

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: Odessa Black
Age: 28
State of Residence: Virginia
Type of Neurofibromatosis: NF1

Odessa's Story, as told by her mother, Lynne:

Odessa was six years old when she was diagnosed with NF1. She had most of the classic signs of NF—lisch nodules in her eyes, freckling in her groin and armpits, and a few café au lait spots on her skin. When she was 14, a routine MRI showed a large tumor on her spine. Over the next five years, she had three major surgeries, resulting in removing the L4 nerve root along with the low-grade malignant tumor. Although she lost the feeling in the front of her lower right leg and top of her foot, she could still walk. From 2003-2007, she had four surgeries on her neck to remove tumors that were compressing her spinal cord. After these surgeries, she started having trouble walking and needed a cane. At 21, Odessa had a Malignant Peripheral Nerve Sheath Tumor (MPNST) removed from her left sciatic nerve. As a result of removing the tumor along with a large portion of her sciatic nerve, she has no function from the knee down and full foot drop. Odessa is a rare MPNST survivor! Since 2010, she has gradually lost the ability to walk and use of her arms/hands. She is now wheelchair bound now and considered quadriplegic. Odessa is now 28 years old. Her neck tumors have grown back and are considered inoperable. She is currently participating in a two-year drug trial of a MEK Inhibitor focusing on the barbell tumors in her neck at C2-3. After 18 months, the MRI results show 25% reduction in volume of her tumors! She is now able to lift her arms/hands and move her legs. That is reason to celebrate! We do not know what the future holds for Odessa, but she continues to defy the odds that are stacked against her with a smile.

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