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## Teen fighting a rare genetic disorder receives humanitarian award

[NORTH FULTON COUNTY](#) | 4 hours ago

By [Adrienne Murchison](#), The Atlanta Journal-Constitution

Jack Burke describes himself as an average teenager but his fight

against a rare genetic disorder that causes multiple tumors has inspired people to help find a cure for his condition. His resiliency over the years has resulted in a total of \$3 million in donations towards research for neurofibromatosis, referred to as NF.

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Jack, a 15-year-old freshman at Cambridge High School in Milton, was honored with a humanitarian award last week by New York-based Children's Tumor Foundation (CTF).

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NF causes tumors to grow on nerves that can result in cancer or heart problems, lead to blindness, loss of hearing, learning disabilities or

bone and mobility issues.

Since age two, Jack has had surgery on his brain, left eye and his feet, which had to be broken and reset, his parents said, in addition to enduring 52 weeks of chemotherapy. The brain surgery, when Jack was in fifth grade, was for a tumor that was compressing a hole in the area of his spinal cord that could've otherwise led to nerve damage, his father Jake Burke said.

The teen brings awareness to the disorder through CureNF with Jack, a nonprofit started by Burke and his mother, Beth O'Brien, to fund research for treatment or a cure. Jack speaks of his journey at events and in videos.

The Burke family and CureNF with Jack have raised \$3 million in private donations as well as through golf tournaments and fun run fundraisers over the last 10 years, according to the nonprofit and CTF President Annette Bakker.

Bakker said 1 in 3,000 people have NF, or about 2.5 million globally. In many cases NF isn't visibly apparent to others, she added.

In 2019, Jack and five other NF patients met with Food and Drug Administration officials in Bethesda, Maryland, to describe their experiences living with the condition.

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Though there is no cure, the U.S. Food and Drug Administration approved a new drug in April by AstraZeneca called Koselugo which could reduce the size of tumors. Bakker said 70% of patients in clinical trials had significant tumor shrinkage.

“At the end of the day, children are much more resilient than we give them credit,” Jake Burke said. “Part of what keeps Jack going is support within the community — not only in Milton but across the country. A lot of people, when they get faced with diversity bury their head in the sand. But that’s not what he did.”

During Jack’s acceptance speech for his humanitarian award, he quoted specialist Dr. Robert Avery as saying, “Jack might have NF but NF does not have him.” The Milton teen added, “I think these are some great words and they remind me to keep going and keep fighting.”

To learn more, visit the [CureNF with Jack](#) and [Children’s Tumor Foundation](#) websites.

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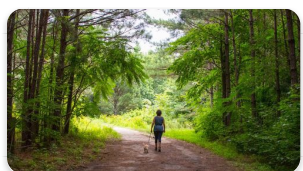
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