement of the society.. This page provides information on how to advocate before Congress, regulatory and federal agencies, and the White House. It also provides “Today’s health care headlines” and further information on physician reimbursement, GME funding, COVID-19 advocacy efforts, and an advocate toolkit (although this is only available to SIR members).
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Stupid Cancer

Website	www.stupidcancer.org
Leadership	Alison Silberman, CEO
Founding Year	2007 as I’m Too Young For This! Cancer Foundation, 2012 as Stupid Cancer
Location	New York, NY, USA
Revenue	\$1,357,619 (2019)
Mission	“Stupid Cancer helps to empower everyone affected by adolescent and young adult (AYA) cancer by ending isolation and building community so that everyone in the AYA community is supported, understood, and accepted.”
Liver Cancer Resources for Patients	Stupid Cancer does not have any resources specific to liver cancer. The organization is a patient support organization and has a variety of different resources that are targeted to patients with any type of cancer. Some of the resources Stupid Cancer provides are: emotional support, financial assistance, insurance navigation, legal counsel, fertility information, gift registries, cancer navigation, regional support groups, meet up calendars, and more. Programs include Cancercon, meetups, and webinars. There is a Stupid Cancer Stories program, which is a blog detailing patient experiences with cancer.
Liver Cancer Resources for HCP/Scientists	Stupid Cancer is a patient support organization and does not have resources for HCP or scientists.
Policy Involvement	Stupid Cancer has a section for resources, which includes a list of education and advocacy organizations that offer specific resources to the AYA cancer community.

Triage Cancer

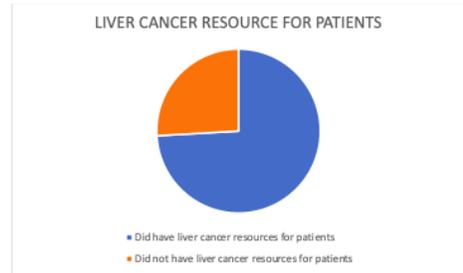
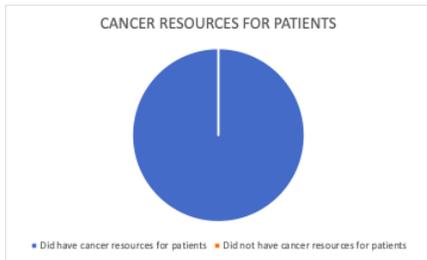
Website	www.triagecancer.org
Leadership	Joanna L. Fawzy Morales, Esq., CEO
Founding Year	2012
Location	Chicago, IL, USA
Revenue	\$591,768 (2019)
Mission	“Triage Cancer is a national, nonprofit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through free events, materials, and resources.”
Liver Cancer Resources for Patients	Triage Cancer has no resources specific to liver cancer. There are general resources for cancer patients, including information on health insurance, employment, disability insurance, COVID-19, navigating health care, finances, estate planning, legal issues, caregiving, psychosocial care, stress management, exercise and nutrition, medical care, clinical trials, multilingual resources, and more.
Liver Cancer Resources for HCP/Scientists	This organization has no liver cancer-specific resources for HCP or scientists, but it does have a multitude of other HCP and scientist resources. Triage Cancer provides information on conferences and educational events for hospitals, cancer centers, clinics, professional associations, and advocacy organizations. The organization also has a library of webinars and has a Speakers Bureau program that sends expert speakers on various cancer survivorship ideas to events. There are free in-service training for oncology HCPs and advocates on employment, cancer health insurance, and disability issues.
Policy Involvement	Triage Cancer provides national, state, and international policy and advocacy resources as well as information on state laws related to employment, disability insurance, and health insurance; advocacy resources. Triage Cancer also has an advocate training program, which aims to provide training for those interested in helping advocate for the cancer community.

