Who we are

Idic15 Canada is a Canadian non-profit organization which provides Collaboration, Advocacy and Research to families living with Chromosome 15q11.2-13.1 Duplication Syndrome. This organization is born from the need to advance medical resources and awareness in Canada.

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What is Idic15

Isodicentric15 (Idic15) is a rare chromosomal disorder. Individuals with Chromosome 15q11.2-13.1 Duplication Syndrome have an extra chromosome made up of some material from the fifteenth pair of chromosomes. This means that there are 47 chromosomes (or occasionally 48 or 49) in these cells rather than 46 (the normal number in a diploid human cell). The extra piece of chromosome 15 is duplicated end-to-end like a mirror image and variations include; ‘isodicentric15’, an ‘inverted duplication 15’ or a ‘supernumerary marker’.

What to look for

Although there are few common physical features, structural differences such as a flat bridge of the nose (button nose), folds at the corners of the eyes, and others may be present. The disorder is diagnosed through chromosomal blood testing and is confirmed by a genetic test called fluorescence in situ hybridization (FISH).

The most common features are:

Hypotonia (reduced muscle tone). This is usually present at birth but usually decreases with age. Babies may appear “floppy” and have difficulty sucking. Motor milestones (rolling over, sitting up and walking) may be delayed. Most individuals are able to walk independently.

Seizures. Many, affected children and adults have seizures at some point in their lives. These may be occasional or frequent, short or prolonged. There is increasing evidence that SUDEP is at higher risk in Idic15, so management of the Epilepsy is crucial.

Developmental delay. Learning difficulties vary in severity but are often moderate to severe.

Autistic behaviours. These behaviours are also associated with isodicentric15, including hand flapping, poor eye contact, repetitive or poorly developed speech and a need for ‘sameness’ in environment or daily routine. Although individuals do not appear unusual, many share similar facial characteristics including a flattened nasal bridge giving a ‘button’ nose, skin folds, called ‘epicanthi’ at the inner corners of the eyes, downward slanting eyes and full lips.

Further recommended testing include

24 Hr. EEG with special attention to background abnormalities
SLEEP STUDY due to a high incidence of Apnea
MRI
ECHO