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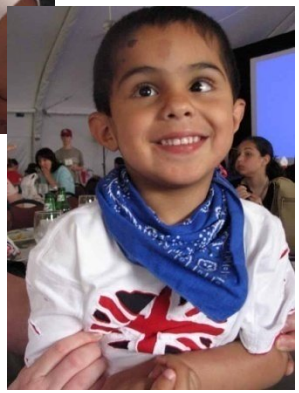
IDEAS is a registered non-profit corporation.
We are the only organization working towards a better tomorrow for individuals with chromosome 15q duplication syndrome. We depend on contributions from individuals, businesses and philanthropic foundations to support our work. Your tax deductible contribution can make a difference. Tax ID number 20-0751232 .

IDEAS
PO Box 674, Fayetteville, NY 13066
info@dup15q.org
www.dup15q.org

IsoDicentric 15
IDEAS
Exchange, Advocacy & Support



Providing family support and promoting awareness, research and targeted treatments for chromosome 15q duplication syndrome.

PO Box 674
Fayetteville, NY 13066
1-877-IDEAS15 (1-877-433-2715)

info@dup15q.org
www.dup15q.org

What is Chromosome 15q Duplication Syndrome?

Chromosome 15q duplication syndrome (dup15q) is a clinically identifiable syndrome which results from duplications of chromosome 15q11-13. These duplications most commonly occur in one of two forms. These include an extra isodicentric 15 chromosome, abbreviated idic15, or an interstitial duplication 15. Individuals with idic15 have an extra chromosome, made up of part of the q arm of chromosome 15, resulting in 47 chromosomes instead of the typical 46. People born with the typical 46 chromosomes but who have a segment of duplicated material within chromosome 15 are said to have an interstitial duplication chromosome 15.

How are people with this syndrome affected?

People with chromosome 15q duplications are frequently affected by developmental disabilities, including:

- Autism Spectrum Disorders
- Cognitive Disabilities

Chromosome 15q11-13 duplications are the most frequently identified chromosome abnormality in individuals with autism. The developmental problems in chromosome 15q duplication syndrome may be accompanied by other neurological, physical, and behavioral problems :

- Seizure Disorders
- Low Muscle Tone (Hypotonia)
- Speech/Language Disorders
- Sensory Processing Disorders
- Small Size for Age
- Attention Deficit and Anxiety Disorders
- Behavior Challenges
- Slightly Increased Risk for Sudden Death

There is a wide range of severity in the developmental disabilities experienced by individuals with chromosome 15q duplication syndrome. Two people with the same dup15q chromosome pattern may be very different in terms of their abilities and skills.

How is it diagnosed?

The extra chromosome can easily be detected through a blood test called a chromosome study. An additional genetic test called FISH (Fluorescence in Situ Hybridization) confirms the diagnosis by distinguishing the chromosome 15q duplication from other types of extra chromosomes. Interstitial duplications of chromosome 15 can be more difficult to detect on a routine chromosome analysis but are clearly identifiable using a FISH study. Each family's situation is unique and the diagnosis and testing options should be discussed with a genetics professional.

Treatment Options

No specific treatment can undo the genetic pattern seen in people with chromosome 15q duplications. However, affected children and adults have been known to benefit from the following:

- Early Intervention (speech, physical and occupational therapy)
- Ongoing Special Education
- Total Communication Systems (speech, sign, gestures, picture exchange)
- Behavioral Strategies
- Sensory Integration Strategies
- Medical Management of Symptoms
- Vocational Training
- Supported Living Options in Adulthood

Providing Information, Education and Support to Families Through . . .

Newsletter

The MIRROR is published quarterly to educate families about duplications of chromosome 15q, share family stories, and provide information about treatment options and current research.

Parent Match Program

IDEAS matches parents seeking support with parent mentors who can provide emotional support.

Regional Family Gatherings

IDEAS supports small regional meetings for families to network, share resources and support.

International Conferences

IDEAS Conferences provide families and professionals with an opportunity to meet and learn about scientific and treatment advances.

Informative Website

www.dup15q.org

Online Community

www.bigtent.com/groups/dup15q

Promoting Research and Hope for Effective Treatments Through . . .

Scientific Meetings IDEAS holds international research meetings on chromosome 15q duplications.

Collaboration with researchers.

Human Tissue & Cell Line donations are encouraged.

Advocacy Together with our scientific advisors we advocate for additional research into chromosome 15q duplications so that one day targeted and effective treatments will be a reality.