



#OctoberIs4Livers

A large, faint background graphic on the left side of the page. It features a globe in the upper left and the year '2022' in a large, outlined font that spans across the middle and bottom of the page.

Liver Cancer *Journeys*

#OctoberIs4Livers





It all
starts with
a patient



#OctoberIsLivers

Liver Cancer

Journeys

Liver cancer can be overwhelming. It is the third leading cause of cancer death worldwide and has a correspondingly low five-year survival rate –only about 20% in the U.S. This creates a significant impact on the global healthcare system. It is, after all, one of the few cancers with rising incidence – while, after years of tremendous effort, incidence for most other cancers has been falling. At Global Liver Institute, we are committed to doubling the five-year survival rate for liver cancers around the world by 2030. We must employ the tools that already exist to increase prevention and early detection.

For patients, a diagnosis of cancer of the liver or cancer of bile ducts (the tubes that carry bile around and outside the liver) brings a slew of appointments, decisions about treatments, and changes in lifestyle. To understand the true threat of liver cancer to society, we must understand the story of liver cancer.

Beyond a clinical narrative, the story of liver cancer is actually a collection of the stories of many patients, in many circumstances, who face a shared foe. When a liver malfunctions, a whole body, a whole person, a whole family, are all affected.

Thus, it is absolutely essential to hear the voices of liver cancer patients and their loved ones. They reflect, on a human level, the journey of liver cancer. As a patient, to tell your story is to transform adversity into purpose, to recognize your individual challenges as part of a collective experience, and to insist on better for those who come after you.

Thank you, so deeply, to the people and families who have trusted us with a window into their personal lives. I am honored to share these twelve stories, a powerful look into the burden that encumbers the families and patients who face liver cancer. I invite you to read, to reflect, and to consider what you can do in this valiant fight.

Donna R. Cryer, JD

President and CEO

Global Liver Institute



Melinda Bachin

LOCATION

Billings, MT, USA

DISEASE

Liver Bile Duct Cancer

2009 - Present

After brushing off the symptoms of shoulder pain, fatigue, and GI issues as part of my career as a paramedic, I eventually scheduled an appointment with my primary care physician in 2009 when I suspected that I had gallbladder stones. The ultrasound revealed that I had a grapefruit-sized tumor on my liver. **Despite having no risk factors or family history of liver disease, the liver resection, which removed two-thirds of my liver, confirmed that I had intrahepatic cholangiocarcinoma.** Three months after the resection, my cancer came back, and I knew that with the limited treatment options for this disease, the only way to beat it was by participating in a clinical trial, which I credit the persistence of my oncologist for finding. However, because my health insurance did not cover the standard of care that went into participating in the clinical trial, I was only left with the option of undergoing palliative treatment, causing tinnitus and neuropathy amongst other side effects, which drastically lowered my quality of life. The barrier that I faced with the lack of coverage from my health insurance

paved my path to advocacy. I, along with other patients from Montana, traveled to the Capitol and shared our stories. This led to the passing of a law that ensured that health insurance companies in Montana would have to cover the costs for cancer patients who wanted to participate in clinical trials. While the results of this law were not quick enough for my benefit, I knew that it would at least help others down the road. Fortunately, through my own research, I came across a federally funded clinical trial that was being conducted by the National Cancer Institute; even though this clinical trial was not specific to cholangiocarcinoma, I was adamant about attempting to enroll in it. Soon enough, I became the ninth person to enter into the trial, the first cholangiocarcinoma patient in the trial, and the first to have a response. This clinical trial and the perpetual support from my husband and children are the reasons why I am here, twelve years later.

My cancer journey has not only changed my life, but my family's – their perception on life, what is important, and their ability to value time. My children have become involved in advocacy, which bleeds into the family whether they want it or not. Through it all, I learned that it is important to be your own advocate. This is especially true for those who do not have access to care – to health experts or to clinical trials – due to financial or geographic barriers. Everyone deserves equal access, but change is a process; nothing moves fast in the cancer world, and I wish we could

“I became the ninth person to enter into the trial, the first cholangiocarcinoma patient in the trial.”

make things move faster. However, there is so much more hope than there was twelve years ago – which is why we must not lose hope because there is a lot of research being done. You don’t realize how big the cancer world is until you’re stuck right in the middle of it, which is why it is important to connect with advocacy organizations, so you’re not alone. Through my experience in advocacy, I learned that every patient just wants to talk to someone else who has been in his/her shoes. If you tell your story, you might make a difference.



