



Fibrolamellar Cancer Foundation 10 Year Report



10 YEARS STRONG!

Fibrolamellar Cancer Foundation





Mission Statement

The Fibrolamellar Cancer Foundation (FCF) mission is three-fold:

1. Find a cure and treatment options
2. Raise awareness of this disease
3. Connect, activate and support the fibrolamellar community of patients and their families



Table of Contents

About FCF

Letter from the Co-Chairs and President.....4

Ten Years of FCF

10 Year Timeline.....6

Fibrolamellar Scientific Landscape: 2009 – 2019

10 Years in Review.....9

Reflections from our Pioneers.....12

Reflections from Fibro Fighters and their Families.....15

Collaborations.....19

Year in Review

Financials & Grant Giving.....23

Board, Committee & Advisors.....26



Dear Friends,

It is hard to believe that it has been over 10 years since our son Tucker searched the internet for information about fibrolamellar carcinoma, and found so very little, while he was battling the disease that eventually took his life. At that time, neither he nor we let ourselves think it would lead to his death. We were frantic for a remedy, some magic pill that would kill his cancer. We will never forget Tucker saying to us, on the way to a chemo treatment, "I hope we find a cure in my lifetime, but if we don't, you have to find it." Of course, as Tucker's parents, we must honor that request, a commitment which we aim to accomplish through the work of The Fibrolamellar Cancer Foundation.

Here we are. A decade later. How much closer are we to an answer? Whether we're 10% or 50% of the way is impossible to determine, but we remain encouraged by the myriad of research initiatives now underway, and by the enthusiasm of our research community telling us we are close.

Here is why:

- We discovered a genetic mutation common to almost all fibrolamellar tumors, and it proved to be the driver mutation of this cancer. This is HUGE. We have a target!
- We have incredibly talented and dedicated researchers collaborating with others on this cancer.
- We are getting recognition from major players in rare disease research, including the National Institutes of Health (NIH), the Broad Institute, the Moonshot Program, and the Chan Zuckerberg Initiative, to name a few.
- Our donors feel the importance of saving our children from this terrible cancer and have been so very supportive.

Maybe this is one of those cancers for which we will find an answer in our lifetime—wouldn't that be something...all indications make us optimistic that this is so.

Our commitment to the future is resolute. With the momentum we have established over this decade, we are poised to press on to the finish line...a cure to fibrolamellar.

Thank you to our Board of Directors, our employees and volunteers, to researchers and partners who investigate fibrolamellar, and to the patients and families who join this fight. A special thanks to all of the donors who have made our mission possible.

Keep on Tuckin'

Marna O. Davis
Co-Chair

Charles "Chuck" A. Davis
Co-Chair



The Fibrolamellar Cancer Foundation (FCF) has come so far in the past 10 years. Launched by Tucker Davis and three close friends, today FCF is the leading funder of fibrolamellar carcinoma (FLC) research as well as a highly respected voice for adolescent/young adult cancers across government, industry, research institutions and foundations.

Through the generosity of our donors, the acumen of our stakeholders, and the fortitude of our foundation leaders, much progress has been made in supporting Tucker's original mission of accelerating research towards curative therapies, raising awareness amongst key constituents, and fostering a robust patient community. With over \$7 million invested across 18 highly respected research institutions, and an insistence on collaboration and data sharing, a pipeline of new discoveries is providing hope that curative therapies are within reach – sooner rather than later.

Given that FLC was hardly known 10 years ago, an important part of our strategy has been to take a visible leadership role in the gastrointestinal and rare cancer communities. This in turn provides FCF access to a broad network of talented researchers and advocates. FCF, in conjunction with Georgetown University's Ruesch Cancer Center, co-created the world's first GI Cancers Alliance (now 40 foundations strong). We also co-founded the first USA Rare Cancer Coalition (nearly 30 foundations strong) through the National Organization of Rare Disorders (NORD) and created a partnership with the renowned Cancer Research Institute, the innovators of immunotherapy. These are but a few examples of FCF leading a robust collaborative community of shared learning across all aspects of cancer research, from which fibrolamellar researchers and patients have benefited.

As we enter our second decade, FCF has been honored with a landmark award from the Chan Zuckerberg Initiative (CZI). From hundreds of applicant organizations, CZI chose FCF to receive one of thirty inaugural Rare as One Project grants. The Project consults and financially supports high potential rare disease organizations to mobilize their patient communities and accelerate research. We believe this high profile support and recognition catapults our opportunity to find a cure for FLC, an "urgent" cancer that steals too many young lives.

From all of us at FCF, thank you for your continued support in whatever form you are providing, now and into the future.

Healthy Regards

A handwritten signature in black ink that reads "John Hopper". The signature is stylized with a large, looping "J" and a long, sweeping underline.

John Hopper
President

10 Year Timeline

FCF incorporated on June 29, 2009



Fibrolamellar Cancer Foundation

Tucker Davis Fibrolamellar Research Facility launched at Rockefeller University



Nearly **\$1M** invested in research



1st FLC tumor line developed by Lola Reid of University of North Carolina, using Tucker's cancer cells

First FLC tissue bank established at Rockefeller University

FCF Founders



2009

2010

2011

2012

2013

2014

First research investment year with \$910K funding six research projects,

including:

- International Cancer Alliance for Research and Education (ICARE)
- Johns Hopkins University
- University of British Columbia
- University of North Carolina
- Memorial Sloan Kettering
- Rockefeller University



1st annual Fibro Fighters patient gathering

1st FCF-funded FLC clinical trial at Memorial Sloan Kettering conducted in conjunction with Johns Hopkins, Dana Farber (Harvard), and UCSF

FCF produces an awareness-raising video

Sanford Simon's team (Rockefeller University) discovers a common mutation across nearly all FLC tumors creating a fusion gene, DNAJB1-PRKACA

FCF hosts **1st FLC Research Summit**

Department of Defense (DOD) selects FCF community members to review liver cancer grants

FCF works with leading rare disease and cancer organizations:

- National Organization for Rare Disorders (NORD)
- Global Genes
- Faster Cures (Milken Foundation)
- Ruesch Cancer Center

Launched a new research grant application process, based on NIH model, attracting proposals from the USA, Middle East, and Asia

Began networking with government agencies:

- National Cancer Institute (NCI)
- Department of Defense (DOD)
- Congressional Childhood Cancer Caucus

