CdLS Foundation
UK & Ireland
The Cornelia de Lange Syndrome Charity Reg. No. 1054033

"The CdLS Foundation UK & Ireland is a family support organisation which exists to ensure early and accurate diagnosis of CdLS throughout the world, promoting research, and enabling individuals, families, friends and professionals make informed decisions and plan for the affected person's present and future."

Cornelia De Lange Syndrome
FACT CHECK

The CdLS Foundation UK & Ireland fully supports all research that will help people with Cornelia de Lange Syndrome (CdLS). Research is on-going all the time across the globe. The Foundation has funded many behavioural research projects that offer practical solutions and management strategies to the complex psychological aspects of CdLS.

Genetic research is also going on, which is how we know about the 7 genes discovered so far that can change to cause CdLS. There are many other research projects that deal with the key issues that affect people with CdLS, giving a better quality of life and helping to avoid life threatening emergencies.

We are aware of many stories circulating in the media around CdLS which are giving a misleading impression of many aspects of the syndrome. This Press Release has been written to address these impressions.

One of the concerns is that families whose children are newly diagnosed with CdLS will see these stories and get a false impression of what the syndrome really entails. It is a challenge to bring up any child with disabilities but there is hope if correct information and advice is followed.

- CdLS occurs in an estimated 1 in 10,000 to 30,000 of the population.
- CdLS can affect many parts of the body and individuals with CdLS may display physical, cognitive and behavioural characteristics.
- Characteristics of CdLS can be widely variable. Not all people with CdLS will show all of the aspects.
- CdLS children who have mobility generally continue to walk in adulthood, unless there are other factors that will impair mobility later in life such as hip problems or obesity, both of which can be managed.
- Seizures occur in 15-20% of people with CdLS and can start any time in life, often in infancy. They too can be managed with medication.
- Later in life, changes in transitioning from childhood to adulthood can cause behavioural problems but not always. Changes to set routines can also cause issues.
- Children with speech continue to speak but sometimes, behavioural issues later in life mean they may choose not to or need time to process information. We call this "selective mutism" which is behavioural, not physiological. Sometimes unfamiliar company or situations mean they don't want to speak.
- There is no set timescale for changes with age. Puberty is often mildly delayed.
- CdLS cannot be "cured." Abnormal development caused by one of the gene changes occurs prenatally. Most of this is unlikely to be reversed by post natal treatment. Missing digits won't grow back, for example. Some improvement in cognition and behaviour may be possible.
- People with CdLS can have a good quality of life if aspects are managed well. Barring complications, a fairly normal lifespan is possible.

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