

Gipsy Hill family's fundraising in memory of kind-hearted 18 year old helps fund vital new leukaemia research

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A Gipsy Hill family's fundraising in memory of their teenage daughter has helped fund a major new research project into children's blood cancer.

Ruby Fuller, 18, died during the COVID 19 lockdown in May 2020, just under a year after she was diagnosed with a rare type of lymphoma. During that time, she spent over 200 nights in hospital and endured incredibly intensive treatments. However, they were not enough to save her when the cancer transformed into leukaemia.

After Ruby died, her parents, Emma Jones and Dylan Fuller, were told how few treatment options exist for patients when T cell blood cancers relapse.

This prompted them to set up a Special Named Fund at CCLG: The Children & Young People's Cancer Association called Ruby's 'Live Kindly, Live Loudly' Fund to fundraise for research into childhood leukaemia and lymphoma.

Emma said: "Hearing that there simply aren't effective treatments yet made it very clear to us that if anything is going to change, it has to start with research."

"Setting up Ruby's fund felt like a way to turn our heartbreak into something hopeful – something that could improve outcomes for other young people in the future."

The fund has since raised over £290,000 and contributed to a new research project exploring better treatments for childhood leukaemia.

Emma feels that the new project embodies Ruby's motto of 'live kindly, live loudly'. She said: "This project is about kindness – developing safer, less brutal treatments – and it's loud because it challenges the status quo and pushes for change where it's badly needed."

"Supporting bold, innovative research like this feels like exactly the kind of legacy Ruby would have wanted."

The project, funded through a collaboration between CCLG and Children with Cancer UK, is led by Dr Maarten Hoogenkamp and Dr Vesna Stanulovic at the University of Birmingham.

Dr Stanulovic said: "We are making a new drug that will interfere with the metabolism of leukaemia cells – basically, it will kill cancer without affecting the rest of the body."

The new drug aims to treat T cell blood cancer both at diagnosis and after relapse. While it is excellent at fighting leukaemia in the lab, the drug currently breaks apart too easily in the body. With this funding, the researchers hope to refine their drug to ensure it can survive long enough to effectively fight the cancer cells.

Dr Stanulovic added: "By only targeting the cancer cells with this treatment, we hope to prevent the huge toxicities that are normally being seen with leukaemia treatment. Our drug should be very friendly for patients and not require any further hospitalisation."

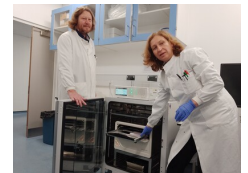
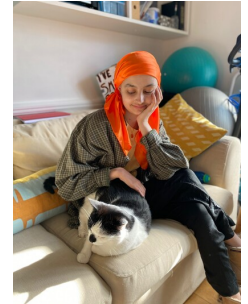
Because of the expected lack of side effects, the researchers hope that their treatment could eventually be taken at home as a tablet.

Emma said that funding the project "means everything" to her family. And, despite Ruby's 'Live Kindly, Live Loudly' Fund now having supported five research projects in total, she has no plans to stop fundraising.

This year's plans include a London Tube Challenge, visiting all 272 tube stations in London as quickly as possible, and an auction to commemorate what would have been Ruby's 25th birthday in October.

Vicki Brunt, Head of Fundraising at CCLG, said: "Ruby's family and supporters have achieved an extraordinary amount in such a short time, and we are incredibly grateful for everything they've done."

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“Their dedication is enabling vital work that could lead to kinder, more effective treatments for young people diagnosed with blood cancer.”

Gavin Maggs, Chief Executive of Children with Cancer UK, said: “Working together with CCLG allows us to achieve more for children and families affected by cancer.

“Between us, we can fund research that pushes boundaries and brings us closer to safer, more effective treatments, maximising impact and accelerating progress. Co-funding like this has to be the way forward, for our donors, for the academics, and most importantly, for the children.”

If you would like to donate a prize for the Ruby's 'Live Kindly, Live Loudly' Fund auction, please contact emmacjones1000@gmail.com or, to support the fund, please visit specialnamedfunds.cclg.org.uk/rubys-live-kindly-live-loudly-fund

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