



Charlotte Savill

MEMORIAL

CHARITY RACEDAY

17th November 2025

Charlotte Savill was born in Dublin on November 23, 2001, the fourth of six children. She went to school in Dublin but loved to travel and attended college at Florida State University in Tallahassee. Beautiful, bright and vivacious, Charlotte was everything you could ever want in a daughter kind, thoughtful, happy, appreciative, sensible, fun, witty and smart. She had an infectious laugh and was loved by everyone. She was the centre of the social life of the young in Dublin, Tallahassee, and the Cayman Islands where her family had a second home. She lit up every room she entered and never had a bad word for anyone.

In 2022 she started to have abdominal pains. Three different doctors diagnosed a variety of causes - heartburn, acid reflux, gerds, a rumbling appendix. None of them sent her for a CT scan which would have revealed the true diagnosis. When, in April 2023, the pain got so bad that she could not sleep, Charlotte called an ambulance and was taken to Tallahassee Hospital. The CT scan revealed that she had Stage 4 Fibrolamellar Liver Cancer (FLC), a very rare form of cancer which attacks children generally aged between 13 and 25.

Over the next sixteen months, she underwent three major operations to remove countless tumours from her abdomen and chest, crossed the Atlantic 23 times in the hope of finding a cure and underwent many months of chemotherapy. But there is currently no cure for FLC

and Charlotte finally succumbed to the disease in August 2024 aged 22. During those sixteen months, she was the same beautiful person, never complaining about her illness, always more concerned about others than herself, positive and brave to the end.

No parent should have to go through the pain of losing a child and the research that is being done to find a cure for this rare disease is badly underfunded because the pharmaceutical companies are reluctant to invest in finding a cure for such a rare disease. The only hope of finding a cure lies with fund raising and the kindness and generosity of private donations.

Fibrolamellar Liver Cancer (or FLC as it is known) is a very rare form of liver cancer which randomly strikes children and young adults. It is anatomically



caused by the fusion of two cells that normally function independently in the body. However, unlike conventional hepatocellular liver cancer (HCC), which is generally caused by sclerosis of the liver, FLC attacks healthy livers. The reasons why young people contract FLC are unknown, and diagnosis is often missed or underestimated.

FLC can spread quickly to other parts of the body and is very aggressive. Life expectancy after diagnosis is generally little more than a year and chances of survival beyond five years are slim. Currently, resection of tumours is the only available and sometimes effective treatment, but resection is only possible in areas of the body that are accessible and do not interfere with the main organs. There is no therapeutic cure yet developed and reoccurrence of the disease is the norm. Promising young lives are cut short before they blossom, leaving families and friends devastated by the loss of their children and siblings. The loss of life is hard to bear at a stage in life when it is least expected.

Research into FLC is seriously underfunded, leaving the few researchers dependent on fund raising and private donations. Much of this research is being done in the United States. Treatments have been developed and clinical trials started but, so far, with no discernible success. Many insurance companies refuse to pay for the treatments, even though they are FDA -approved, on the grounds that they are not approved specifically for FLC. The fact that there are no drugs that have been approved by the FDA to specifically treat FLC leaves insurance companies with a loophole, and many families are therefore unable to pay for treatment.

The leading expert in the world in FLC research is the biochemist Professor Sandy Simon. He is affiliated to Rockefeller University and Soane Kettering Hospital in New York and has devoted his life to finding a cure ever since his daughter Elena contracted FLC in 2008. His laboratory and department of



Some of Sandy's team with student volunteers at the Rockefeller University, New York.

about 20 people are researching the underlying causes and connections between FLC patients, searching for better and more accurate diagnostic methods, and developing therapeutic solutions. Some of the researchers working with Professor Simon are themselves suffering from the disease.

Sandy needs financial assistance in all these areas. Progress is slow because of government and pharmaceutical underfunding but he is making good progress and is getting closer and closer to winning the battle. Significant fund raising and private donations are urgently required so that families with children and young adults do not have to experience the pain and grief that too many are living with. Your help would be so gratefully welcomed.