“

You don’t realize how big the cancer world is until you’re stuck right in the middle of it, which is why it is **important to connect with advocacy organizations, so you’re not alone.**

Lisa Craine

LOCATION

Akron, OH, USA

DISEASE

Liver Bile Duct Cancer

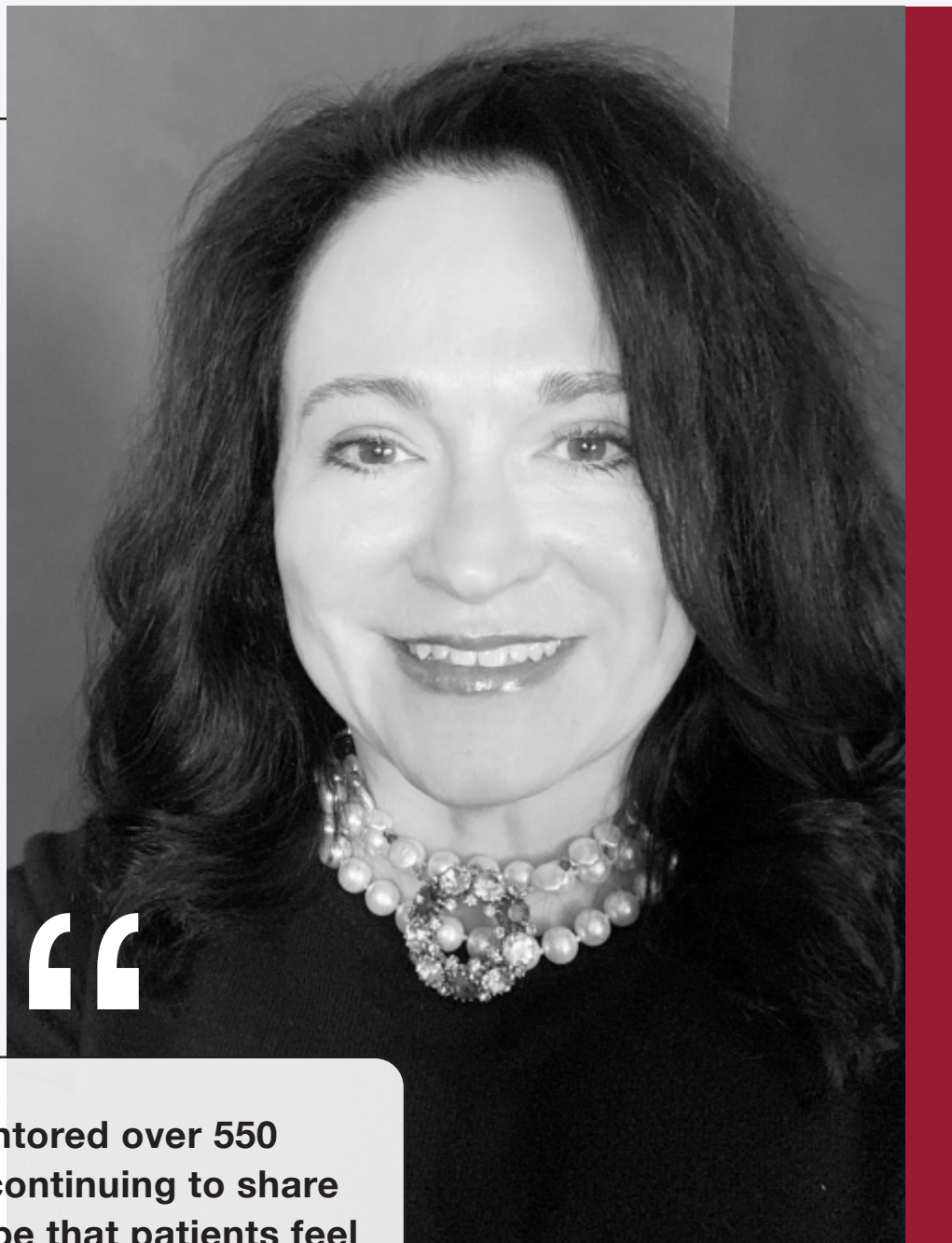
(2010 - 2014)

