



NEWSLETTER
SPRING 2026



Helping Patients and Caregivers Affected by Fibrolamellar Carcinoma

Spring Message from the Founder

Hello Friends, and Fibrolamellar community,

For our Spring Newsletter, we want to acknowledge Adolescent and Young Adult (AYA) Cancer Week. This week recognizes patients between the ages of 15 and 39, a demographic that sits at the very heart of the FibroFighters community. Because Fibrolamellar Carcinoma (FLC) predominantly strikes teens and young adults, understanding the AYA experience is crucial. AYA patients face a unique set of challenges that differ drastically from pediatric or older adult patients. A diagnosis often abruptly disrupts pivotal life milestones (such as finishing school, building careers, gaining independence, or navigating relationships and family planning), bringing complex emotional, financial, and fertility concerns to the forefront of an already daunting medical fight.

At FibroFighters Foundation, recognizing FLC as an AYA cancer means fighting for the whole person, not just treating the disease. We understand that standard healthcare systems aren't always built to support young adults navigating rare cancers, which is why our foundation steps in to fill those gaps. Through our free patient navigation services, the FibroFighters Foundation International Tumor Board, and our dedicated peer support network, we focus on bridging the divide between medical teams and families. Our goal is to ensure that every adolescent and young adult facing FLC is empowered with the best possible treatment options, sharing our tumor boards' consensus notes with your medical team, and a united community, so that no young person ever has to fight alone.

United in Hope, and here to support,

Tom Stockwell

Announcements & Upcoming Events

- Adolescent and Young Adult (AYA) Cancer Awareness Week April 6-10
- American Association for Cancer Research (AACR) Conference in San Diego, California, April 17-22. Our poster will be shown April 19th, titled *Maintenance therapy in first remission for advanced fibrolamellar carcinoma*
- American Society of Clinical Oncology (ASCO) Conference in Chicago May 29-June 2

Fighter Feature: International Collaboration

AWARENESS WEEK APRIL 6-10



Siddharth from New Delhi, India

Siddharth, a 23-year-old aspiring detective from New Delhi, India, stands as a remarkable testament to the power of strategic clinical collaboration. We were first alerted to Siddharth's case by his sister early last year. He followed the multidisciplinary protocol led by our Medical Director, **Dr. Paul Kent**.

By strictly following our systemic, interventional, and radiation recommendations, Siddharth achieved remarkable disease stability. This strategic "downstaging" - shrinking existing tumors while preventing new growth - ultimately cleared the way for him to undergo a life-changing surgery with **Dr. Mohamed Rela**, widely regarded as one of the world's premier hepatobiliary surgeons.

Siddharth's case underscores a critical clinical truth: **the importance of following a structured pre-surgical paradigm cannot be overstated**. It is this sequence of care that made a surgical cure possible. Now in a **No Evidence of Disease (NED)** state, Siddharth will soon begin adjuvant treatment to maintain this status. We are honored to have worked with him, his family, and his dedicated medical team, and we look forward to seeing him fulfill his dream of becoming one of India's finest detectives.

Fighter Feature is an opportunity to showcase the incredible stories of fibrolamellar fighters. If you are interested in sharing your story in our next newsletter, we'd love to hear from you! Please email laura@fibrofighters.org to share your story.

AYA Awareness Week April 6-10

The first week of April is AYA (Adolescent and Young Adult) Cancer Awareness Week! It's an important and much needed time to spotlight a population that too often falls through the cracks of the healthcare system. Adolescents and young adults (AYAs) are generally considered to be between the ages of 15 and 39. **AYAs diagnosed with cancer face unique challenges that differ significantly from those experienced by younger children or older adults.**

Research has identified a troubling survival gap for AYAs compared to both pediatric and older adult populations. This disparity, often compounded by other factors such as race, socioeconomic status, and geographic access to care, is unacceptable. While advances in cancer treatment have improved survival rates overall, AYAs have not benefited equally from these gains.

Addressing this gap requires more than just effective medical treatments (though those are, of course, essential). AYAs need comprehensive support systems that help them access care, manage the physical and emotional toll of treatment, and navigate life during and after cancer. From fertility preservation and mental health services to financial guidance and peer support, the needs of this group are multifaceted.

There is reason for hope! AYA Cancer Awareness Week serves as a call to action for healthcare providers, researchers, policymakers, and communities. By increasing awareness, advocating for equitable care, and supporting continued research, we have already seen that survival gap close in the past decade. AYA Awareness week is an opportunity to highlight the variety of resources and organizations that work tirelessly to serve this population.

