

Remember our faces



Remember our name



CdLS Foundation
UK & Ireland

www.cdls.org.uk

About CdLS

Cornelia de Lange Syndrome (CdLS) is a rare genetic disorder affecting between one in 10,000 and one in 30,000 live births.

The condition is caused by a random change in one of at least seven known genes. It is rarely inherited from parents and can affect people from all different races and social backgrounds.

Affected people have multiple disabilities. All people with CdLS have learning difficulties ranging from moderate to profound. Many have physical disabilities that include growth problems, gastrointestinal issues, seizures, cardiac, neurological and behavioural difficulties.

A large proportion of the children born with CdLS have limb defects or missing limbs.

The biggest shock for new parents is that doctors have often never heard of CdLS. It is that rare.

This is where the CdLS Foundation comes in.

About The Foundation

The CdLS Foundation UK & Ireland is part of a World Federation, working to raise awareness of

CdLS within the professions, and providing support for families with an affected person.

Our mission: "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."

We do this by organising conferences around the UK and Ireland, where we bring families to meet experienced doctors from around the world who will share their knowledge. We help professionals to pool information. We bring families together so CdLS people can meet others of a similar age. We support research into the cause and effects of CdLS by working with leading universities. We produce a magazine, information booklets, a website and offer a family support service.

Once families are in touch, they are part of an extended global family that will help to guide them.

But we are small. There are no large grants from central government. Everything we raise is raised

by the families and friends of people affected by CdLS. That's why any help you can give us will make a difference.

By helping us raise funds, you help us achieve our goals. By just recognising the face of a CdLS child and remembering our name, you may help another 'lost' family to get in touch.

We appreciate your support.



CdLS Foundation UK & Ireland

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e: info@cdls.org.uk

w: www.cdls.org.uk (links to Justgiving, MyDonate)

How you can help?

Please make cheques payable to: CdLS Foundation
Send to: CdLS Foundation UK & Ireland, PO Box 8368,
Ripley, Derbyshire, DE5 4DA

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