



Fibrolamellar Cancer Foundation

John Hopper

Fibrolamellar Cancer Foundation: President
Greenwich, CT

GI Cancers Alliance: Co Chair/ Founder
Washington, DC

National Pancreas Foundation: Executive Board/Board Director
Washington, DC

NORD: Co founder-Rare Cancer Coalition; State of CT Rare Disease Day Spokesperson

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Rare Cancers

- **Represent approximately 20%** of rare diseases and growing
 - As genomic profiling and targeted therapies increase, more variations of cancers are noted, and defined as Rare
 - With nearly 30 Million US citizens having a rare disease, **approximately 6 million of those are cancers**





Fibrolamellar Cancer Foundation

What is Fibrolamellar:

Form of Liver Cancer – Fibrolamellar Hepatocellular Carcinoma (FLC)

Ultra Rare Cancer : 1 in 5 million

Adolescent /Young Adult: 12- 30 year old

Survivorship rate : Less than 30 % (5 year)

No known cause: Victims are young with normal /healthy livers



FACES OF FIBROLAMELLAR

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



Fibrolamellar Cancer Foundation





Fibrolamellar Cancer Foundation

Founded in 2009

26 year old Tucker Davis of Greenwich, CT :

18 month battle

Died on Rare Disease Day 2010 at age 28



Mission



- Find a cure and treatment options
- Raise awareness of this disease
- Connect and support the fibrolamellar community of patients and their families

Research FCF Funded



Research 2017 Fibrolamellar Summit

November 1st/2nd Stamford Hilton, Stamford, CT.

Focus

- Research Updates
- Collaboration
- Road Map Input

Participants from FL-HCC research community

- Academia
- Private Sector
- Government
- FCF Board
- Partner Foundations



Corporate/Partner Research



How can you help

Rare Cancers Understand Budget Constraints

...but there are **MANY** ways to help make progress for rare cancers such as Fibrolamellar

...and help **Save** important lives!

How can you help

Rare Cancers Understand Budget Constraints but there are MANY ways to help address these important young people and their families:

Awareness/ Education

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Patient Support

We Need Your Help: Take Action with Us!



Thank You!

JOHN HOPPER

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