



Advocacy Organization Landscape Assessment:
Liver Cancer Resources
Phase II



May 2019

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Introduction

Liver cancer is the second most deadly cancer in the world, accounting for 788,000 deaths in 2015.¹ It is also the only cancer to have increasing incidence and mortality rates.² The risk factors for liver cancer, which include hepatitis B and C, obesity, and diabetes, are 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.

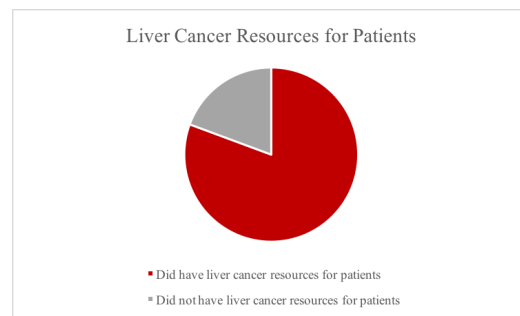
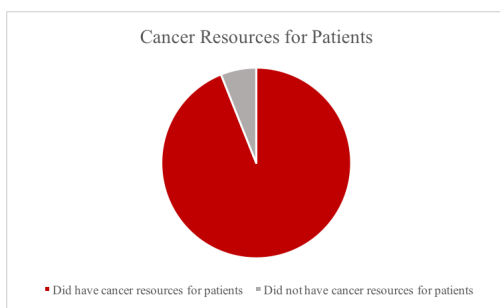
Methodology

The Global Liver Institute (GLI) set out to gather information on the available liver cancer resources from cancer advocacy organizations and professional medical societies directly by electronic survey questionnaire. Due to insufficient response GLI convened a meeting of liver cancer-focused organizations at the June 2017 ASCO conference - the Liver Cancer Advocacy Agenda Working Group Meeting after which GLI staff proceeded to collect 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.

Results

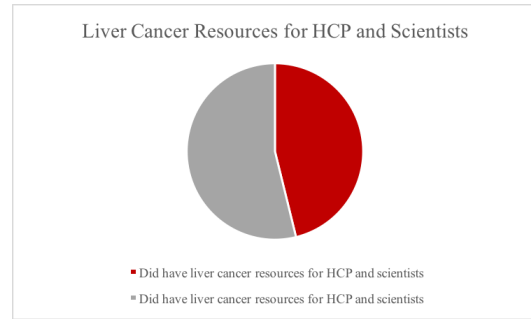
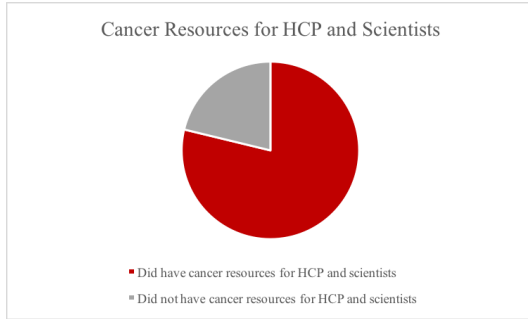
GLI gathered information from 34 organizations that address or provide services for cancer patients and/or healthcare professionals (HCP). The information collected demonstrates both the variety of resources available to those affected by cancer and the professionals who care for them and the significant gap in liver cancer-specific resources.



31 of the 33 organizations have cancer resources for patients. Of those 31 organizations, 25 have liver cancer-specific resources for patients.

¹ “Cancer.” *World Health Organization*. Feb. 2017

² Siegel, Rebecca L., et al. “Cancer Statistics, 2017.” *CA: A Cancer Journal for Clinicians*, 5 Jan. 2017



26 of the 33 organizations have resources for HCP and scientists, and 12 of those organizations have liver cancer-specific resources for HCP and scientists.

The average annual revenue for 29 organizations (not including NCI and organizations with unknown revenue) is \$42,254,371. The median annual revenue for 29 organizations (not including NCI and organizations with unknown revenue) is \$5,955,714.