2015

2016

FCF hosts 2nd FLC Research Summit with **over 50 attendees**



Two independent studies confirm DNAJB1-PRKACA fusion gene initiates FLC

Broad Institute (MIT/Harvard) launches cell line creation for FLC with FCF assistance

Social Security Administration designates FLC for compassionate allowance funding support

Pro bono partnership formed with major healthcare/media company MJH Life Sciences for marketing materials and video production

2017

2018

2019

Over **\$7M** in FCF research funding since 2009

FCF hosts 3rd FLC Research Summit with over 70 participants from government (NCI), biopharmaceutical industry, and academia

DOD grants **\$1.7M for FLC research to FCF Principal Investigators** at University of Washington; announces a new rare cancer focus funding category

FCF BioBank established at Harvard's Massachusetts General Hospital to accelerate development of human FLC research models

FCF funds therapeutic vaccine clinical trial at Johns Hopkins to begin in 2020

Chan Zuckerberg Initiative awards FCF a major grant for 2020-2021

Highest research investment year—over **\$2M** granted to 10 research institutions

FCF co-founds the first GI Cancers Alliance, with over 40 foundations participating



Department of Defense awarded **\$500K for FLC research.**

Partnership with immunotherapy leader Cancer Research Institute funds four postdoctoral research grants

White House Moonshot initiative invites FCF onto rare cancer advisory team

Over **\$6M** in research funding since 2009

FCF welcomes its first Scientific Director



FCF co-founds **first USA rare cancer coalition with NORD**

Launch of research visits at academic institutions, including patients and caregivers

NCI launches Rare Solid Tumor initiative with FCF as a top-tier cancer focus

FCF featured at the **World Orphan Drug Conference**

Department of Defense (DOD) announces Adolescent Young Adult Cancers (AYA) grant focus

A close-up, profile view of a young man with dark hair looking through the eyepiece of a light-colored compound microscope. He is wearing a white lab coat. The background is a blurred laboratory setting with various equipment. The image is partially covered by a green and blue geometric overlay on the left side.

Fibrolamellar Scientific Landscape

2009 to 2019

Ten Years in Review

What a difference a decade can make. **Tucker Davis** and friends created the Fibrolamellar Cancer Foundation (FCF) 10 years ago. Since the first detailed description of fibrolamellar carcinoma by current FCF Board Member Dr. John Craig in 1980, research on this rare liver cancer of adolescents and young adults had been limited largely to basic description and clinical studies on small numbers of patients. Only in 2010 was FLC finally recognized as a distinct entity by the World Health Organization (WHO).

The Problem

Then, as now, the only known effective treatment was aggressive surgical resection. Sadly, by the time FLC is diagnosed 70 to 80 percent of patients have inoperable tumors and/or will suffer recurrence of the cancer and its spread to distant organs, which generally proves fatal within five years. In 2010 researchers possessed neither the tools with which to study FLC in the laboratory, nor the fundamental knowledge of FLC's underlying cause and driving mechanism that are crucial to finding a cure for this devastating cancer.

The Beginning

From the Foundation's inception, pioneering researchers began to address a critical need for experimental model systems, the "ecosystem" of resources essential to advance FLC research. Dr. Lola Reid (featured later in this report) and colleagues at the University of North Carolina created the first renewable source of FLC cells. They used mice lacking a functional immune system to grow human tumor cells — a patient-derived xenograft (PDX). Subsequently, investigators adapted cells from this PDX line to grow in laboratory cultures. In 2019 FCF established a BioBank of human fibrolamellar cancer specimens at Harvard's Massachusetts General Hospital to accelerate the development of more FLC models. They enable both basic studies on how the cancer cells multiply and directed searches for effective drugs.



Tucker Davis

In parallel, clinical investigators sought to address FLC patients' stark need for novel therapies. Most of the chemotherapeutic drugs in current use, many developed in the mid-20th century, act as general poisons of rapidly dividing cells. Unfortunately, these toxic compounds have shown little value against FLC. By contrast, much current cancer drug discovery focuses on "precision" therapies designed to inhibit biochemical pathways that are essential for the survival and proliferation of particular tumors. While FLC's most vulnerable points remained to be elucidated, Dr. Ghassan Abou-Alfa of Memorial Sloan Kettering Cancer Center (also featured in this report) led a multi-institutional team to initiate several drug trials based on growing knowledge of the cancer's unique biology.

First Clinical Trials

Beginning in 2011, FCF supported a trial of combinations of everolimus, leuprolide, and letrozole, designed to inhibit possible tumor-promoting activity of female hormones overproduced in certain FLC patients. Subsequent clinical studies tested molecules active against specific protein kinases, members of a large class of signaling enzymes often associated with cancers and elevated in FLC. Trials of the Aurora kinase inhibitor ENMD-2076 and the HER2/EGFR receptor tyrosine kinase inhibitor neratinib began in partnership with CASI Pharmaceuticals and Puma Biotechnology, respectively. While none of the trials to date have shown dramatic benefit against FLC, the ability to recruit enough patients to assess new treatment strategies bodes well for future efforts to attack the cancer's fundamental driving mechanisms.

We Have A Target

In 2014 Sanford Simon's laboratory at the Rockefeller University, with funds from FCF, reported a giant leap toward understanding FLC. They discovered a unique genetic abnormality present in FLC cancer cells, but not found in normal cells anywhere in the body. Specifically, the mutation is a deletion (loss of DNA) that joins two neighboring genes on chromosome 19 named DNAJB1 and PRKACA. The resulting fused gene specifies a hybrid protein chimera, abbreviated DP. Remarkably, the "P" portion of the chimera contains the biochemically active domain of protein kinase A (PKA), an enzyme known to play a key role in regulating how cells metabolize and multiply.

"Molecular engineering might then introduce that precise receptor into a large number of the patients' T-cells, to create a veritable army of cancer killers."

Multiple laboratories have confirmed the presence of the DNAJB1-PRKACA fusion in tumors of the vast majority of FLC patients. Molecular analysis for the characteristic gene fusion facilitates accurate diagnosis of FLC. While confirming that the cancer is rare, such studies indicate that its incidence may be considerably higher than previously believed—possibly more than 500 cases annually in the United States alone.

Not only is the DP fusion a signature for FLC, but it is central to the cancer's uncontrolled growth. Studies reported in 2017 showed that introduction of the DNAJB1-PRKACA deletion into the livers of mice suffices to cause tumors akin to those in FLC patients.

