

# London musician with brain tumour inspires Brighton triathlon fundraiser

Tuesday 26 August, 2025

A talented musician from London, who died from a rare brain tumour in January this year aged just 23, has inspired three friends to take part in the Brighton and Hove Triathlon on 31 August to fundraise for vital research into the disease.

Alexander Bernard-Bell, a singer/song writer who performed under the name <u>Syren</u> was diagnosed with a low grade glioma called DLGNT in October 2021. At the time there were only 100 cases of DLGNT in medical literature and his oncologist had never heard of it.

His family consulted doctors and researchers across the world to find any kind of treatment that would extend Alexander's life. But in August 2024, his condition worsened, and he was admitted to Charing Cross Hospital.

Alexander spent 178 days in intensive case where he had four major brain surgeries and developed HSV encephalitis. He passed away at the end of January as no further treatment was available.

Alexander was a much-valued Young Ambassador for <u>The Brain Tumour Charity</u>, which is the largest dedicated funder of research into primary brain tumours globally, His sister, Hannah, also a Young Ambassador, continues in role - raising awareness of the disease and support ing others affected by a diagnosis.

Hannah's husband, Alex Preston, ran the London Marathon the day after their wedding in April, raising £30,000 for The Charity. He is now taking part in the triathlon in a relay with friends - Theo Jessel is swimming, Andy Dodds is cycling, and Alex will run the final leg.

Alexander's mum, Katie, said: "It took a year to diagnose Alexander's brain cancer, despite relentless migraines, nausea and papilledema (swelling of the optic nerve) which eventually led to him losing the sight in in his right eye.

"Alex had a brain biopsy which revealed nothing and an operation to implant a shunt to control the pressure in his brain. It was only as a result of a third operation on his lower spine, that he was finally diagnosed with a type of paediatric low-grade glioma called DLGNT - Diffuse Leptomeningeal Glioneuronal Tumour.

"At the time of Alexander's diagnosis, we felt completely lost as a family. We didn't know anyone else with DLGNT. We didn't know who to turn to, who to believe and we were terrified at the dawning realisation that there is no cure for this rare form of cancer.

"Since then, we have set up a <u>website</u> to provide information on DLGNT and created an international community of DLGNT patients, neuro-oncologists and researchers. We have partnered with three world class brain tumour charities - Kindred Foundation in Canada, the Pediatric Brain Tumour Foundation in the USA and The Brain Tumour Charity in the UK - to raise awareness and funds for brain cancer research.

"So far we have raised over £124,000 for The Brain Tumour Charity under the banner of Team Syren. Our family and Alexander's friends are driven to do what we can so that in the future other families don't have to go through the heartache we've experienced."

To support Alex and Team Syren's efforts, visit: <a href="https://www.justgiving.com/page/alex-preston-4">https://www.justgiving.com/page/alex-preston-4</a>

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