30 of the 33 organizations are headquartered in the United States, and three are located outside of the U.S.

Continue reading for snapshot briefs of the 33 organizations included in this landscape assessment.

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.
AASLD	X*	X*							X*
ACS	X	X	X			X		X	X*
ACS-CAN									X*
ALF	X	X	X					X	X
ASCO	X	X			X	X			X*
CCF									
ACCC	X	X				X			X*
Beat Liver Tumors	X	X	X		X	X	X	X	X
Blue Faery	X	X			X	X			X
BLT	X	X				X		X	X
CLF	X	X						X	X
Cancer 101	X	X	X*		X*			X*	
CHN									
CRI	X				X				
CSC	X	X		X			X		X*
CancerCare	X	X					X	X	
Cholangio.	X	X	X		X	X		X	X
ELPA		X*							X*
FCF	X	X		X	X		X	X	
HBF	X	X*	X*		X*			X*	X*
HBF LCC	X	X		X					
ICC		X*							X*
The II	X	X			X				
Latinas Contra Cancer	X*	X*	X*		X*				X*
NCI	X	X			X*	X			X*
NCCN	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*
Ulman Fund		X*	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
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*
CCF	X*	X*				X*		
ACCC	X	X*	X*	X*	X*			X*
Beat Liver Tumors			X		X			
Blue Faery				X				
BLT	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	
ELPA	X		X*		X*	X*		
FCF				X	X	X	X	
HBF		X*	X*	X*	X*	X*		
HBF LCC								
ICC								
The II								
Latinas Contra Cancer								
NCI	X	X	X	X	X	X	X	X*
NCCN	X*	X*	X	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*	X*		X*

*These resources are not specific to liver cancer.

American Association for the Study of Liver Diseases (AASLD)

Leadership	Michael W. Fried, MD, FAASLD, President
Founding Year	1950
Location	Alexandria, VA, USA
Revenue	\$14,825,316 (2017)
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.
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 lobbyists and convenes a Liver Capitol Hill Day with patient advocacy involvement.

American Cancer Society (ACS)

Leadership	Gary Reedy, CEO; Richard Wender, Chief Cancer Control Officer
Founding Year	1913
Location	Atlanta, GA, USA
Revenue	\$885,574,000 (2016)
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. Liver cancer has also been featured in The American Cancer Society Family of Journals.
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)

Leadership	Lisa Lacasse, President
Founding Year	2001
Location	Washington, DC, USA
Revenue	\$36,936,972 (2017)
Mission	<p>“ACS CAN is committed to the mission of eliminating cancer as a major health problem. Ending cancer as we know it in this country is as much a matter of public policy as it is medical science and discovery.”</p> <p>“ACS CAN is a nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem.”</p>
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.
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. 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	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)

Leadership	Tom Nealon, President and CEO
Founding Year	1976
Location	New York, NY, USA
Revenue	\$9,409,699 (2017)
Mission	“Our mission is to facilitate, advocate and promote education, support 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, and access to ALF’s video bank.
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 could be used for liver cancer research. The “For Physicians & Researchers” 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 both supported and opposed. ALF provides advocates with direct links to policies and means to sign on to letters of support and opposition. The ALF website also includes a feature that allows advocates to search legislation for key words, including “liver cancer” and other related terms.

American Society of Clinical Oncologists (ASCO)

Leadership	Clifford A. Hudis, MD, FACP, FASCO, CEO
Founding Year	1964
Location	Alexandria, VA, USA
Revenue	\$124,918,070 (2017)
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, clinical trial information, follow-up care, latest resources, 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, 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 "Advocacy & Policy" page includes information on: 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.