The discovery that the DP fusion protein

drives FLC is a game changer. It points the way to discover innovative mechanism-based treatments. DP itself is one possible target for precision drugs, either by blocking all PKA activity (both of DP and the remaining normal PKA enzyme) or, better, inhibiting DP preferentially. Other potential targets are being revealed by systematically mapping the biochemical pathway via which PKA normally regulates cell multiplication and determining how the aberrant DP fusion protein perturbs that pathway to drive cancerous growth.

Members of the Foundation's integrated research network at Cornell University, the University of Washington, Harvard University, the University of California at San Francisco, Duke University, and the University of Vermont, among others, already have made important strides towards identifying rational new ways to attack FLC. Fortunately, biopharmaceutical companies have developed drugs that inhibit some of the candidate biochemical targets, and which already are being tested against a range of cancers. We anticipate that this will lead to accelerated trials in FLC patients. In other cases the Foundation is working with colleagues in academia and industry to promote the discovery of new targeted drugs.

On the Horizon, Immunotherapy

Another rapidly emerging precision approach that promises to revolutionize cancer therapy focuses on stimulating the body's immune response to tumors. Special excitement arises from the exceptionally complete, long-lasting benefit



Marna, Chuck and Tyler Davis



observed in some patients with certain types of cancers. Can these advances be extended to FLC?

In 2016 FCF began a fellowship program in partnership with the Cancer Research Institute, a pioneering nonprofit that has championed cancer immunology since the early 1950's. Together we recruited four promising young researchers to begin studies of FLC in excellent immunology laboratories. This already has begun to reveal mechanisms by which this cancer evades potential killing by patients' immune cells. Furthermore, at the completion of their three-year awards, two of the fellows have just begun faculty positions, at the Fred Hutchinson Cancer Center and the Albert Einstein College of Medicine, where they will expand the community of laboratories with active FLC research programs.

A special challenge to develop immune therapies for FLC, in common with other cancers that are most prevalent among children and young adults, lies in their relative genetic simplicity. Many adult cancers accumulate vast numbers of mutations and produce hundreds or thousands of abnormal proteins that might be recognized as foreign and trigger eradication by the immune system. By contrast, FLC tumors appear to generate only a relative handful of such targets, making them immunologically "cold." Nevertheless, virtually all FLC tumors contain at least one potential immune target – the essential DNAJB1-PRKACA driver protein itself, in which the junction between the "D" and "P" domains is unique to cancer cells.

Members of the Foundation's research network have now initiated two complementary approaches aimed at promoting the immune response against DP as a novel way to treat FLC. One team seeks to identify in FLC patients a class of immune T-cells with specific surface receptors for the DP junction sequence that would allow them to find and kill the cancer cells. Molecular engineering might then introduce that precise receptor into a large number of the patients' T-cells, to create a veritable army of cancer killers.

The second approach seeks to develop a therapeutic vaccine to stimulate the production of killer T-cells that can recognize DP-expressing cancer cells. This would be given in combination with two already approved drugs that "uncloak" cancer cells by overcoming checkpoint systems that can mask cancer cells from immune attack. A team at Johns Hopkins University led by Dr. Mark Yarchoan and Dr. Elizabeth Jaffee initiated the first clinical trial of an FLC vaccine in early 2020, with support from FCF and Bristol-Myers Squibb.

The road ahead continues to be hopeful with some of the world's most talented PhDs and MDs focused on FLC. Importantly, our community's spirit of collaboration and data sharing is at an all-time high. Patients and caregivers together with research teams in government, the private sector, academia and collaborating foundations remain determined to conquer this urgent cancer.

Reflections from our Pioneers



“I hope we’ll see an increased awareness of both FLC and FCF as it’s important for engagement and donor support.”

–Dr. Ghassan Abou-Alfa

The Start of FCF and its Clinical Research

Ghassan Abou-Alfa, MD, of Memorial Sloan Kettering Cancer Center was FCF Founder Tucker Davis’s medical oncologist. He reflects, “Tucker was a lovely young man with no risk factors for cancer but who ended up with fibrolamellar. Unfortunately, Tucker’s experience is similar to most other patients with this disease, and there is no systemic therapy available.”

Systemic therapies are drugs such as chemotherapy, hormonal therapy, targeted therapy, or immunotherapy that spread throughout the body to treat cancer cells wherever they may be. FLC’s current lack of systemic treatment, beyond surgical resection, is one of the ways that the disease differs from many other cancers. Additionally, despite its location, FLC is clearly distinct from other liver and gastrointestinal cancers which occur because of risk factors such as viral infection.

As such, FLC is something of a research black hole. Young, healthy people with no family history and no risk factors come down with it and, to date, benefit little from either long-established approaches or recent advances in cancer therapy.

Tucker’s family set out to change that.

“The Davis family came to us and said they wanted to start a foundation to increase awareness. I was at the table from day one and I’ve been beyond impressed,” says Abou-Alfa.

Together, Abou-Alfa and FCF launched their first clinical trial in what was an otherwise sparse research niche. Although it did not show the desired efficacy against FLC, they raised awareness and paved the way for future studies on this rare cancer. Importantly, they proved that enough patients could be recruited to make a trial informative.

As basic research improves the understanding of FLC, scientists and physicians continue to search for the new therapies that patients so desperately need. To help accelerate the translation from discovery to treatment, Abou-Alfa, along with colleagues at Harvard University and the University of California at San Francisco, started the Fibrolamellar Consortium. They continue to seek additional institutions to join in innovative attacks against FLC.

Abou-Alfa says, “I hope we’ll see an increased awareness of both FLC and FCF, as it’s important for engagement and donor support. I also want patients to be aware that there are people working for them. We have to keep trying to find a cure.”



Dr. Lola Reid

Creating a First-Ever Tumor Line

Lola Reid, PhD, is Professor of Cell Biology and Physiology at the University of North Carolina School of Medicine and a recipient of the “Innovator of the Year Award” for her contributions to the school. Her research focuses on understanding how stem cells give rise to normal specialized cells and tissues. She also is an expert in developing research models for normal tissue development and for cancers.

In 2009 Marna Davis, Tucker’s mother, was connected with Reid via ICARE (International Cancer Alliance for Research and Education). Marna asked Reid if she could try to keep some of Tucker’s tumor cells alive. FLC was then a poorly understood, virtually unknown cancer. Perhaps these cells would reveal clues to help unravel its mysteries.