When I received the phone call from my doctor informing me that 75% of my liver was being occupied by a mass, I was in disbelief. The remainder of the phone call was beyond what I could remember. In fact, my diagnosis of stage IV intrahepatic cholangiocarcinoma in 2010 came as an utter shock, since I had no risk factors of liver cancer. It all began when I took my son to an appointment with his gastroenterologist, who noticed I looked fatigued and began asking how I was feeling and if I had any pain. After revealing that I had been experiencing pain under my breastbone, I was given a slip to get an abdominal ultrasound the next day. The following years were filled with surgeries, chemotherapy, and radiation, with my first surgery lasting 11.5 hours long that resulted in the removal of 78% of my liver. About a year after my first liver resection, I had another surgery to remove 35% of my regenerated liver. Stereotactic body radiation therapy was the answer to my multiple recurrences of cancer. My fifth recurrence required the

persistence of my radiation oncologist at Cleveland Clinic to locate a safe pathway to radiate the tumor. While I have been cancer-free since 2014, survivorship comes with its own difficulties: sepsis, a partially obstructed bowel, a collapsed lung, incisional hernias, and permanent neuropathy. On top of these physical challenges, liver cancer patients are faced with stigma that feels isolating. Oftentimes I felt like people looked at me differently; unfortunately, when you say “live cancer,” people assume that you did this to yourself.

Even though my liver cancer experience was challenging, it made me a better version of myself, which forged my path of advocating for patients. The paradox of stepping into a room filled with hundreds of people yet still feeling extremely lonely stems from the rarity of cholangiocarcinoma. By having mentored over 550 patients and continuing to share my story, I hope that patients feel less lonely and gain a sense of hope, as I was once told I had only 6 months to live. Through hope, patients are able to advocate for themselves. After all, our voice is equally important as that of medical professionals. It takes collaboration between doctors and patients to improve liver cancer awareness, research, and treatment. This is true in our reality where access to medical care is not equitable, especially in rural areas. This is what lights a fire under me.

“My diagnosis came
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Cat Evans

LOCATION

Castle Rock, CO, USA

DISEASES OF LOVED ONE

Hepatitis B; Liver Cancer

Hepatitis B – the silent killer that ultimately led to my father’s battle with hepatocellular carcinoma. It had already progressed to stage IV by the time he was diagnosed in February 2020. Almost a decade earlier, my uncle passed away from liver cancer, which likewise evolved from hepatitis B. My uncle’s passing sparked a concern among the family and prompted my father and his nine siblings to get tested. All but one sibling tested positive for hepatitis B, which was transmitted through blood from my grandmother. My father managed his illness for years by getting routine screenings and taking medication. But, after moving from Arizona to Colorado and, ultimately, ending up in California, he no longer had insurance nor a primary care physician, meaning he didn’t have access to a specialist who would ensure he was getting proper care for his illness. This gap in healthcare was the beginning of a rapid progression from hepatitis B to liver cancer. Soon enough, doctor’s visits for GI tract issues and excessive

weight loss led to the harsh reality of his liver cancer diagnosis.

While the world was dealing with the COVID-19 pandemic, my father and I were navigating hepatology, oncology, and primary care in a virtual environment. Not being able to be at my father’s bedside due to COVID-19 restrictions and miscommunication between specialists caused a lot of frustration. So, I turned to conducting my own research to find answers, to continuously advocate on my father’s behalf, and to ensure continuity of care. Being my father’s caregiver meant more than just feeding him, draining his ascites, giving him a bath, or giving him his medication. It was about showing him how much he is loved in life and ensuring that he didn’t see me crumbling.

At the end of the day, caregiving goes beyond the walls of a hospital. You’re not simply disconnected from the patient. There is a reason why you’re the caregiver and not someone that is assigned by the insurance company or a doctor. So, there is a lot more invested into the experience – physically, spiritually, and emotionally – which is why caregivers need to have a support system, too.

I have lost three uncles, an aunt, and my father to liver cancer, all by way

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liver cancer.”

of hepatitis B. This
is what motivates
me to raise
awareness. As a
first generation
American, I am part
of the bridge that
helps start these
conversations,
especially for
an illness that is
deeply stigmatized.
Ultimately,
everybody deserves
care; this is my
driving force
every day.



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Maria Gonzalez

LOCATION

Greensboro, NC, USA

DISEASE OF LOVED ONE

Liver Cancer

My mom. My hero. When someone you love and care for so deeply is battling cancer, there is no easy way

to or overcome it. My mom had high liver enzyme levels throughout 2019. By the end of the year, her doctors began testing her to determine the cause of it, leading up to a diagnosis of hepatocellular carcinoma. Curveball after curveball – from an allergic reaction to the contrast for her CT scan to having to change doctors due to a lack of insurance coverage one month after her diagnosis – my mom always felt loved and supported. I was my mom's champion. I accompanied her to all her doctor's appointments, translated for her, educated myself by seeking guidance from local oncologists and specialists, and networked with those who faced similar challenges. To ensure that she didn't feel alone, my dad prepared homemade food, such as soup and bowls of fruit and vegetables, on days when my mom was getting treatments or when she was hospitalized. During the weeks in the ICU, the staff brought warm shower caps filled with shampoo, and I lathered

her with lotion, which she loved. We called this "spa day."