Conquer Cancer, The ASCO Foundation

Leadership	Nancy Daly, MS, MPH, Executive Vice President and Chief Philanthropic Officer
Founding Year	1964
Location	Alexandria, VA, USA
Revenue	\$32,386,087 (2018)
Mission	"Conquering cancer worldwide by funding breakthrough research and sharing cutting-edge knowledge."
Liver Cancer Resources for Patients	CCF has no liver cancer-specific resources for patients.
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). CCF provides online medical education, meetings, symposia, workshops, and information on its research opportunities and research results. CCF’s Quality Oncology Practice Initiative (“an oncologist-led, practice-based quality improvement program”) for HCP is also featured on the website.
Policy Involvement	CCF 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)

Leadership	Thomas A. Gallo, MS, MDA, President
Founding Year	1974
Location	Rockville, MD, USA
Revenue	\$11,151,216 (2018)
Mission	“To be the leading education and advocacy organization for the multidisciplinary cancer team.”
Liver Cancer Resources for Patients	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. Liver cancer is listed as a cancer type under ACCC website’s “Learn” tab. This page includes 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.
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. Liver cancer is listed as a cancer type under ACCC website’s “Learn” tab. This page includes 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.
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.

Beat Liver Tumors

Leadership	Suzanne Lindley, Co-Founder
Founding Year	2006
Location	Canton, TX, USA
Revenue	Unknown
Mission	“To provide information, resources, support, and HOPE to those affected by advanced cancer or cancer that has spread to the liver from the original cancer.” Also, “to change the face of primary liver cancer or advanced cancer that has spread to the liver by: advocating for increased funding for cancer research, educating liver tumor survivors of possible surveillance and treatment options, and by being a point of contact and support for those affected by liver tumors.”
Liver Cancer Resources for Patients	Beat Liver Tumors provides information about what the liver is, what it does, and why it is important. The organization also provides information on different types of liver tumors and treatment options for patients. There are also cancer specific resources and resources on end of life care, insurance assistance, travel assistance, prescription assistance, and clinical trials. Beat Liver Tumors also has a support page for those with liver cancer, which gives patients information on online support groups, telegroups, meditation, survivor lines, stories of hope, and the organization’s newsletter.
Liver Cancer Resources for HCP/Scientists	Beat Liver Tumors is a patient support organization and does not have resources for HCP or scientists.
Policy Involvement	Beat Liver Tumors and its affiliated organizations (see below) do appear to be involved in some policy and advocacy work. There is a page on the website titled “Here’s a simplified process by which you might consider your own journey into preparing and becoming an advocate” that also has information on how to become an advocate, the “Ten Principles for Advocacy Success,” and how to get the information needed to be the best advocate one can be.
Other	Beat Liver Tumors is part of the overarching organization, United Ostomy Associations of America, Inc. (UOAA). Beat Liver Tumors is also known as YES, You Can Too. The information above has been compiled from the information available online.

Blue Faery

Leadership	Andrea Wilson, Executive Director
Founding Year	2002
Location	Birmingham, AL, USA
Revenue	\$17,020 (2011)
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 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

Leadership	Professor Oliver James, FMedSci, President
Founding Year	1988
Location	Bournemouth, UK
Revenue	912,112GBP (2018) (\$1,195,412)
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. We work across the UK – England, Scotland, Wales and Northern Ireland. We are a small charity tackling a serious and growing health problem – every donation makes a difference.”
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. 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 is one resource specific to liver cancer for HCP that links to another organization called SIRT (provides information on radioembolization to treat malignant liver tumors). The British Liver Trust also has a British Liver Nurses Forum and information on their partnership with the Royal College of General Practitioners which aims to make liver disease a clinical priority. In addition, there is a list of events for professionals across the country.
Policy Involvement	The British Liver Trust has some information and news articles about policy regarding liver health upon a “policy” search of the website. The “Campaigns” page includes the following: “The Trust actively campaigns on a range of issues, ensuring that the patient voice is heard, to improve services for those affected by a liver condition, promote early intervention and diagnosis, and to raise awareness.” Some of these campaigns include Love Your Liver, Alcohol Health Alliance, Lancet Liver Commission, and the Liver Task Force. None of British Liver Trust’s policy involvement is liver cancer focused.