Reid recalls meeting Marna for the first time. “I went to the airport expecting simply to receive a package,” explains Reid, “and then I saw Marna and Tucker’s aunt walk off the plane carrying a large container of Tucker’s tumor cells. In that moment I knew how deeply invested the family was.”

Reid immediately escorted the visitors to her lab and gave them masks and gowns. Throughout the night they observed as Reid and her colleague Eliane Wauthier worked on the sample. “What happens next is that investigators put a sample of a tumor into a flank of a mouse that doesn’t have the immunity to reject it,” explains Reid. “This process hadn’t worked before with fibrolamellar, so we had to go and pick out very specific cancer cells. We first put

the cells under special lab culture conditions that allowed those that maintain the cancer in the body to survive (cancer stem cells). When we injected these selected cells into the mice, they grew into tumors resembling those in fibrolamellar patients.”

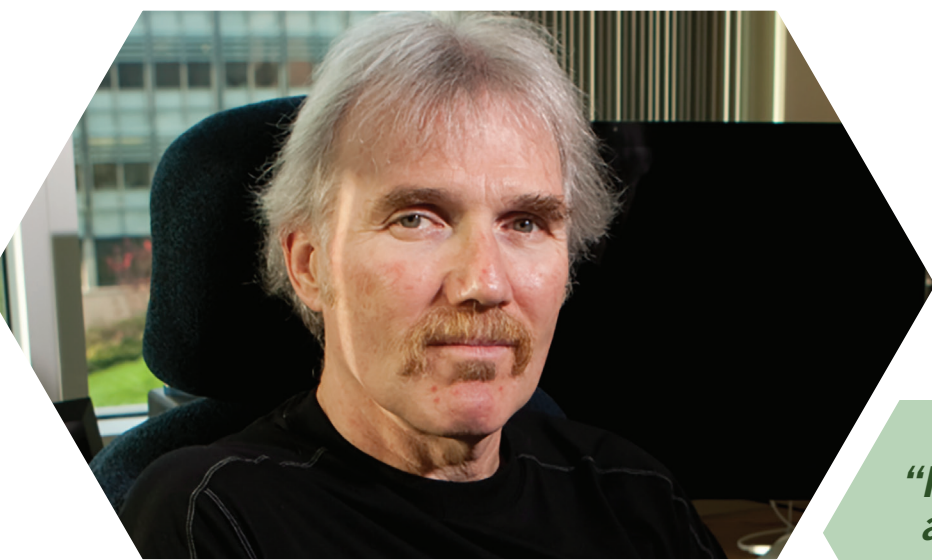
The establishment of this first FLC tumor line has allowed Reid and other researchers to learn much about its unusual properties. One striking feature is the high proportion of cancer stem cells—up to 60-70% in the model line, compared to fewer than 1% in many cancers.

FLC findings have implications for other cancers

The availability of a research model helped bring other scientists into the FLC field, with expertise in tumor biology, molecular genetics, and biochemistry. “It takes a village of people thinking about problems in innovative, interactive ways,” says Reid. “I have great hope that there will be new routes by which to treat these patients. There are also other wider applications,” she explains. “This is a rare cancer. There is often overlap of what we learn from this research and where else we can apply that information. For example, FLC has some similar characteristics with biliary cancer and with pancreatic cancer. These cancers also badly need improved treatments. Our goal, and what we rely on donor funding for, is to take FLC findings and explore ways to apply them to other cancers and ultimately, to find a cure.”

“What’s wonderful is that Marna and Chuck kept this foundation going and, instead of ignoring it after their son died, they have invested even further in it. They are going to generate a whole new way of dealing with these endodermal cancers that will foster interaction across many research groups. They should be very proud of what they have accomplished.”

“It is no small feat for an individual family to have such a major impact on science and on patients.”



“FCF does a lot of things right and it’s a wonderful legacy,”

–Dr. John Scott

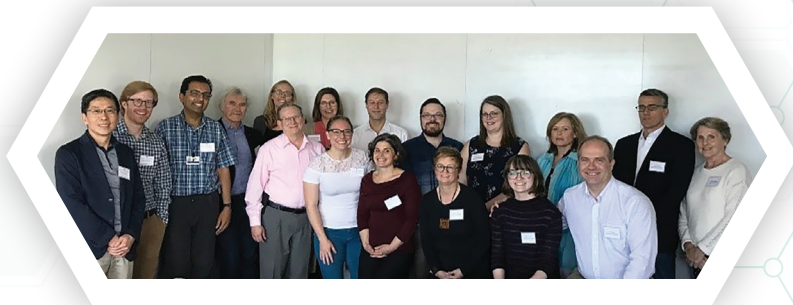
Precision Pharmacology: A Possible Breakthrough for FLC

“FCF has really catalyzed a lot of communication between researchers and clinicians,” says John Scott, PhD, Chairman of the Department of Pharmacology at the University of Washington and the Edwin G. Krebs-Hilma Speights endowed Professor. “This has enabled us to develop precision pharmacology.”

“Discovery of new drugs is a meticulous and slow process,” Scott explains. “There are drugs that have been developed as anti-cancer agents and we’ve taken drug screening protocols to see if we can use them to combat FLC using sophisticated pharmacology.”

Scott admits that there is no magic bullet; however, his team has made interesting discoveries that could help further inform the FLC field. For example, they found that a certain mix of drugs could target the characteristic fusion protein of FLC (DP) and the enzymes that protein recruits—effectively slowing down cancer cell growth.

The research is still in its early stages and the drug combinations will need further assessment in tumor-bearing animal models. However, the early results are encouraging.



*2018 Patient/Research Gathering
at University of Washington*

Scott shares that FCF goes beyond research. “Last year we met more than 20 patients and patient advocates and it brings everything home for both groups about why we’re doing this work and who we’re doing it for. FCF does a lot of things right and it’s a wonderful legacy.”

Reflections from Fibro Fighters & their Families



Liza Findley

“FCF: It stands for hope. The Foundation are angels.”

—Melissa Findley

Remembering a Fibro Fighter

“My daughter Liza went into the doctor’s office as a perfectly healthy 24-year-old and, by the time the tests were over, she was given a year to live,” says Melissa Findley.

Liza’s doctor had studied fibrolamellar cancer in medical school but had never seen it before in the clinic. Unfortunately, for many patients, by the time symptoms appear treatment options are limited and the prognosis has become bleak. At diagnosis Liza had a large liver tumor and another mass behind her heart. There were also signs the cancer had metastasized elsewhere in her body. Surgery was not an option.

