



FOR IMMEDIATE RELEASE

Two Different Rare Diseases Before Age 20: Chansen Savakinus' Rare Disease Awareness Day Message

Greenwich, CT - (February 26, 2022) – February 28th is designated [Rare Disease Awareness Day \(RDAD\)](#). Since its launch in 2008 by the [National Organization of Rare Disorders \(NORD\)](#), Rare Disease Day focuses attention on the fact that more than 30 million Americans, one in every 10 people, have been diagnosed with a rare disease, and less than 5% of the 7,000+ known rare diseases have a FDA approved treatment. Despite these staggering numbers, research funding into rare diseases remains low.

One such rare disease is fibrolamellar carcinoma (FLC), an aggressive form of liver cancer that tends to strike teens and young adults with otherwise healthy livers. FLC is an example of a devastating rare disease that has no clinically-proven systemic therapies, but where new research efforts are beginning to identify details about the disease that could eventually lead to the development of new treatments.

Chansen Savakinus, age 21, of Coral Springs, Florida was diagnosed with fibrolamellar carcinoma last year. Despite that recent diagnosis, Chansen's rare disease journey has already been extremely long. When he was six years old, he was diagnosed with B-cell acute lymphocytic leukemia (ALL) and underwent treatment for that blood cancer for 3 ½ years. He then suffered a relapse at age 11 and received another 2 ½ years of leukemia treatment. While ALL is the most common type of pediatric cancer, any childhood cancer is considered a rare disease. Today, Chansen is battling his second distinct rare form of cancer – fibrolamellar carcinoma. Chansen taped [this video segment](#) to share his cancer journey and describe the surgery and systemic therapies he has endured since diagnosis. His experiences illustrate the difficulty of establishing treatment protocols for rare diseases, especially aggressive cancers like FLC which is typically not diagnosed until the disease is already in an advanced stage.



“We are hoping that Chansen's message spreads nationwide, and worldwide,” said John Hopper, President of the Fibrolamellar Cancer Foundation. “Generating awareness of struggles like Chansen's can lead to increases in research and funding that can accelerate the development of effective treatments and possible cures for rare diseases like fibrolamellar.”

Senator Richard Blumenthal echoed the need to increase investment to help patients like Chansen. “This Rare Disease Day, I'm proud to join the National Organization for Rare Disorders and the Connecticut-based Fibrolamellar Cancer Foundation, as we renew our commitment to supporting patients, families, and essential caregivers. With robust federal investment, we can and will spur innovation of research, treatments, and cures for those living with rare diseases – saving countless lives in Connecticut and across the country.”

The National Organization of Rare Diseases (NORD):

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing all patients and families affected by rare diseases. NORD is committed to the identification, treatment and cure of the more than 7,000 rare diseases, of which approximately 90% are still without an FDA-approved treatment or therapy. Visit rarediseases.org.

About Fibrolamellar Cancer Foundation:

FCF, a public 501c3 nonprofit organization based in Greenwich, CT, was founded in 2009 by 27-year-old Tucker Davis, who lost his life to Fibrolamellar on Rare Disease Day in 2010, after an 18-month fight. FCF has funded nearly \$10 million in research across more than 24 major institutions in the U.S. and internationally. 100% of all donations go towards research. All FCF's overhead and administrative costs are paid by the Charles A. and Marna Davis Foundation and Stone Point Capital. For more information, visit www.fibrofoundation.org and also interact with us on our social media channels: [Facebook](#), [Twitter](#) and [Instagram](#).

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