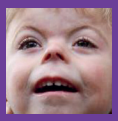
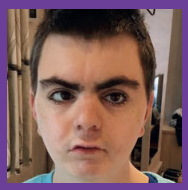
Remember our faces

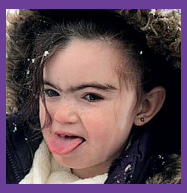



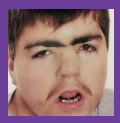













Remember our name

CdLS Foundation
UK & Ireland

www.cdls.org.uk

What is CdLS?

Cornelia de Lange Syndrome, (or CdLS), was named after a Dutch professor of paediatrics who worked in Amsterdam and was the first to identify the syndrome in 1933. There are many aspects of the syndrome. Children with CdLS are small at birth and remain small compared to other children of the same age. They are all slow learners, which varies from mild to severe. Some children can have upper limb abnormalities, from extremely small or malformed hands to complete absence of parts of a limb. They will frequently have problems with feeding and the digestive tract as well as other medical issues. People with CdLS may exhibit behavioural problems, such as anxiety, autism or challenging behaviour, often pain-related. The most striking feature of the syndrome is that all the children can have similar facial features, like brothers and sisters.

It is very difficult to be certain just how common the syndrome is, but it is probably somewhere around one in every 30,000 babies born. The CdLS Foundation is aware of more than 500 children and adults with the syndrome in the UK and Ireland, and more than 4,000 worldwide. Even with the least prevalent estimate, this is still merely skimming the surface.

Who are the CdLS Foundation?

"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."

The Foundation is run entirely by volunteers, plus a part-time Office Administrator. They support those affected by CdLS, their families and carers by providing telephone and email based help and information. They produce booklets and information packs about the syndrome, as well as publishing best practice in diagnosing and managing CdLS - for carers and professionals alike.

The Foundation holds family conferences twice a year where families get to meet each other and talk informally about the condition, learning from the experiences of others. Presentations that focus on specific aspects of the condition are given by doctors and researchers to help guide families and these professionals will hold one to one consultations. As the syndrome is so rare, conferences are often the only chance for families to meet with professionals that know CdLS. These events move around the regions so everybody gets a chance to attend.

The Foundation also produces a magazine, "Reaching Out," published twice a year, featuring stories about research, news from families and articles on issues affecting people with CdLS as well as keeping everyone up to date with the activities of the Foundation.

The CdLS Foundation UK & Ireland is part of the World Federation of CdLS Support Groups. This umbrella organisation brings all of the national support groups for CdLS together, to share latest advice, best practice and updates on new research happening around the globe.

Why an Awareness Day?

The second Saturday in May each year is International CdLS Awareness Day. This day is very important to us in helping to achieve our mission of early diagnosis and the resulting medical and emotional support so vital to the development and health of a child with CdLS. Due to the rarity of the syndrome a diagnosis can often take many years, delaying correct treatment and support for those affected.

By lighting up buildings around the UK in purple, we aim to make public and professionals aware of CdLS, encourage discussion and enable recognition of an extremely rare condition. Even if just one person recognises a child with CdLS and makes the family aware of it, then Awareness Day will have achieved its aims, and the child will get the diagnosis, treatment and support that is so badly needed.

For more information about CdLS and the Foundation, please visit our website or contact us:
www.cdls.org.uk Tel: 01375 376439 E-mail: info@cdls.org.uk

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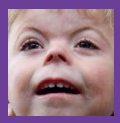









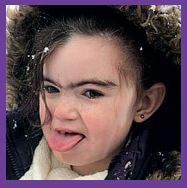


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