Melissa voraciously consumed every piece of research on FLC she could get her hands on, many of which she found on the FCF website (fibrofoundation.org). Melissa often knew more about FLC than the doctors she and Liza met. “When they tell you that your child has cancer, you do everything you can,” she says, “but I knew from day one that my child was going to die.”

According to her mother, Liza was a tour-de-force: part Janis Joplin-like hippie, part outspoken Southern girl. She wasn’t afraid to speak her mind and cancer couldn’t stop that. She got up every day and fought like hell and turned her 12-month outlook into 18 months.

“I told her if there’s anything you want to do, do it!” says Melissa. “It wasn’t all bad. We made it an amazing journey for our family. “We went to New Orleans and danced on Bourbon Street, and I appreciated every moment I got to have with her”

Melissa participated in the Fibrolamellars of the World Unite Facebook group, which brings individuals together from all over the United States and, indeed, the world. But this is a tough disease. “These are children dying,” says Melissa, “and not a single one of them from when I first joined that Facebook group is still alive.”

Although it has been seven years since Liza’s death, Melissa continues to be involved in the community and in championing the cause of curing FLC. Each year she attends the FCF patient gathering in Stowe, Vermont, to connect with other families affected by this cancer.

“I lost my child. It’s the ultimate tragedy,” says Melissa, “but we didn’t go through all this in vain. We need to support each other and to make people aware of this disease.”

Although Liza is gone, her legacy lives on. “She changed a lot of lives,” says Melissa.

A doctor and nurse grieved over Liza’s death while on a mission trip together. Fast forward years later and the two are married and recently welcomed their own baby “Liza” into the world.

Melissa’s advice to others facing FLC is to research as much as they can, to reach out to other people, to find a doctor who will perform surgery, to connect with FCF and their myriad resources, and to donate toward research so that one day a cure will be found.

“Keep fighting and Keep On Tuckin,” she says.

Defeating the Odds: Here Today Thanks to Fibrolamellar Research

This wasn't supposed to happen. Terra Goudge was a healthy, active 29-year-old woman with her whole life before her, but something was amiss.

Terra felt full and nauseous at meals. Physical after physical, bloodwork after bloodwork, the results kept coming back normal, but Terra knew her body and knew something wasn't right. Finally, the doctors ordered a CT scan on her stomach.

"I had moved to Seattle by myself so I was all alone when the doctors came back with the results," says Terra. "They said I had a rather large mass on my liver and it was pushing on my stomach."

She distinctly remembers that life-altering night. Following the diagnosis, Terra stood cold and alone at a payphone outside of the University of Washington Medical Center and made a phone call that no child should ever have to make to their parent.

"I called my father first. I told him the doctors found a tumor—and when you hear tumor, you think cancer. There was a pause on the other end of the phone and then I heard my father crying. There were a lot of tears from both of us. We were in shock."

Terra's father flew out the next morning to meet her. Together they celebrated Terra's 30th birthday with



emergency surgery. Collectively, they held their breath as the medical team came in to report on how it went. The good news was that they had gotten clean margins. The diagnosis, however, was so rare and unknown that the medical team had to read it aloud out of a book. "They weren't even sure how to pronounce it," says Terra, which only added to her confusion and terror.

As Fibrolamellar does not respond to usual cancer treatments, Terra's surgery was the best—and really only—option. Terra and her family set off doing research to understand as much as they could about this foreign disease. "My family members rallied around me and were the biggest cheerleaders," says Terra. "But we felt in the dark—shocked and concerned by how little was known about this cancer." FCF and its wealth of information and resources did not yet exist.

One thing is for certain: Terra is a fighter—or a "fibro fighter" as she calls it. Day after day, year after year, Terra has surpassed the odds.

Terra's road, however, has been far from easy. Her family struggled to even find facilities that would take her given the rarity of the disease.

Keep on Tuckin'

Keep-On Tuckin' is the expression Tucker and the Davis family adopted to represent his struggle to survive. Now it has become the slogan anchoring his legacy and a symbol for other fibrolamellar fighters. Keep on Tuckin' stands for *hope*.

Hope that we can help find treatment options that will extend patients' lives and preserve quality of life.

Hope that the research we are funding will lead to effective therapies...soon.

Hope that all fibrolamellars have the strength to keep on fighting.

Hope that cure is more than a word!



PIG GIG ARKANSAS



A CANCER BENEFIT IN HONOR OF JAY ALEXANDER

“Finally, my liver had had enough,” says Terra. “I went into liver failure and I was told to find hospice and enjoy my last days on earth. That didn’t settle well with me.” By then Terra was married and had two children of her own. She wasn’t just fighting for herself any more.

Terra and her family sent packets of information with photographs of their family across 12 states pleading for help. Unfortunately, due to a spot found on Terra’s lung years earlier, she was not permitted to be on a liver transplant list.

Enter the Fibrolamellar community.

One FLC caregiver, who had lost his son to fibrolamellar, learned of Terra’s story. He connected Terra with a liver transplant doctor in Pittsburgh who found Terra’s case particularly intriguing. This was the only surgeon willing to take her case.

Terra went from “weeks to live” to “more life to lead.” Her best friend served as a living donor and, in addition to her liver transplant, Terra had the metastases removed from her lungs.

“It’s miraculous that I can wake up in the morning and take a breath,” says Terra.

It has been 18 years since Terra’s initial diagnosis. In that time both she and the fibrolamellar field have come far. “From when I started, there are now a lot more knowledgeable people, more willing doctors, and thankfully, FCF funding research, spreading the word, and increasing awareness,” says Terra. “I feel like we are on the brink of finding something that will work for this disease, and I pray that’s the case.”

As Terra reflects on what she calls a rollercoaster of a ride, she says, “My advice to other patients would be to keep up your tenacity and will to survive through good and bad. Stay focused on what could possibly be. All of my docs told me I was dying but, somehow, I’m still here.”

A Family of Fundraising Events

Jay Alexander was a 20-year-old college student who passed away just two months after symptoms began. His family and friends have remained amazing supporters for years since Jay’s passing in 2011—honoring his memory by raising funds for FCF in support of research to help other families.

Events have included Jumpin’ for Jay, a skydiving event; a New York City Marathon run; and the mainstay - a Pig Gig (which is a concert and pig roast held in both New Jersey and Arkansas annually). To date, the family has raised more than \$100,000 in memory of Jay for FCF and has no intentions of slowing down.