The Ulman Cancer Fund for Young Adults

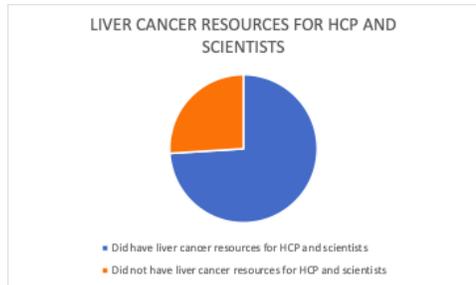
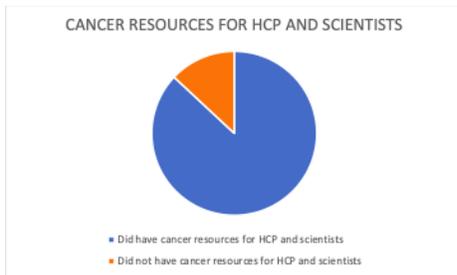
Website	www.ulmanfoundation.org
Leadership	Brock Yetso, President, CEO
Founding Year	1997
Location	Baltimore, MD, USA
Revenue	\$2,372,940 (2019)
Mission	“We change lives by creating a community of support for young adults, and their loved ones, impacted by cancer.”
Liver Cancer Resources for Patients	The Ulman Cancer Fund for Young Adults does not have any liver-cancer specific resources. That being said, they have a variety of resources for cancer patients, such as information for newly diagnosed patients, including how to search for information, choosing a medical team, questions to ask a treatment team, making medical decisions, and fertility. Ulman also has sections for patients dealing with being in treatment, after treatment, and end of life. There is also a resource directory and programs involving meetups, scholarships, and cancer and exercise. Ulman offers Remote Navigation through telephone and email communications for young adults and families.
Liver Cancer Resources for HCP/Scientists	The Ulman Cancer Fund for Young Adults is a patient focused organization and does not have resources for HCP or researchers.
Policy Involvement	The Ulman Cancer Fund for Young Adults is a patient focused organization and is not involved in policy.

Summary of Findings

GLI gathered publicly available information from 47 organizations that address or provide services for cancer patients and/or healthcare professionals and scientists (HCP). The information collected demonstrates both the variety of resources available to those affected by cancer and the professionals who care for them as well as the significant gap in liver cancer-specific resources. Although more liver cancer focused organizations have arisen in the last two years, it is still evident that the number of liver cancer focused organizations continue to lack funding and recognition.



All of the organizations listed in this landscape analysis have cancer or advocacy resources for patients. Of these 39 organizations, 29 have liver cancer-specific resources for patients.



34 of the 39 organizations have resources for HCP and scientists, and 29 of those organizations have liver cancer-specific resources for HCP and scientists.

33 of the 39 organizations are headquartered in the United States, and six are located outside of the U.S in European countries.

GLI as a Leader of Liver Cancer Organizations

It is evident that GLI is a leader of liver cancer focused organizations by offering a wide array of resources for both patients and healthcare professionals/scientists. In the time since the last landscape analysis update in May 2019, GLI’s liver cancer department has secured funding to

develop and deliver critical materials that leverage expertise from world renowned experts in liver cancer. GLI's team has created a comprehensive suite of patient educational materials called *Liver Cancer Lessons* that covers the entire disease continuum and serves as a guide to all stages of the cancer journey. The very successful 2019 & 2020 #OctobersIs4Livers programs have demonstrated increasing reach. The most successful campaign being in 2020 with a total reach of 100 million individuals. In tandem with the 2020 campaign was the creation of a first-of-its-kind global liver cancer map that was assembled by GLI staff using publicly available data. This map helps to highlight the disproportionate impact of liver cancer across the United States. Finally, in the last two years, GLI has drastically increased the number of partnerships with like-minded programs and organizations. These invaluable alliances are a critical step towards elevating the dialogue around liver cancer commensurate with its prevalence and impact.

Goals for GLI in 2021 include the continued growth and development of meaningful and impactful programs for the liver cancer community. This includes additional patient education materials, innovative support programs and more opportunities for engagement in advocacy. All materials are developed with the goal of being available in both digital and print formats to ensure information can be easily accessed and attained by individuals that need it the most to broaden the reach and impact of GLI's resources and materials.

In terms of resources that are available to healthcare professionals/scientists, GLI has plans to create a *Liver Cancer Screening White Paper* that would be housed on the GLI website and serve as a gold standard for clinical management and care of liver cancer patients. Additionally, GLI plans to create a set of evidence-based clinical interventions in the treatment of liver cancer (primarily HCC) that have been peer reviewed and provide extremely promising outcomes for maximizing end of life care for cancer patients. The interventional recommendations will be housed on the GLI website and will be readily accessible to healthcare professionals. Both initiatives are being led by our expert Liver Cancers Council members in collaboration with patients and others in the liver cancer community to ensure the patient perspective is incorporated into all materials.