Canadian Liver Foundation (CLF)

Leadership	Gary Fagan, President and CEO
Founding Year	1969
Location	Ontario, Canada
Revenue	7,390,744 CAD (2017) (\$5,497,973)
Mission	“The Canadian Liver Foundation is a national non-profit organization committed to promoting liver health and providing hope to people living with liver disease through: investing in liver research, sharing the knowledge gained through liver research with the medical community and the public, delivering support programs through committed volunteers, and advocating for liver health for all Canadians.”
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 “Patient Support” page that includes the Canadian National Help Line, “Living with Liver Disease Programs,” the LIVERight Health Forum, and a Peer Support Network.
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, physicians directories, 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. They also have a patient survey for hepatitis C patients on their advocacy page, used to gauge gaps and ways CLF can better advocate for patients. 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

Leadership	Sarah Krug, Executive Director
Founding Year	2002
Location	New York, NY, USA
Revenue	\$409,383 (2013)
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 NCI information is in the form of a booklet and provides information about the liver, cancer cells, risk factors, symptoms, diagnosis, staging, treatment, second opinion, rehabilitation, nutrition, follow-up care, support, and research. There are also generic cancer resources that may be valuable to liver cancer patients, such as treatment navigation and wellness information.
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

Leadership	Jesus Repetto, CEO
Founding Year	1981
Location	Chester, NJ, USA
Revenue	\$427,786 (2017)
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 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)

Leadership	Jill O’Donnell-Tormey, CEO, Director of Scientific Affairs
Founding Year	1953
Location	New York, NY, USA
Revenue	\$24,905,501 (2017)
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 is no liver cancer-specific 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 is does not have any obvious policy involvement.

Cancer Support Community (CSC)

Leadership	Kim Thiboldeaux, CEO
Founding Year	1982
Location	Washington, DC, USA
Revenue	\$8,607,303 (2017)
Mission	<p>“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. This global network of 175 locations, including CSC and Gilda’s Club centers, health-care partnerships, and satellite locations that deliver more than \$50 million in free support services to patients and families. In addition, CSC administers a toll-free helpline and produces award-winning educational resources that reach more than one million people each year. Formed in 2009 by the merger of The Wellness Community and Gilda’s Club, CSC also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients. In addition, CSC advocates at all levels of government for policies to help individuals whose lives have been disrupted by cancer. In January 2018, CSC welcomed Denver-based nonprofit MyLifeLine, a digital community that includes more than 30,000 patients, caregivers, and their supporters that will enable CSC to scale its digital services in an innovative, groundbreaking way.”</p>
Liver Cancer Resources for Patients	<p>CSC has a liver cancer page with information on the disease (stats, risk factors, diagnosis, staging, treatment), educational resources, a "Find a Treatment Center" function, clinical trial information, information for patients in different stages of cancer and their caregivers, 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.</p>
Liver Cancer Resources for HCP/Scientists	<p>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.</p>
Policy Involvement	<p>CSC’s "Policy and Advocacy" page has information on the Cancer Policy Institute (CPI), which allows CSC “to work with friends and advisors to advance the mandate that comprehensive, quality cancer care includes medical care and social and emotional care.” 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 and legislation supported, videos, webinars, online training, and the CPI Advisory Board. CSC also provides Advocacy Tool Kits, which include guides for patient advocates and information on how to work with regulators.</p>

CancerCare

Leadership	Patricia Goldsmith, CEO
Founding Year	1944
Location	New York, NY, USA
Revenue	\$16,968,842 (2018); CancerCare Co-Payment Assistance Foundation: \$28,766,995 (2016)
Mission	“CancerCare® is the leading national organization dedicated to providing free, professional support services including 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.
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, 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

Leadership	Donna Mayer, Executive Director
Founding Year	2006
Location	Salt Lake City, 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 and caregivers, which provides support for those who are newly diagnosed, research opportunities, clinical trials, patient registries, educational materials, external resources, a glossary of terms, webinars, discussion boards, and an “Ask Dr. Giles” feature.
Liver Cancer Resources for HCP/Scientists	The Cholangiocarcinoma Foundation hosts an annual conference for HCP and scientists in the field. 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.