“Jay lived life to the fullest, and we want to keep his memory alive. I am so glad we found in FCF a worthy organization to which to donate our proceeds. If it can help one family from going through what we did with Jay, it will be worth it.”



Grandparent Takes Action

“FCF spends 100 percent of their donations on research, which is pretty phenomenal, as well as pretty unheard of,” says John Mitchell, MD.

Although John is a trained medical provider, his foray into the FLC world was a personal one.

“My granddaughter, Emma, found a lump in her abdomen. A week later she was in the hospital having surgery to have a tumor removed,” he explains.

Despite John’s granddaughter catching her FLC early, there was vascular invasion and it had spread to her lungs, causing complications. “She is very bright. She received almost perfect scores on her ACTs and received a scholarship to Northwestern on a full-ride. She was 19 years old at the time.”

It was Emma’s physician who connected the family to FCF. John underscores how little the medical community knows about fibrolamellar cancer and that it’s critical to fill this knowledge gap—because if physicians don’t know, how can we expect patients and the family members who advocate for them to know? He is incredibly impressed by what the foundation is doing to elevate awareness and advance understanding in the field, and where they’ve come over the years:

“This disease hits younger people in large numbers, many who are college-age kids. These are people who are reaching the peak of their lives,” he says. “I really hope FCF finds a treatment modality that helps patients with this disease and that it’s shared with other types of tumors.”

Although research and knowledge gaps still abound, John’s financial support of the organization has helped make possible advances that wouldn’t have happened without him.

Today, after a successful surgery and with continued monitoring, Emma is healthy and back in college.



“This disease hits younger people in large numbers”

—John Mitchell, MD

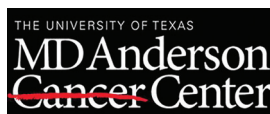
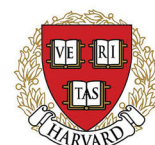


Collaborations

Collaboration is at the core of FCF. We have sought out partners so that we can go further and faster towards our mission.

Bringing Thought Leaders Together

FCF hosts a biennial research summit that provides an important forum for concerted exchange among outstanding tumor biologists and GI cancer doctors.





10 Years of Support

A Thank You to Our Donors

We have come so far over these last 10 years. What began as Tucker's idea has become a one-of-a-kind foundation that is engaging some of the biggest names and universities in research. Our work is connecting not only researchers to one another but also researchers to clinicians and clinicians to patients and patients to clinical trials. We are helping connect patients and their loved ones to resources so they can advocate for themselves—and connect to each other so they can create the community of support that they need. Indeed, our work has come full circle. This is all possible because of your generous support.

Thank You

The Foundation thanks you and we know Tucker would thank you, too. Your contributions are helping us get that much closer to his dream—to treatment options and a cure. But make no mistake. The road from here is still unknown and there is still work to do. Together, with continued support, just imagine what we can accomplish next year—and in the next 10 years.

Thank you for believing in us. We'll Keep On Tuckin'



