

What is chromosome 15q duplication syndrome and how are people with dup15q syndrome affected?

A syndrome is characterized by a set of associated symptoms and can be made up of various genetic causes.

Dup15q syndrome is a clinically identifiable syndrome that results from the duplication (or multiplication) of a portion of chromosome 15. The extra genetic material contains the bands on the q arm labeled 11.2-13.1. It can span past these bands but must contain the 11.2 - 13.1 region to be identified as dup15q syndrome.

The extra genetic material of this region can cause the following associated symptoms, making it by definition "a syndrome": hypotonia, developmental delay, motor delays, speech delays, autism, seizure disorders, anxiety disorders, behavior issues, and sensory processing disorder. There is a wide range of severity in the developmental disabilities experienced by individuals with dup15q syndrome. Two people with the same dup15q chromosome pattern may be very different in terms of their abilities and skills.



We empower individuals living with Dup15q Syndrome and other related rare diseases to reach their full potential by advancing breakthrough research and life-changing therapeutic treatments, supporting families affected by dup15q, and promoting advocacy.



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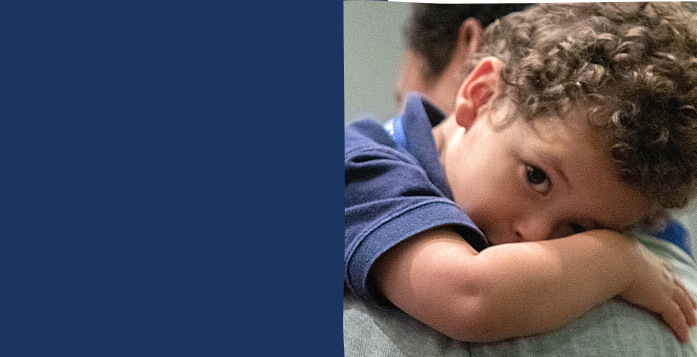
FOR 15Q 11.2-13.1 MULTIPLICATIONS

Dup15q Alliance provides family support and promotes awareness, research, and targeted treatments for dup15q syndrome.

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Dup15q Alliance is a U.S. 501(c)(3) Organization.

We depend on contributions from individuals, businesses, and philanthropic foundations to support our work. Donations are tax-deductible to the extent allowed by law.



Research

Research and Fellowship Grants: Dup15q Alliance funds basic direct patient research around dup15q syndrome and its symptoms, supporting established researchers through grants. We foster interest in new ways of thinking through fellowships for aspiring researchers.

Scientific meetings: We bring together researchers and clinicians by hosting an annual international scientific meeting on dup15q syndrome. These meetings allow for collaboration and sharing of knowledge on the latest research and treatments.

Clinic trials: We connect families with treatment research to improve the lives of those with dup15q syndrome. The Alliance works with industry partners to help clinical trial protocols become accessible to the dup15q community. We assist in recruitment for clinical trials aimed at including dup15q syndrome as a treatment indication.



Clinical

Clinical Research Network: We have 20 operating clinics providing standardized care for patients with 15q disorders. Our clinics serve as a platform for robust research, including the collection of integral natural history data.

Database: We are engaged in a new network platform of patient-powered data designed to increase caregiver and clinician understanding of 15q disorders. This modern platform is titled LADDER - Linking Angelman and Dup15q Data for Expanded Research.



Education and Outreach

International Family Conference: We connect families and professionals, from the US and internationally, to provide pertinent information regarding dup15q syndrome advances and treatments. Tailored to benefit the entire family, our conferences include scientific, genetic and clinical discussions, respite care, sibling sessions and group activities.

Newsletter: We generate monthly email blasts and create quarterly newsletters to educate families about dup15q syndrome. Our posts provide beneficial information on treatment options, research updates and clinical trial opportunities.

Website: Available in multiple languages, our website provides the most current information on dup15q syndrome for families, clinicians and the community. Our site, www.dup15q.org, provides useful materials and support programs to further strengthen the dup15q community.



Who Are We

We are advocates providing support for patients, families and caregivers. We are passionate about personal connections, community awareness and scientific research.

Dup15q Alliance connects families online through our Parent Support Facebook Group and face-to-face through regional gatherings and conferences. In addition to connecting families, Dup15q Alliance funds and encourages a variety of research studies. Our goal is to improve clinical care and to discover treatments, such as behavioral and drug therapies, targeted specifically for dup15q syndrome.