

# Rare Cancer Day: Making Noise to Find Cures

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GREENWICH, CT, UNITED STATES, September 28, 2021 / EINPresswire.com/ -- Over 25% of all diagnosed cancers are considered rare. And few have any standard of care, or curative therapies. On this year's Rare Cancer Awareness Day (#RareCancerDay), September 30th, one rare cancer foundation, [Fibrolamellar Cancer Foundation](#), is showcasing how working together can create a loud impactful noise and help advance research for this patient community.

Fibrolamellar (FLC) is a rare and aggressive adolescent/young adult liver cancer typically diagnosed in an advanced stage. Fibrolamellar is a prime example of an overlooked, urgent rare cancer with no known effective systemic therapies. John Hopper, President of the Fibrolamellar Cancer Foundation (FCF) and Co-chair National Organization Rare Disorders (NORD) Rare Cancer Coalition (RCC) said, "FCF, now in the 12th year of its mission to fund research for FLC curative treatments, is using a collaborative approach to research,



***Fibrolamellar Cancer Foundation***

**September 30 is #RareCancerDay**

FCF Awareness for #RareCancerDay



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awareness and patient support – and it’s making a difference.”

FCF has spent over \$9 million, across more than 20 academic research institutions who all agree to the principals of collaborating and sharing data with one another. This approach has led to important new discoveries such as a driver mutation for this aggressive cancer, new clinical trials and screening of thousands of existing drugs with potential hope one or

several may show promise to slow down the progression or cure cancers such as FLC. FCF also believes in encouraging data sharing amongst other rare and gastro intestinal (GI) cancers, and has helped create global alliances and coalitions with many other cancer foundations, such as the GI Cancers Alliance in addition to RCC.

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*John Hopper, President of the Fibrolamellar Cancer Foundation*

FCF’s collaboration formula has grabbed the attention of major pharmaceutical companies and powerhouse global foundations like the Chan Zuckerberg Initiative, which is currently funding FCF as one of the inaugural rare cancers in its Rare as One Network.

How can you be part of [Rare Cancer Day](#)?

- Give: Hopper suggests donating to the rare cancer foundation of your choice, especially those like FCF where 100% of funds go directly to research.
- Learn: Increase your understanding of rare cancers by attending educational webinars celebrating Rare Cancer Day. One example is a 45-minute NORD webinar, “Rare

Cancers: Breaking Down Barriers to Diagnosis, Treatment and Research”, which will discuss rare cancer challenges on Thursday, September 30, 2021 at 2:00pm EST. The distinguished panel will include:

oJohn Hopper, moderator – FCF President, NORD RCC Co Chair

oMargarita Raygada, PhD – Research Geneticist and Oncology Genetic Counselor, National Institutes of Health, National Cancer Institute

oSimron Singh, MD, MPH – Medical Oncologist, Sunnybrook Health Sciences Center

oRobert Taylor – Patient Advocate, Life Raft Group and SWOG Cancer Research Network.

Patients, caregivers, families and the general public are encouraged to attend. For more information or to register, [click here](#).

- Build awareness: Help raise awareness of rare cancer issues by sharing Rare Cancer Day



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information with your community and using the hashtag #RareCancerDay.

About Rare Cancer Day: Rare Cancer Day is an annual awareness day devoted to shining a light on rare cancers and the issues people living with them face. Spearheaded by the NORD Rare Cancer Coalition™, which is composed of 27 rare cancer-specific member organizations, Rare Cancer Day is observed on September 30 to highlight the challenges patients face and to unify individuals living with rare cancers for awareness and early diagnosis.

About the National Organization for Rare Disorders (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 more than 7,000 rare diseases, of which approximately 90% are still without an FDA-approved treatment or therapy. Rare diseases affect over 25 million Americans. More than half of those affected are children. Information about NORD can be found at [www.rarediseases.org](http://www.rarediseases.org)

The NORD Rare Cancer Coalition, composed of 27 rare cancer-specific member organizations, asks individuals and groups to visit [rarediseases.org/get-involved/rare-cancer-coalition/rare-cancer-day/](http://rarediseases.org/get-involved/rare-cancer-coalition/rare-cancer-day/) for downloadable assets, a social media toolkit, event details and more information.

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 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](http://www.fibrofoundation.org) and also interact with us on our social media channels: Facebook, Twitter and Instagram.

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