European Liver Patients’ Association (ELPA)

Leadership	Marko Korenjak, President
Founding Year	2005
Location	Brussels, Belgium
Revenue	862,878EUR (2017) (\$968,792)
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 are no programs specific to liver cancer for patients, and there are no resources available for liver cancer patients. There are, however, events that liver cancer patients and caregivers can support and participate in, as well as research opportunities for patients.
Liver Cancer Resources for HCP/Scientists	ELPA does not have any liver cancer-specific resources available to HCP or scientists. That being said, ELPA does have many 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 advocates of liver health is important in the further progression of policy making affecting these populations.

Fibrolamellar Cancer Foundation (FCF)

Leadership	John Hopper, Executive Director
Founding Year	2008
Location	Greenwich, CT, USA
Revenue	\$1,606,246 (2017)
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 a rare liver cancer and provides information on the disease, research, where to find help and support, information for both patients and families, how to connect with others who are affected by the disease, a glossary of terms related to liver cancer, and external resources (transportation, housing, financial support, medical communication, reading, films, etc.).
Liver Cancer Resources for HCP/Scientists	FCF provides some information on current research projects, research news, available grants, and tissue banks.
Policy Involvement	FCF does not have any obvious policy involvement.

Hepatitis B Foundation (HBF)

Leadership	Timothy Block, Co-Founder and President
Founding Year	1991
Location	Doylestown, PA, USA
Revenue	\$7,722,243 (2017)
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 has many resources available for liver cancer patients. There are basic resources, such as an overview of the liver and what it does to online support groups to information about the relationship between liver cancer and hepatitis B. HBF also has a program called Liver Cancer Connect.
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. 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. HBF’s goal is 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 an established connection between hepatitis and liver cancer, so efforts by HBF have the potential to prevent liver cancer.

Hepatitis B Foundation: Liver Cancer Connect

Leadership	Joan Block, Executive Director
Founding Year	2012
Location	Doylestown, PA, USA
Revenue	Liver Cancer Connect is a program of the overarching Hepatitis B Foundation.
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)

Leadership	Pamela M. Jackson, MS, Executive Director, ICC; Jennie R. Cook, Immediate Past President, ICCC
Founding Year	1995
Location	Nashville, TN, USA
Revenue	Unknown
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 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

Leadership	Susan Jackson, MBA, CEO
Founding Year	2015
Location	Oakland, CA, USA
Revenue	\$121,419 (2016)
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?" tab that gives basic information on what the liver is and information on 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. There is no mention of how The Interventional Initiative will change that.

Latinas Contra Cancer

Leadership	Darcie Green, CEO and Executive Director
Founding Year	2005
Location	San Jose, CA, USA
Revenue	\$414,292 (2015)
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. They do have resources related to other cancers, including research, 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.

National Cancer Institute (NCI)

Leadership	Douglas R. Lowy, MD, Acting Director
Founding Year	1937
Location	Bethesda, MD, USA
Revenue	FY 2019 Department of Defense and Labor, Health and Human Services, and Education Act included \$5.74billion for NCI. NCI received an additional \$400million for Beau Biden Cancer Moonshot.
Mission	“The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.”
Liver Cancer Resources for Patients	NCI has a page dedicated to liver cancer, which includes information on the disease and its treatment, research, causes, screening, prevention, statistics, coping resources. NCI also provides a variety of general cancer resources for patients, including cancer basics, information for newly diagnosed patients, cancer terms, and more.
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 recently 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.”
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.

