

CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH



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: Ryker Bennett
Age: 6
State of Residence: Utah
Type of Neurofibromatosis: NF1

Ryker's Story, as told by his mother, Sarah:

My son Ryker was diagnosed with NF1 at six months after a brain MRI. Ryker has a sphenoid wing dysplasia and a plexiform tumor that wraps around his left orbit, left cheek, neck, and brain. When Ryker was one-year old he was treated for two optic nerve gliomas with 12 months of Vincristine and Carboplatin Chemo, including port surgeries. Ryker has had one major tumor de-bulking surgery and five de-bulking surgeries on his eye to help preserve his vision. The de-bulking surgeries have not been successful. Ryker has had sedated MRIs every four to six months since he was only six months old. He is now six, and his tumor has continued to grow and grow. When he was born his face was symmetrical, and now doctors consider him to have a major facial disfigurement. Ryker's vision is greatly affected, and we hope he doesn't lose vision entirely in his left eye. On a daily basis he has the challenge of being treated differently because of his tumor, which is hard when you are six years old. Ryker went through 12 months of a clinical trial PEG-Intron in the hopes of shrinking his plexiform tumor, and was considered to be unsuccessful in shrinking it. He is currently on the MEK inhibitor trial and after only four months his tumor has shrunk 27%. We are extremely hopeful in this new trial for Ryker!

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