For the patient, the journey can feel scary and lonely. As my mom's caregiver, I wanted to be her source of strength, especially on days when she felt hopeless, exhausted, or afraid. There are a lot of factors of the cancer journey that are beyond our control, and this is where it gets emotionally taxing. Moments of driving in solitude became my emotional outlet. I would wipe my face and jump right back into reality upon arriving at my destination. I used Facebook groups to search for answers – those human-to-human, story-to-story type of answers. In the search for help, however, guilt can sometimes arise. But, as a caregiver, it is important to take care of yourself while caring for your loved one.

While my journey as a caretaker made 2020 the most difficult year I've ever faced, I became more empathetic and appreciative of others who are overcoming a health diagnosis or caring for their loved one. We never know when our last day will be, so love intensely and live like there is no tomorrow.

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Karen Hoyt

LOCATION

Tulsa, Oklahoma, USA

DISEASES

Hepatitis C

(2010-2012)

Liver Cancer

(2014-2015)

A radiant future over the horizon – this was the vision that kept me going during my journey with liver disease, including liver cancer.

Eleven years ago in the scorching hot summer of Oklahoma, I was told I wouldn't make it to Christmas. As the "health nut" of the family, my diagnosis of hepatitis C was unexpected. From extreme bruising to extreme weight loss and from jaundice to hepatic encephalopathy, my liver was quickly deteriorating – even my hepatologist was wary of treating me. But, through the support of my friends and family and a rigorous 52-week treatment, I defeated hepatitis C in 2012. Two years later, however, I was diagnosed with hepatocellular carcinoma, or liver cancer. While waiting for a transplant, I came close to giving up on my treatments, but after the doctors found additional tumors in my liver, my hunger

to fight rose up in me. I received an alcohol ablation, which left me feeling like I was on the edge of death. Days after my final alcohol ablation treatment, a young man who suffered from a traumatic brain injury donated his liver to me and also saved five other lives. While the road to recovery was rough during the initial days after surgery, I was discharged from the hospital four days after my transplant, feeling like a teenager again.

In the midst of my battle with hepatitis C a lot of questions arose: What is esophageal bleeding? What is portal vein hypertension? What are varices? So, I relied on personal research and began creating a glossary. I started sharing my findings and experience on private patient forums. Eventually, with the help of my husband, I created a WordPress site where I wrote and shared blogs. Through these private patient forums and my blogs, I witnessed the power of storytelling, which stems from trust from one patient to another. As an educator, taking complex ideas, simplifying them, and spreading them to others came naturally. Through my work in advocacy, I encourage others to find their voice and share their story, which I believe helps build resiliency for patients. Ultimately, resilience along with self-confidence and self-love drive the fight to keep going and reach a radiant future that is beyond liver disease.

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Ultimately, **resilience along with self-confidence and self-love drive the fight to keep going** and reach a radiant future that is beyond liver disease.

Donald Melillo

LOCATION

West Chester, OH, USA

DISEASE

Liver Cancer (2012)

I was woken up by unbearable stomach pain at 5 o'clock in the morning. Soon, my wife rushed me to the hospital.

For three months, my gastroenterologist ran tests to find out what was causing my ongoing stomach pain. With his persistence, he recommended a scan, and I was diagnosed with liver cancer in February 2012. Having no known risk factors in my life, I was shocked by this diagnosis. A transplant was my only option for treatment. While waiting for a transplant, I received chemoembolization to prevent further growth. Despite the risk, my doctor's assurance gave me the confidence to proceed with this procedure, which was successful. On the other hand, being allergic to an antirejection medicine made my transplant experience incredibly challenging – coding at one point, being on the ventilator for two weeks, and losing over twice the amount of blood that the human body has. Since then, I have been very careful in managing my health because I don't want to ruin the gift I was given.

My biggest fear was telling people I was going to have a liver transplant – I instantly knew what the thought process was going to be on the other end. The stigma of heavy alcohol consumption that is associated with liver disease prevents people from telling their story or seeking help. But, we have to realize that just because we have liver issues it does not make us wrong; liver disease is just like any other disease, except it carries a stigma, unfortunately. I am hopeful about how much the liver cancer landscape has changed over the past 10 years, especially with drastic advancements in research and technology. At the end of the day, however, it comes down to awareness and education; both of which shape the stigma around liver disease.