Tucker Davis

Donate Today
www.fibrofoundation.org/donate/

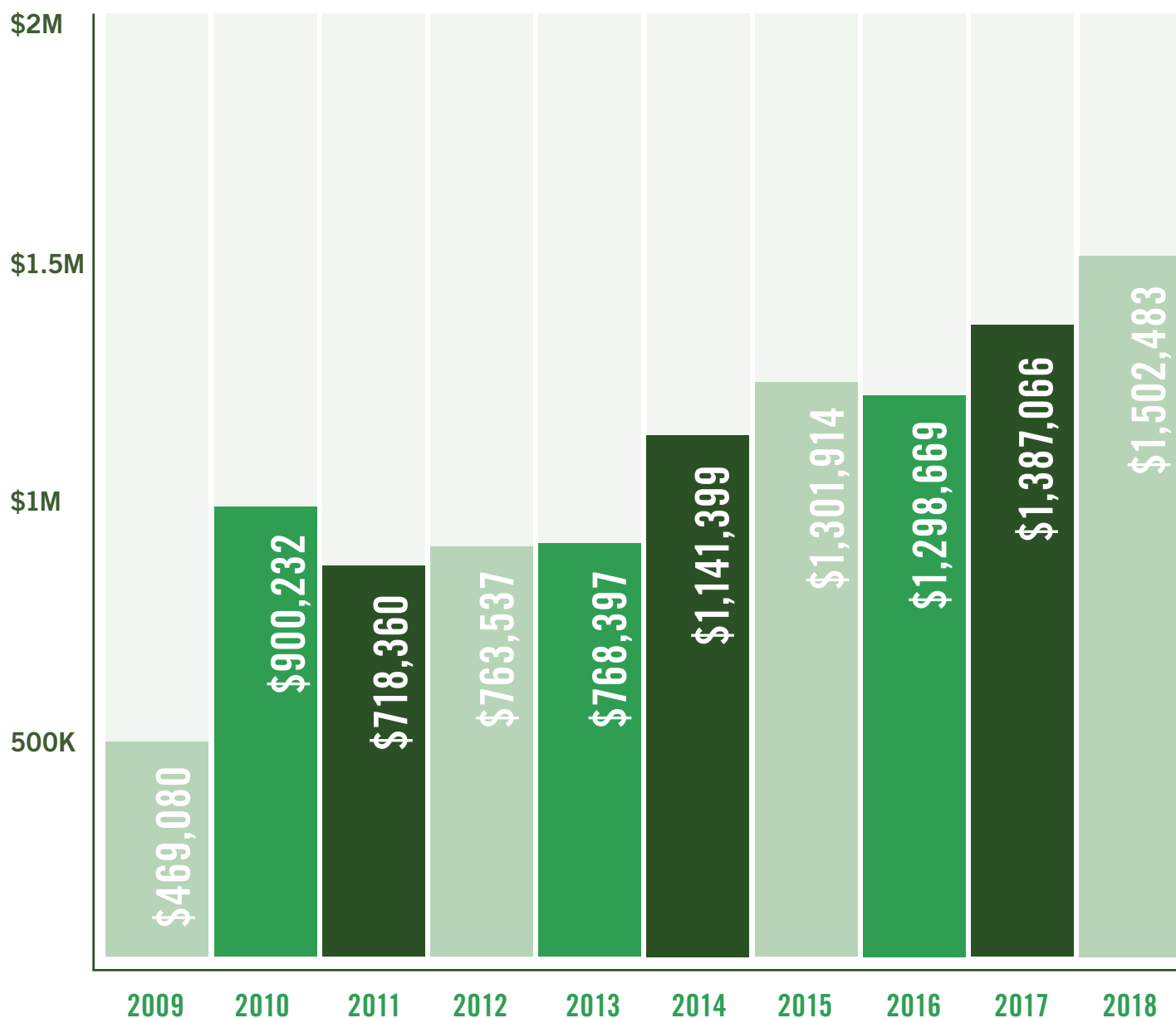




Financials & Grant Giving

10 Years of Donations

100% of donations support research



Totals to Date \$10,251,137

10 Years of Grant Giving

***Includes grants awarded and committed 2009 - 2019**

Institution	Number of Grants	Total (\$000)
Rockefeller University	6	\$1,433
University of California San Francisco/Harvard University	2	\$927
University of Washington	2	\$755
Memorial Sloan Kettering Cancer Center	3	\$662
Cancer Research Institute (CRI)	1	\$642
Johns Hopkins University	3	\$559
Cornell University	3	\$523
Stanford University	1	\$292
Duke University	1	\$292
Broad Institute of MIT and Harvard	1	\$285
University of North Carolina	3	\$200
Massachusetts General Hospital	1	\$156
Yale University	1	\$127
International Cancer Alliance for Research and Education (ICARE)	1	\$110
Mayo Clinic	1	\$100
International Center for Cell Therapy and Cancer Immunotherapy (CTCI)	1	\$85
University of Vermont	1	\$65
The University of British Columbia	1	\$50
Boston Children's Hospital	1	\$50

Total \$7,313

**Full financials are available on our website*



Board, Committee & Advisors

FCF Board of Directors and Officers

Charles A. Davis, *Co-Chairman*

Marna O. Davis, *Co-Chairman*

John A. Hopper, *Executive Director and President*

Charles W. Beermann, *Founding Director*

Derek Gilchrist, *Founding Director and Board Secretary*

Alisha Sternenberger, *Founding Director*

Anne Adler, *Director*

John Craig, MD, PhD, *Director*

Tal Friedman, *Director*

Leslie Graves, *Director and Board Treasurer*

Craig Martin, *Director*

David Wermuth, *Member*

Executive Committee and Staff

Marna O. Davis, *Co-Chair*

John A. Hopper, *President*

Mark Furth, PhD, *Scientific Director*

Anne Adler, *Internet Communications*

Lynn O'Malley, *Patient Coordinator*

****Megen McKinney**, *Foundation Administrator*

Senior Scientific Advisors

John Craig, MD, PhD

Lola Reid, PhD

University of North Carolina

Grantees and Advisors

***Ghassan Abou-Alfa, MD**

Memorial Sloan Kettering Cancer Center

Nabeel Bardeesy, PhD

Massachusetts General Hospital (Harvard)

Kevin Barry, PhD

Fred Hutchinson Cancer Center

Michael Choti, MD, MBA

Banner MD Anderson Cancer Center

Anna Mae Diehl, MD
Duke University

Ephraim Fuchs, MD
Johns Hopkins University

Wayne Furman, MD
St. Jude Children's Research Hospital

*John Gordan, MD, PhD
University of California San Francisco

Tim Greten, MD
National Cancer Institute

Yi Guo, PhD
Mayo Clinic

Cynthia Guy, MD
Duke University

W. David Hankins, PhD
Johns Hopkins University/ICARE

William Harris, MD
University of Washington

*Elizabeth Jaffee, MD
Johns Hopkins University

Ahmed Kaseb, MD
MD Anderson Cancer Center

Amy Kim, MD
Johns Hopkins University

Michael LaQuaglia, MD
Memorial Sloan Kettering Cancer Center

Ron Levine, MD
Greenwich, CT

Andrew Liss, PhD
Massachusetts General Hospital (Harvard)

Jian Liu, PhD
University of North Carolina

Scott Lowe, PhD
Memorial Sloan Kettering Cancer Center

Mark McNiven, PhD
Mayo Clinic

Sofia de Oliveira, PhD
Albert Einstein College of Medicine

*Allison O'Neill, MD
Dana-Farber Cancer Institute (Harvard)

Venu Pillarisetty, MD
University of Washington

Jon Ramsey, PhD
University of Vermont

Kimberly Riehle, MD
Seattle Children's Hospital

Julien Sage, PhD
Stanford University

*John Scott, PhD
University of Washington

Praveen Sethupathy, PhD
Cornell University

Sanford Simon, PhD
Rockefeller University

Josh Sommers
Chordoma Foundation

Gary Stein, PhD
University of Vermont

Scott Strome, MD
University of Tennessee Health Science Center

Kevin Sullivan, MD
University of Washington

Paul Thomas, PhD
St. Jude Children's Research Hospital

Michael Torbenson, MD
Mayo Clinic

Khashayar Vakili, MD
Boston Children's Hospital (Harvard)

Mark Yarchoan, MD
Johns Hopkins University

Raymond Yeung, MD
University of Washington

Andrew Yen, PhD
Cornell University

*Jessica Zucman-Rossi, MD, PhD
Université Paris Descartes

*FCF Scientific Advisory Board

**FCF Staff

Patients and Researchers Meet



FCF Launches Our Second Decade with a Significant Game Changer

Chan Zuckerberg Initiative Awards Fibrolamellar Cancer Foundation Rare As One Network Grant

(Announced February 3, 2020)

**Chan
Zuckerberg
Initiative** 

**Rare
As
One**

Founded by Dr. Priscilla Chan and Mark Zuckerberg in 2015, CZI is committing \$13.5 million to the **Rare As One Network** to support and lift up the work patient communities are doing to accelerate research and drive progress in the fight against rare diseases like fibrolamellar carcinoma.

<https://chanzuckerberg.com/science/programs-resources/rareasonone/>



FCF Patient & Family Gathering

Almost every autumn, starting in 2009, the foundation has brought together FLC fighters and their families for a weekend of bonding, sharing, and togetherness. It is generally held at a lodge in Stowe, VT. All patients and their families are guests of the Davises for this gathering. It is this gift that makes it possible for so many to attend.

