



In recognition of **NF Awareness Month**, the Children's Tumor Foundation is highlighting exceptional stories from Neurofibromatosis (NF) patients across the country that have participated in, and benefited from, crucial clinical trials of targeted therapies that aim to treat NF and its symptoms. NF is a genetic disorder that affects 1 in 3,000 people of all populations, and causes tumors to grow on nerves throughout the body. It has three distinct forms: NF1, NF2, and schwannomatosis, and can be presented in a number of harmful ways, such as blindness, deafness, learning disabilities, disfigurement, bone abnormalities, disabling pain and cancer. Results from NF research can therefore be applied to other disease areas, and benefit the broader public. The story below reflects both the adversity faced by this NF hero, as well as new hope from promising new treatments.

NF Hero: Aidan Fraser

Age: 16

State of Residence: New York

Type of Neurofibromatosis: NF1

Aidan's Story, as told by his mother, Suzanne:

My beautiful son, Aidan, was diagnosed with NF1 at eight months old. He had many cafe-au-lait spots that multiplied every day. At 14 months old Aidan's legs gave out, paralyzing him from the waist down. His doctors found a tumor in his neck that could not be completely surgically removed. He went through nine-hour surgery that same week for a partial resection, and regained his mobility. His tumor was pressing on his spinal cord, so part of his spinal column had to be removed. When Aidan was 21 months old, his father was killed on September 11th. Two months later, he began his first chemotherapy treatment. Aidan was also surgically implanted with a MetaPort. Once a week, he had what looked like a fishhook put into his heart while treatments ravaged his system for seven hours to no effect. He screamed in terror every minute—the memory still wakes me in horror. Over the years, he had three surgical resections and was subjected to Thalidomide and PEG-Intron. Nothing worked. When Aidan was seven, his legs gave out again. He was paralyzed, catastrophically. A team of five surgeons performed life-saving surgery. He then had two, 12-hour surgeries a week apart where they rebuilt his spinal cord with his ribs and he spent six months in a halo. There was no treatment for Aidan then, but there is hope now. Aidan has been on the MEK Inhibitor for two years. His tumor has shrunk 38% and he is no longer in pain. It is miraculous, except that his shrinkage is slowing down and it will soon stop. Please help a community that is in need!

FOR MORE INFORMATION ON NF, PLEASE VISIT WWW.CTF.ORG