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The boy with very rare 'aging disease', Sam Berns dies at 17—he inspired millions!

June 7, 2017 [SHARE](#)

The 17-year-old boy with the so-called 'Benjamin Button disease' passed away just last week. His fatal condition called progeria, which caused his body to age at an accelerated rate, also claimed the life of this inspiring teen who touched the lives of so many.

The boy's mother, Lesslie Gordon shared on an [ABC program](#) last year just how precious their limited time together was:

"He gets off the bus, it's a moment. And I treasure it," she said. "Every moment in and of itself is special to me."

Last year, Sam Berns garnered major media attention because of his extremely rare genetic condition, which affects only 1 in every 1 to 2 million born. There are only around 250 children who have this disease, which causes the body to grow 'old' very quickly.



Credit: Facebook | [Boston Children's Hospital](#)

His story was also featured in an [HBO documentary](#), 'Life According to Sam', which helped to shed some light on the illness around the world.

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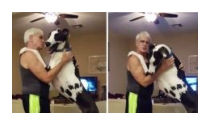
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Sam also debuted on [TED Talk](#) to speak a little bit about the uses of 'old' medications for new diseases—such as progeria.

Although Sam passed away when he was only 17 years old, most children diagnosed with the rare condition are expected to live no longer than 13 years.



Credit: Facebook | [Diario Tiempo](#)

His mother Leslie, a doctor, strove above and beyond in order to find a cure for her son, who was diagnosed with the disorder at the age of 22-months. She even organized a research team in order to determine the cause of the illness and with any luck, find a cure.

Along with her husband (also a doctor), Scott Berns, she founded the Progeria Research Foundation in 1999. Their team even made some significant headway in their research, managing to isolate the gene that carries the disease, as well as the abnormal protein that is significantly higher in children affected by it.

They also found that a certain cancer-fighting drug showed some promise in treating progeria.



Facebook | [Hindustan Times](#)

Thinking of his mother, Sam mentioned in the ABC interview last year: "I kind of just want my mom to be done with progeria for her sake because my mom will keep working forever until progeria is cured."

After his sad passing away, the research foundation posted a statement online:

"The entire [Progeria Research] community mourns the loss of this remarkable young man who not only inspired [Foundation]'s creation but also touched millions of people worldwide."



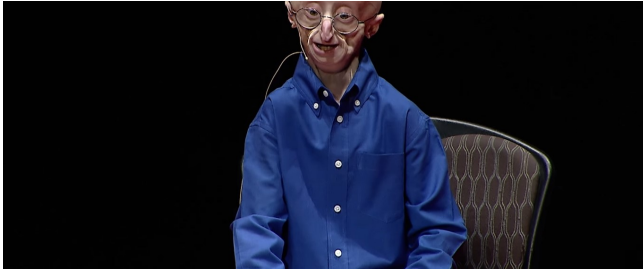
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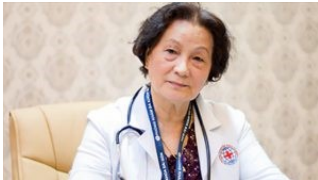
Youtube Screenshot | [TEDx Talks](#)

Sam also touched the heart of others such as New England Patriots' CEO Robert Kraft, who posted a statement in memory of Sam on the team's website, which stated:

"I loved Sam Berns and am richer for having known him. He was a special young man whose inspirational story and positive outlook on life touched my heart."

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