National Comprehensive Cancer Network (NCCN) and NCCN Foundation

Leadership	Robert W. Carlson, MD, CEO, NCCN; Marcie R. Reeder, MPH, Executive Director, NCCN Foundation
Founding Year	1995
Location	Plymouth Meeting, PA, USA
Revenue	\$1,898,624 (2016, NCCN Foundation)
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, clinical trials, finding cancer care centers, and other resources for both patients and caregivers.
Liver Cancer Resources for HCP/Scientists	NCCN has liver cancer guidelines available to physicians that are behind a login page. 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 Oncology Policy Program allows stakeholders in the field of oncology to discuss the challenges they face in health policy. The program convenes Policy Summits that address a wide range of health policy concerns that oncology professionals wish to discuss and change.

Oncology Nursing Society (ONS)

Leadership	Laura Fennimore, DNP, RN, President
Founding Year	1981
Location	Pittsburgh, PA, USA
Revenue	\$28,215,090 (2015)
Mission	“To advance excellence in oncology nursing and quality cancer care”
Liver Cancer Resources for Patients	ONS is an organization for nurses and have 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 continuing nursing education, practice resources, nursing journals, quality guidelines, and standards and reports.
Policy Involvement	The ONS website has a tab titled “Advocacy and Policy” that includes the subheadings Policy Priorities, Position Statements, Get Involved, Health Policy Resources, Public Health Issues, Health Policy Coalitions, and ONS 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

Leadership	Carolyn “Bo” Aldigé, President and Founder
Founding Year	1985
Location	Alexandria, VA, USA
Revenue	\$6,413,454 (2016)
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, early detection, treatment options, and options to talk to team members. Prevent Cancer Foundation also provides patients with information on at risk groups, clinical trials, and extra materials available to order.
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. 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 and that may be of interest to oncology professionals.
Policy Involvement	Prevent Cancer Foundation has an “Advocate” page 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 how to be an advocate, on legislation and regulatory action, and provides Prevent Cancer Foundation’s policy statements and resources. 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.

Society of Interventional Radiology (SIR)

Leadership	Laura Findeiss, MD, President
Founding Year	1973 as Society of Cardiovascular Radiology, 2002 as Society of Interventional Radiology
Location	Fairfax, VA, USA
Revenue	\$9,931,415 (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 and outreach” page that includes a link to a government affairs page. 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, CME funding, grassroots leadership, health policy and economics, and SIR’s advocacy toolkit.

SIRFoundation

Leadership	Susan E. Sedory, MA, CAE, CEO; Carolyn Strain, Executive Director
Founding Year	1993
Location	Fairfax, VA, USA
Revenue	\$1,086,866 (2018)
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 brochure as the one on the SIR website. It can be accessed through a website search.
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.
Policy Involvement	SIRFoundation has the same policy, advocacy, and outreach information as SIR: an “advocacy and outreach” page that includes a link to a government affairs page. 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, grassroots leadership, health policy and economics, and SIR’s advocacy toolkit.

Stupid Cancer

Leadership	Elizabeth Woolf, Interim CEO
Founding Year	2007
Location	New York, NY, USA
Revenue	\$1,745,885 (2017)
Mission	“Our mission is to empower those affected by young adult cancer by building community, improving quality of life, and providing meaningful survivorship”
Liver Cancer Resources for Patients	Stupid Cancer does not have any resources specific to liver cancer. The organization is a patient support organization, so they do have 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.
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 an advocacy library with advocacy tools and documents for patients to advocate for their own health.

Triage Cancer

Leadership	Joanna L. Fawzy Morales, CEO
Founding Year	2012
Location	Culver City, CA, USA
Revenue	\$331,842 (2017)
Mission	“Triage Cancer helps survivors, caregivers, health care professionals, and advocates to navigate cancer survivorship through educational events, a national Speakers Bureau, and online tools and resources.”
Liver Cancer Resources for Patients	Triage Cancer has no resources specific to 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 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.
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.

The Ulman Cancer Fund for Young Adults

Leadership	Brock Yetso, President
Founding Year	1997
Location	Baltimore, MD, USA
Revenue	\$3,652,088 (2016)
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 1 on 1 support and help, meet ups, direct sources, a cancer resource directory, scholarships, and ways to get involved in fundraising.
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.