My goal is to destroy myths about liver cancer, inspire the youth to better understand liver disease, and continue to assist in community outreach – especially at my local academic center at the University of Cincinnati. I have become an avid advocate for liver cancer patients since my diagnosis by leading patients to resources, as there is a lot of information on liver disease of which many are not aware. When I walk into a room full of potential liver transplant



“The stigma of heavy alcohol consumption that is associated with liver disease prevents people from telling their story or seeking help.”

recipients, whom I speak with every month at University of Cincinnati Health, there is an incredible amount of hope as they see me as a symbol of overcoming this difficult journey. Everything that I went through reflects that I am here for a reason, so giving back is my way of honoring my donor.



Everything that I went through reflects that **I am here for a reason**, so giving back is my way of honoring my donor.

Terri Milton

LOCATION

Houston, TX, USA

DISEASES

NASH

(2017 - 2022)

Liver Cancer

(2018 - Post-transplant May 31, 2022)

Because I was diagnosed with NASH and cirrhosis in 2017, I had been receiving routine scans every 6 months. By May of 2018, one of my scans revealed that I had hepatocellular carcinoma. Between three tumors and four courses of treatments, the journey has been challenging – from thinning of hair to aches and pains and from indigestion to exhaustion – all of which were side effects of radioembolization and transarterial chemoembolization. While my cirrhosis is still progressing, I have no evidence of cancer. But, like many other patients on a similar journey, my anxiety rises within the month leading up to my routine scans. Thankfully, I am fortunate to live in Houston, home to some of the best hospitals and doctors. Unfortunately, those who live in areas where access to treatment and specialists is limited do not have the same opportunities as I do.

On top of barriers to accessibility, there is a lot of misinformation around liver cancer – not only amongst patients but also medical professionals. During one of my visits for hepatic encephalopathy, I was caught off guard when a GI doctor instantly asked when I last had an alcoholic beverage. Unfortunately, this is the first thought that crosses people's minds, and this reflects the stigma that is associated with liver cancer. Just because a person has cirrhosis, it does not mean they are an alcoholic. Change around fighting this stigma goes beyond the realm of what the public knows. It also involves what the doctors are taught. One of the organizations I run is a liver cancer group, which has grown substantially during COVID as patients and caregivers are trying to find answers and support during this time. My role in this organization is to ensure that nobody who would want to induce harm or give misinformation gains access to the group. Another organization that I actively volunteer for is for patients and caregivers impacted by all liver diseases. This organization aims to educate and provide the tools participants need in order to advocate for themselves. Because there is a lot of misinformation out there, advocacy has become a part of my life as I want to ensure that patients are informed and that they don't wait as long as I did.

“I was caught off guard when a GI doctor instantly asked when I last had an alcoholic beverage.”

Through my cancer journey, I have learned that there is life – there are good days and there are bad days, but there is life. You rest on the days that are hard, and you realize that tomorrow is a new day. You live for the good days because there are still a lot of those, and that is important to know because that's what brings a sense of hope. Even patients' stories drive hope which can be the source of strength that gets patients to fight. One should never give up.



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Tanet Rost

LOCATION

Greenwood Village, Colorado, USA

DISEASES

Hepatitis C

(1999 - 2015)

Liver Cancer

(2011 - 2012)

Four decades ago, I was pronounced dead after being ejected from a car in an accident. What helped save my life – a blood transfusion that replaced half of my blood – ironically ended up being the source of my long battle with liver disease. **Twenty years after the accident, I was diagnosed with hepatitis C,** which was highly suspected to stem from the blood transfusion. Prolonged scarring of my liver led to end-stage liver disease. My liver was gradually degrading – not having energy to walk 40 feet to my mailbox, taking 4-5 hours to simply get ready to leave the house, and using a long handled back scratcher to scratch areas of my back that I couldn't reach. Later that year, I began having severe pain in my abdomen, then threw up about a teaspoon of blood. I was diagnosed with liver cancer, and I soon received chemoembolization treatment, resulting in spending the holidays flat on my back in bed due to the

side effects. Five months later, during my tearful and dreadful phone call to schedule my second chemoembolization procedure, I received an incoming phone call that changed the trajectory of my liver cancer journey. I was getting a new liver.

Living my life in fear was something of the past. My liver transplant opened up a whole new world – one that allows me to be active and be an advocate. From participating in the Donor Dash 2K five weeks after my transplant to bicycling 32 miles on Team Transplant in a bicycle race one year later, I showed the world that a liver transplant was not going to stop me from living my life. Nevertheless, my road to transplant was terrifying, and it lacked opportunities to speak with those who were once in my shoes. This was what forged my path to advocacy. Online support groups, such as those on Facebook, make this experience less lonely because patients can find a source of comfort from the stories and advice of those who have already gone through this journey. From mentoring patients and helping them find live donors, I want to be an example of hope and a reminder of the importance of pushing yourself. Following doctors' orders is key to survival, but the power of your mind is equally important.