The Gathering has become a much-anticipated event in the FLC community. It is a time when young people fighting this terrible cancer can talk with others fighting the same battle. Young adult cancers are rare, and many in our community find themselves very much alone. The ability to connect in this peaceful place helps their caregivers and those who have lost someone to fibrolamellar as well.

This is a tough journey.

“This weekend is a respite of sorts. We understand. We know. We have been there. Your meals will be served. You can hike, swim, relax, take a breath...We will take care of you...if just for a few days...We will give you strength to fight on...”

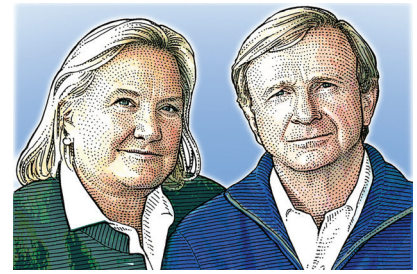
- Marna Davis

100% of Donations Go to Research

**Few foundations can make this claim.
This is due to the generosity of Chuck and
Marna Davis and Stone Point Capital.**

The Charles A. and Marna Davis Foundation has covered FCF's operating costs from the beginning (salaries, benefits, patient outings, etc.) Importantly, this gift assures every donor that each dollar raised is being spent helping to find a cure.

The Wall Street Journal profiled the Davis's philanthropic vision.



Marna and Chuck Davis

THE WALL STREET JOURNAL
WSJ.com

CREATING CANCER MILESTONES

Donor of the Day By Melanie Grayce West

The Davis family has a simple motto when it comes to their foundation's work: "Keep on Tuckin'."

That's Tuckin', as in Tucker Lowe Davis, who died in 2010 from a rare form of liver cancer called fibrolamellar hepatocellular carcinoma. The family launched the Greenwich, Conn.-based Fibrolamellar Cancer Foundation to find life-extending options and treatments, and provide support to patients and money for research. To date, the foundation has raised a little over \$3 million, about half of which is in reserve for future projects.

"Tucker actually said to us once, 'Maybe I got this, Mom, because you and Dad can figure it out,'" recalls Marna Davis, chairwoman of the foundation and Tucker's mother. She says her son believed that there was a cure for his cancer and that in his diagnosis there was a way to turn a bad situation into good. "I think the last 18 months of Tucker's life were his finest years," she says.

Mrs. Davis and her husband, Charles Davis, the chief executive of Greenwich-based private-equity firm Stone Point Capital, support the foundation through private gifts. They cover the administrative costs of the foundation and have given some \$500,000 to various research efforts. Mr. Davis's firm also donates money raised from its annual golf outing to the Fibrolamellar Cancer Foundation.

Among the foundation's accomplishments is the launch of a research consortium comprised of hospitals and doctors from around the country who are focused on fibrolamellar. The foundation says that there are about 200 cases diagnosed annually, world-wide.

The foundation also helped to launch, with a \$500,000 grant, the first clinical trial specifically for fibrolamellar. The trial is open at Memorial Sloan-Kettering Cancer Center and, just recently, started at Johns Hopkins Medical Center. The trial is a "big boon" to patients and researchers because pharmaceutical companies don't tend to fund studies in rare cancers, says Mrs. Davis.

"When we really look back and have to sort of tally up what we've done, we've come a long way in the last three or four years," says Mrs. Davis. Still, she says, the trial and current treatments for fibrolamellar are talked about in terms of controlling the cancer, but not necessarily a "cure."

"I have learned, kind of the hard way and it's not what I originally wanted to hear when Tucker was sick, but I've learned that in a lot of cancer research they define success in life-extension. They can extend life by six months, or two years," says Mrs. Davis. "For me, as the mother of a child with a fatal cancer, that doesn't sound like a lot. But in the cancer research world, that's a milestone."

This article appeared in the April 3, 2013 Wall Street Journal.

Stone Point Capital

An important partner since the beginning

The Fibrolamellar Cancer Foundation is extremely grateful for the generosity of Stone Point Capital since Tucker and his friends began their mission to find a cure. The major areas of support include:

Fundraising:

Stone Point Capital hosts an annual “sold out” golf outing in the autumn of each year, which has become the Foundation’s #1 fundraising event. In recent years, this event has averaged over \$800,000 annually in support of important research efforts.



In Kind Donations:

Stone Point Capital management and staff supports FCF’s accounting, IT, legal, and human resource functions, at no charge.

Office Facilities and Support:

FCF’s office space, conference facilities and supplies are fully donated by Stone Point Capital.

The Foundation extends heartfelt thanks to all the Stone Point Capital management and staff for their continuing support!

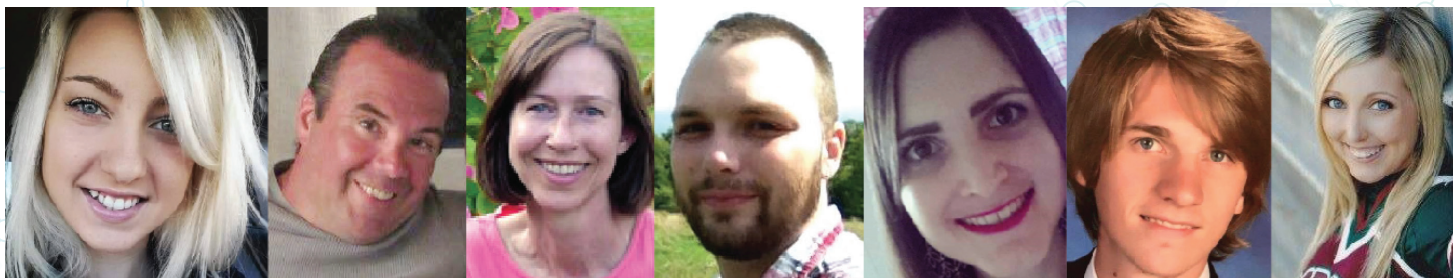


Tucker Davis, 1981-2010

STONE POINT CAPITAL



Fibrolamellar Cancer Foundation



Faces of Fibrolamellar

Your support brings a cure closer to those facing this rare and devastating teen/young adult liver cancer



Fibrolamellar Cancer Foundation



Donate Today

fibrofoundation.org/donate/

Fibrolamellar Cancer Foundation

20 Horseneck Lane, Greenwich, CT 06830

Email: info@fibrofoundation.org | Tel: (203) 340 7800



10 YEARS STRONG!

Fibrolamellar Cancer Foundation



@fibrofoundation



#fibrofoundation



www.facebook.com/fibrofoundation