

Chair Burke, Vice Chair Beagle, Ranking Member Tavares, and members of the Senate Health, Human Services and Medicaid Committee, thank you for giving me the opportunity to offer testimony in support of House Bill 45 to raise awareness of Neurofibromatosis.

I am Larry A. Gossard and I represent the great State of Ohio on the Children's Tumor Foundation's Advocacy Task Force which is comprised of 12 members from different states across the country and I am also a member of the Children's Tumor Foundation Leadership Council. I was also named the Children's Tumor Foundation's 2017 Ardent Advocate of the year. One of the main missions of the task force is to raise awareness about Neurofibromatosis or more commonly known as NF.

(NF) is a genetic disorder that causes tumors to grow on the cells that surround nerves anywhere in the body. NF can be inherited or it can develop by spontaneous mutation or complete deletion of the gene that protects the body from developing tumors in the nervous system at birth. Most prevalent are tumors in the brain, tumors on the optical nerve which can cause blindness, or tumors on the spine.

NF can also cause deafness,

disfigurement,  
seizures,  
headaches,  
short stature,  
larger than normal head,  
severe pain,  
itching,  
bone deformities,  
learning disabilities,  
developmental delays,  
cardiovascular problems,  
low muscle tone,  
ADHD,  
developmental behavior difficulties and many other serious health issues.

There are 3 types of NF. NF1 occurs in approximately one in every 3000 to 3500 births, NF2 is one in every 25,000 births and Schwannomatosis occurs one in every 40,000 births. NF is more prevalent than cystic fibrosis, Duchene muscular dystrophy and Huntington's Disease combined. There are no effective treatments nor is there a cure.

A lot of children are diagnosed after they are in school due to the learning difficulties that become evident with difficulties in areas such as math, reading and writing, due to low muscle tone, social difficulties and low self-esteem. Some are diagnosed in early adulthood as well. Neurofibromatosis affects over 100,000 Americans and yet it is still relatively unknown to many people.

My 10 year old son Bryce Wells-Gossard was diagnosed with NF1 with features of Noonan's syndrome and pulmonic stenosis at 10 months old. He has slight curvature of the spine, ADHD, developmental behavior difficulties, has worn glasses since he was one year old and other issues due to his NF. His was a spontaneous mutation and he has complete gene deletion. Due to his early diagnosis we were able to implement things he needed to help him in the areas we knew he was going to need help in such as speech therapy, physical therapy, and occupational therapy. He is in third grade in a public school and is doing great right now even though he still has some issues that a lot of kids with NF1 have.

It is devastating to a parent when they are told their child has an illness and that there are no effective treatments or a cure. That is why it is so important to raise awareness about NF here in Ohio because it is unknown to many Ohioans. Also to let everyone know It can happen to any newborn child for no reason. It can happen to any newborn child in your families.

May 17<sup>th</sup> was World NF Awareness Day with over 150 landmarks, bridges and buildings all over the world lighting up with the colors of blue and/or green to raise awareness about NF. Here in Ohio Terminal Tower in Cleveland and the Jacks Casino in Cincinnati as well as the Hardin County Courthouse in Kenton were lit up in honor of World NF Awareness Day.

This is also the 8<sup>th</sup> year we will have put on a Cruise-In For A Cure Family Fun Day and Car Show on Behalf of Bryce Wells-Gossard and the Children's Tumor Foundation in Kenton to raise awareness and funds for research. We have grown every year and all of the proceeds go to the Children's Tumor Foundation on behalf of NF Hero Bryce Wells-Gossard for research

That is why I am here to raise awareness about NF and with the introduction of House Bill 45 by State Representative Robert Cole Sprague, if passed, will designate the month of May as “Neurofibromatosis Awareness Month” and help bring awareness to many Ohioans what NF is and how dramatically it changes the lives of those affected by it. It has changed my life forever.

Thank you for your time and consideration. I am happy to answer any questions that the committee might have.

More information about NF can be obtained at [ctf.org](http://ctf.org)