“I received an incoming phone call that changed the trajectory of my liver cancer journey.”



My road to transplant was terrifying, and it lacked opportunities to speak with those who were once in my shoes. This was what forged my path to advocacy.

Anthony Villiott

LOCATION

Springfield, Illinois, USA

DISEASES

Type II Diabetes

(1985 - Present)

NASH

(2014 - 2018)

Cirrhosis

(2015-2018)

Liver Cancer

(2017 - 2018)

St. Patrick's Day seems to be a recurring theme throughout my liver cancer journey: I was diagnosed with Hepatocellular Carcinoma on March 17, 2017, and exactly one year later, I received the phone call telling me that I was getting a new liver. Before my battle with liver cancer, I had struggled with weight problems, diabetes, NASH, and cirrhosis. Within months after my liver cancer diagnosis, I received stereotactic body radiation therapy, which successfully stopped the growth of the tumor as I waited for a liver transplant. The wait was filled with emotional ups and downs, which was the worst part of the whole ordeal. I went from being optimistic for a new liver one day to writing my obituary the next. My liver was

deteriorating. Hepatic encephalopathy and ascites were some of the many symptoms I experienced. After nine months of being on the transplant list, I finally received a liver transplant. Managing my health post-transplant has had its fair share of challenges: Anti-rejection medication has made it more difficult to control my diabetes and weight, my kidneys have been damaged, and I still worry about the recurrence of NASH. So, having a successful transplant is half the battle, while keeping up with doctors' recommendations is equally important.

A transplant can be a lifesaver, but it is not a get out of jail free card; after all, it carries ramifications that highlight the importance of early diagnosis and prevention as you are much better off not having to go through this obstacle in life. Unfortunately, early diagnosis and prevention is hampered by a lack of awareness around liver health. We grow up not knowing much about our liver. This further drives the stigma against having liver cancer. When my wife shared my liver cancer diagnosis with others, people often made assumptions about my alcohol consumption patterns. I was not destined to get liver cancer; rather, it was the end result of a combination of factors, including not being diagnosed early enough to take actions to prevent it. This is why as President of NASH-kNOWLEDge, I made it my and my organization's mission to increase public awareness of non-alcoholic liver disease.



“We grow up not
knowing much about
our liver.”



**A transplant can be a lifesaver,
but it is not a get out of jail
free card.**

Meg Wilson

LOCATION

Louisville, KY, USA

DISEASES

Primary Biliary Cholangitis

(2008 - Present)

Cirrhosis

(2008-2020)

Liver Cancer

(Post-transplant biopsy on original liver)

I would later find out that there were even medical professionals who held the same misconceptions, bombarding me with interrogation about suspected drug or alcohol use. As a teacher, I hid my ailment from parents of my students, fearing that they would have similar negative perceptions.

Symptoms increased over time and included debilitating exhaustion, digestion problems, gallbladder attacks, and in the final years of my illness, night blindness due to vitamin A deficiency, excruciating hand, foot, and leg cramps, and hepatic encephalopathy (HE). While the cramps were the most painful, and often felt as if my muscles were tearing apart, the HE was the most terrifying. The loss of my personality, my ability to think and reason, and my awareness was far more horrifying than the fear of dying. As hard as it was for me, it was worse for my caregiver, my husband. On top of that, there were treatments that seemed unaffordable. In nearly every case, however, it turned out that almost every pharmaceutical intervention had options that made it possible.

My life changed forever following my transplant on September 18, 2020, and with the encouragement of my transplant doctors, I began working as an advocate to support others facing liver disease. I am fortunate to live near an excellent transplant center, yet many patients only have access to a primary

My liver cancer journey was unusual.

My cancer wasn't discovered until a post-transplant biopsy revealed that I had it. Prior to the transplant, I had been treated solely for symptoms of my known liver disease, primary biliary cholangitis (PBC), which ultimately led to the cancer.

My PBC was initially diagnosed in 2008 following a year of extreme itching that would strike at night and which included my soles, palms, and even the inside of my mouth and throat. It was so intense that it kept me awake most nights.

On nights when I was able to sleep, I would awaken to blood-stained sheets from scratching in my sleep. My diagnosis came as a shock. Like many who haven't experienced liver disease, I associated it with alcohol or drug abuse and insisted that my blood work must have been wrong – as I had never even consumed alcohol.

