

Logan Walker's Story



Logan is 11 years old and is a funny, loving, affectionate child. He loves to swim, fish, hunt and most of all he loves animals. After being told when he was a baby that he was developmentally delayed and having received early intervention until he was 3, we knew in our gut there was something else. At the age of 5 Logan was diagnosed with Fragile X Syndrome.

What is Fragile X?

Fragile X Syndrome is the most common form of inherited mental retardation. Individuals with this condition have developmental delay, variable levels of mental retardation, and behavioral and emotional difficulties. Presently there is no cure for fragile X syndrome. Management includes such approaches as speech therapy, occupational therapy, and physical therapy. The expertise of psychologists, special education teachers, and genetic counselors may also be beneficial. Drugs may be used to treat hyperactivity, seizures, and other problems. Establishing a regular routine, avoiding over-stimulation, and using calming techniques may also help in the management of behavioral problems. Mainstreaming of children with Fragile X syndrome into regular classrooms is encouraged because they do well imitating behavior. Peer tutoring and positive reinforcement are also encouraged.

Since we had never heard of Fragile X Syndrome, we started researching it and sought out a specialist who could help us. Unfortunately, there is not a Fragile X specialist in the state of New Jersey. We've traveled to Staten Island and to Colorado to actually meet someone who could tell us

why our child was acting the way he was. It was a relief but sad. It has been a long, frustrating, and draining experience. We have also been told that he will probably stop learning by the age of 14. So these next few years are very important to all of us as we try to get as much learning in him as possible.

To most, Logan looks like your typical child. When he has behavioral issues, people think it's bad parenting when he acts out but is really one of the symptoms of Fragile X.

Logan currently receives speech, occupational therapy and social skills but the struggles continue. Logan has low muscle tone in his upper body, melt downs (since his brain cannot self-regulate itself), and has trouble socializing with kids his age. He cannot read, write, learn numbers, or tell time. He has about 50+ words in his binder (he learns through picture/word association).

It's hard to watch your child want to be accepted by other children his age but because he doesn't know how to act or know what to say, the other kids do not understand him. We have struggled with kids making fun of him and not wanting to be around him or be his friend. It breaks our hearts to see this happen to him.

We are hoping that one day there will be a cure and he'll be able to drive or even be on his own when he gets older.