Here are just a few examples the resources available for AYAs and some of the organizations that offer them:

- 🏕️ **Adventure Trips & Camps** Send It Foundation, First Descents, and True North Treks take survivors into nature to kayak, hike, ski and more along with others who "get it"
- 💰 **Financial** We all know cancer is expensive. Cancer Survivors Fund, Mom Bomb, and Cancer for College all provide various types of financial assistance

- **♥ Social Support** Cancer as an AYA can feel isolating. Caregather, Cactus Cancer Society, and Twist Out Cancer all provide various social and emotional supports, from meet up groups to art therapy.
- **⚖ Legal & Career** Cancer disrupts so much of life. Cancer and Careers and the Cancer Legal Resource Center offer resources and support.
- **👤 Caregivers** Caregivers have an incredible important, and often exhausting role to play, and need support, too! Stupid Cancer and Teen Cancer America offer resources specific for caregivers as well as patients.

To explore organizations providing support and resources for AYAs, [check out this spreadsheet](#). *FibroFighters Foundation is not affiliated with any of these organizations, these organizations and resources are shared for informational purposes only.*



Right Upper Quadrant

with Medical Director Dr. Paul Kent



This week marks **Adolescents and Young Adults (AYA) Awareness Week**. It highlights the unique medical, emotional, and social hurdles this demographic encounters, such as navigating school, beginning careers, and maintaining relationships while undergoing treatment. These challenges are often compounded by a decrease in family support and an abrupt shift in expectations as patients transition from pediatric to adult healthcare models. Compared to children or older adults, AYAs face distinct obstacles. These include slower improvements in survival rates, fertility concerns, and significant disruptions to their education, careers, and early adult lives. **Notably, the average age of diagnosis for fibrolamellar carcinoma (FLC) falls directly within this demographic at 21 years old.**

Survival Disparities in the AYA Population According to the National Cancer Institute, cancers diagnosed among AYAs, ages 15–39, represent only **4.2%** of newly diagnosed cases (**see graph right**). Research indicates that even when controlling for era, histology, age, and stage, AYA patients experience lower survival rates when treated at adult institutions using adult protocols rather than at pediatric institutions using pediatric protocols.



AYA patients benefit significantly from receiving the same treatment protocols as children with identical diagnoses. When managed in this manner, AYA patients achieve excellent outcomes comparable to their pediatric counterparts.

How FibroFighters Foundation Bridges the Gap for an Underserved Population

- We **collaborate with patients across the United States and globally** to connect them with medical teams that thoroughly understand this unique demographic. This may involve finding a pediatric specialist willing to take on a case, or an adult physician who possesses a deep understanding of the specific needs of fibrolamellar patients. I am fully committed to collaborating with all parties on behalf of our FLC patients.
- We assist in writing **appeal letters and peer-to-peer phone interviews for insurance denials**, achieving a 95% success rate. Many young adults lack the time or inclination to fully advocate for themselves, and medical teams often lack the specific knowledge required to successfully overturn these critical denials.
- We offer patients multiple care options by reviewing their cases in our unbiased, **international tumor board**. This helps identify appropriate interventional procedures,

surgical options, innovative systemic treatments, transplant opportunities, and relevant clinical trial referrals. Additionally, we provide access to CLIA-approved programs that offer insurance coverage, financial assistance, or deeply discounted rates for key clinical studies.

- **Support Groups and Peer Connections** We utilize Slack and Zoom meetings to connect our AYA fibrolamellar patients, recognizing the immense power of unity and shared experiences.
- **Empowerment and Empathy** We remain empathetic and attuned to the unique needs of AYA patients. By balancing compassion with education, we teach patients to advocate for themselves effectively. Our goal is to empower individuals who might otherwise feel helpless following an FLC diagnosis.

Though these challenges are scary, there is so much hope, and we will never stop in our mission to help patients. Our mission is to change this paradigm fundamentally. In 2026, cancer treatment is a highly complex endeavor that requires experts from multiple disciplines working in concert. Providing hope, viable options, and collaborative care helps to create a tangible survival advantage. Our Fibrolamellar patient base, consisting of approximately 90% AYA individuals, deserves optimal care!

We dedicate our support to all the incredible AYA patients, past and present, those who have survived, and those who have sadly passed.

Thanks for reading,

Dr. Kent

Medical Director Dr. Paul Kent responds to Frequently Asked Questions and highlights work in Fibrolamellar Carcinoma Medicine. Read the entire piece on our website by following the link.

Submit questions via ContactUs@fibrofighters.org or PaulKentMD@fibrofighters.org

Support Fibrolamellar Fighters

Your generosity will help provide better treatments, clinical trials, and support important patient-driven initiatives!

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"SLAYING THE FIBROLAMELLAR BEAST TOGETHER"

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