History and Prevalence of Cornelia de Lange Syndrome

Prevalence

As diagnosis has improved, the number of people with Cornelia de Lange syndrome is much higher than originally thought.

It is estimated that the incidence of Cornelia de Lange syndrome is between 1 in 10,000 - 25,000 live births.

History

Cornelia de Lange syndrome is named after a Dutch paediatrician who described the syndrome in 1933.

The disorder is occasionally referred to as Brachmann de Lange syndrome after a German doctor who is also thought to have described a patient with the syndrome in 1916.

At the top left of this page is the first known photograph of a child with Cornelia de Lange Syndrome – she is one of the two children described by Dr de Lange in her original paper.

Prof Cornelia de Lange

A photograph of Cornelia de Lange can be viewed at the top right of this page.

Cornelia de Lange was a Professor of Paediatrics and in 1933 she described two children with the syndrome. Despite the fact that these two girls were not related, their remarkable facial similarities led both the nursing staff and Cornelia de Lange herself to confuse them as being the same person.

In 1941 having described a third patient with the disorder, she presented an account of the syndrome at a meeting of the Neurological Society of Amsterdam.