What is Dup15q Syndrome?

Dup15q syndrome is a disorder resulting from extra copies of genes on chromosome 15, region 15q11.2-13.1. Our genes tell our bodies how to grow and develop, so having extra genes can alter a person's development. Children with dup15q syndrome usually have poor muscle tone, which can affect everything from walking to writing and a lot in between. Most individuals with dup15q syndrome have cognitive delays beginning when they are very young. It usually takes these children longer to learn skills than their typical peers. People with dup15q syndrome often also have autism and difficulty communicating.

Many people with dup15q syndrome also have seizures. Sometimes it's hard to find medicines that make the seizures stay away. This can make it even harder for a person with dup15q syndrome to learn and develop. Sometimes the seizures might be the kind where the person falls down, but other times it might just mean they look like they're daydreaming for a bit. Other issues that people with dup15q syndrome can have are attention and anxiety disorders, sensory disorders, gastrointestinal issues and vision delays.

Even with all of these complex behavioral and medical issues, people with dup15q syndrome are sweet, curious, energetic and live life to its fullest.

A Brief History of Dup15q Alliance

Dup15q Alliance was originally founded under the name IDEAS in 1994 by a mom of a boy with dup15q syndrome and a genetic counselor who found thirteen families with children who had dup15q syndrome. As the internet grew, medical technology improved, and our understanding that too many genes on chromosome 15 caused many of these specific problems increased, this group of parents grew.

In 2004, we became a nonprofit organization. Dup15q Alliance represents include both isodicentric and interstitial duplications that cause dup51q syndrome.

Today, there are over 1,000 families from around the world affiliated with Dup15q Alliance. The organization is governed by a board of directors and a professional advisory board and is a supported by grants, donations and many hours of volunteer effort.

Together We Believe DUP15q ALLIANCE Together We Achieve

Our Mission

Dup15q Alliance provides family support and promotes awareness, research and targeted treatments for chromosome 15q11.2-13.1 duplication (dup15q) syndrome. Through our work to raise awareness and promote research into chromosome 15q duplications, we seek to find treatments specific to the genes affected by dup15q syndrome so that individuals can live full and productive lives. Together with our families, Dup15q Alliance is working towards a better tomorrow for children with dup15q syndrome.

Our Work

Dup15q Alliance provides family support by connecting families online and face-to-face. We help families have regional gatherings, provide a Parent Support Facebook group, and host family and science conferences.

Our goal is to one day find treatments, such as behavioral and drug therapies, targeted specifically for dup15q syndrome. Dup15q Alliance funds and encourages a variety of research studies, including studies that look at animal models of dup15q syndrome and those that look at patients with dup15q syndrome directly.

Dup15q Alliance has helped to create dup15q clinics located in major medical centers around the United States. Because dup15q syndrome is a rare disorder, it's often difficult for families to find doctors in their communities that know about dup15q syndrome. The dup15q clinics provide comprehensive evaluation and treatment to individuals with dup15q syndrome and collect information on all dup15q syndrome patients. Our hope is that by collecting more information, we can better learn the problems that people with dup15q syndrome face and what therapies and treatments help the most.