“I would awaken to blood stained sheets from scratching in my sleep.”

care doctor who may not have deep expertise in the most current knowledge of hepatology or direct experience working with rare liver issues. Hepatic disease is painful, exhausting, debilitating, and isolating. My life was saved by doctors, nurses, nutritionists, and former patients who supported me to press on through unimaginably difficult times. Without them, I would have never survived the disease long enough to receive my transplant. Excellent resources and support exist, and it's important for patients and caregivers to be able to find and access them.

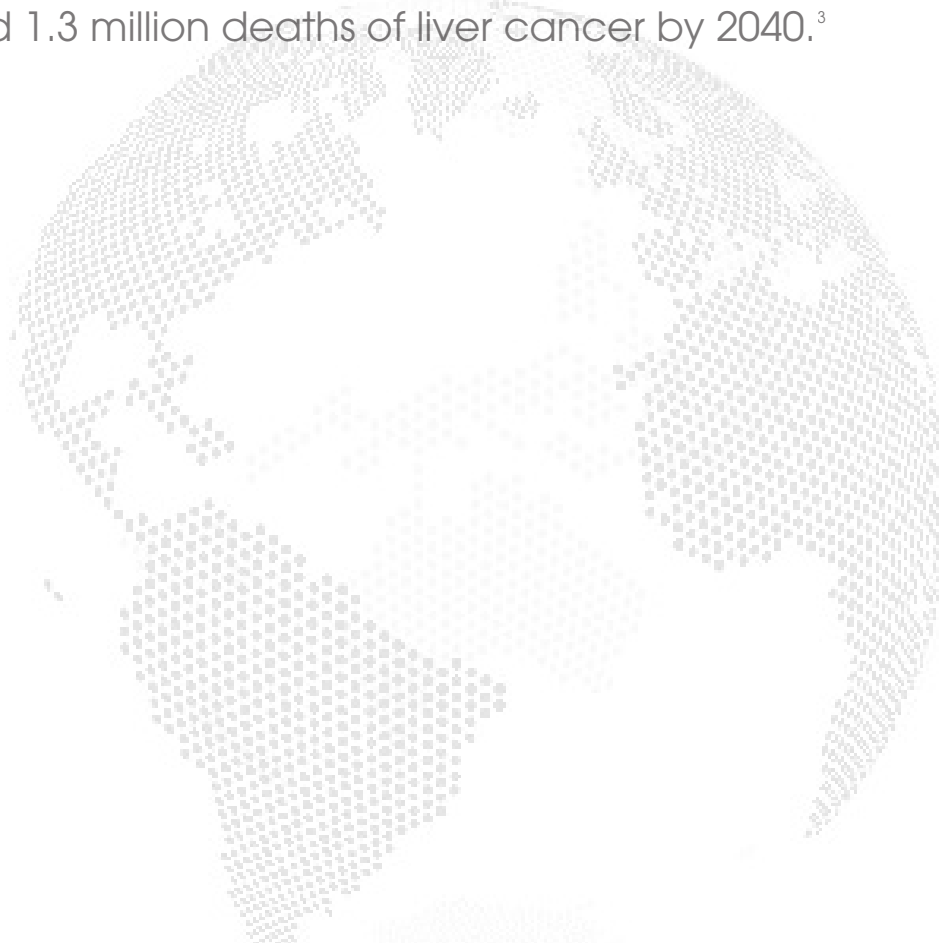


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**Liver cancer is the 3rd leading cause
of cancer death** in the world.¹

At least **70% of cases of liver cancer could
be prevented** with the elimination
of modifiable risk factors.²

**Liver cancer is one of the fastest growing deadliest
cancers**, with an estimated 1.4 million new cases
and 1.3 million deaths of liver cancer by 2040.³



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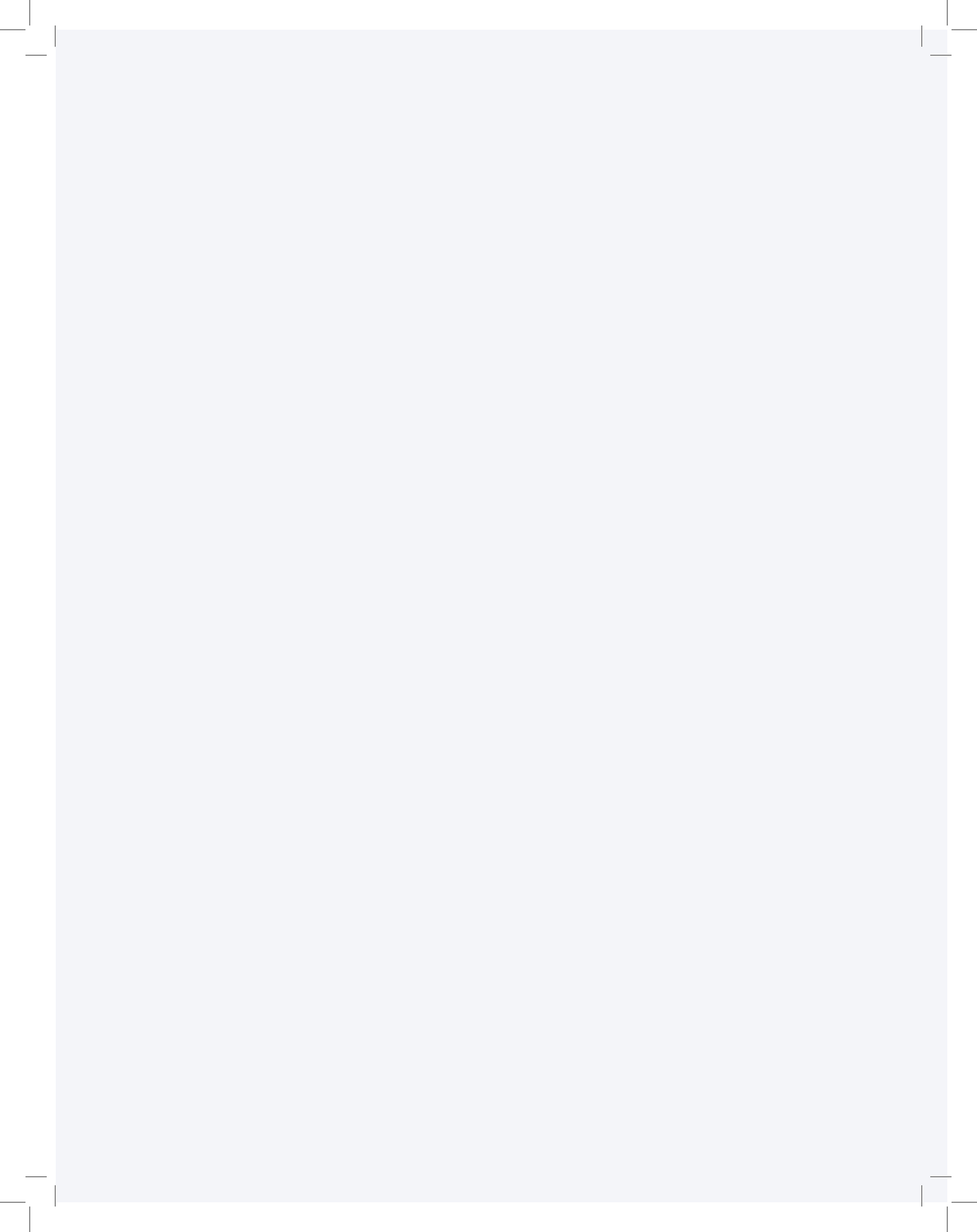


Global Liver Institute

Global Liver Institute is a 501(c)(3) tax exempt not-for-profit organization, with headquarters both in the United States and in Europe. **Our mission is to improve the effectiveness of the liver community by promoting innovation, collaboration, and scaling optimal approaches to eradicating liver disease.**

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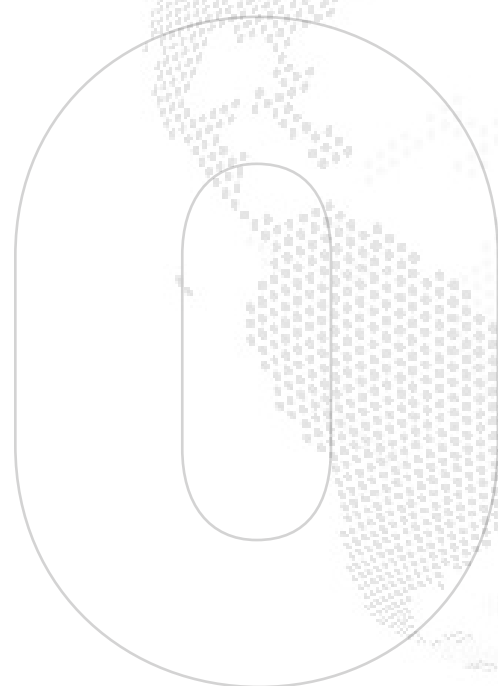




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