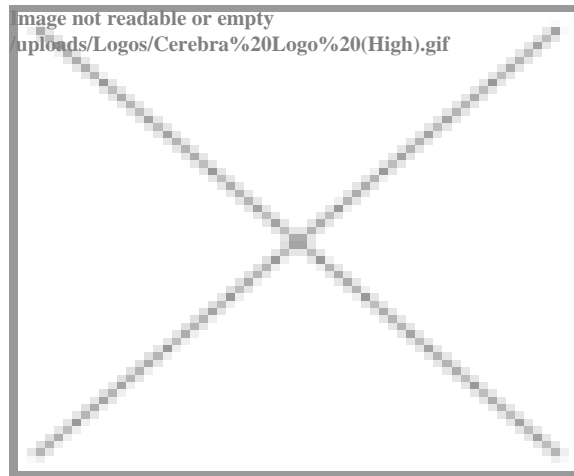


Get Involved - Research Projects

Long term outcomes of individuals with Cornelia de Lange and Cri du Chat syndromes



Funded by Cerebra from 2009 to 2012

Background

There is very little known about how people with genetic syndromes progress and change over time. This follow up study will allow us to better understand how people change as they grow older. The families involved in this study will have been visited 6.5 – 7 years ago by Jo Moss.

Aims

We aim to:

- (i) further our understanding of cognitive, language and behavioural characteristics in individuals with Cornelia de Lange (CdLS) and Cri du Chat (CdCS) syndromes and
- (ii) understand what happens to these cognitive, language and behavioural characteristics as children and adults with Cornelia de Lange and Cri du Chat syndromes develop.

Method

This study is 6.5 – 7 year longitudinal follow up of behavioural, cognitive and physical characteristics in CdLS and CdCS. Each participant will have been assessed as part of a previous study conducted at the University of Birmingham. In this study, we will investigate progress at this 6.5 – 7 year follow up in the areas of autism spectrum symptomatology, cognitive and language ability and adaptive behaviour skills.

Participants

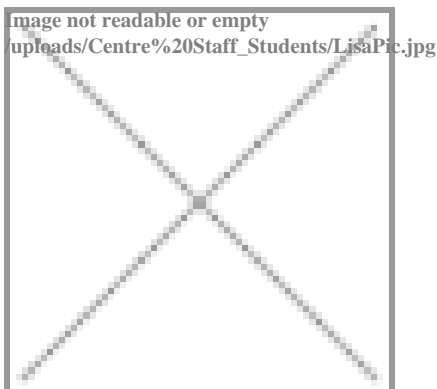
Parents and carers of individuals with CdLS and CdCS and their children/ the person they care for were invited to participate in this study. We invited 34 individuals with CdLS and 23 individuals with CdCS and their carers, who participated in a research study between 2004 and 2005 at the University of Birmingham (Moss et al., 2008) investigating the nature of ASD phenomenology in these syndromes to participate.

Progress to date

Long term outcomes of individuals with Cornelia de Lange and Cri du Chat syndromes received ethical approval from the Nottingham Research Ethics Committee 1 branch of the NHS national research ethics service in 2010. Data collection began in early 2011 and finished in 2012. Data collection involved a visit to the participant's school or home. During the visit, we used a variety of games and activities to assess language, behaviour and cognitive abilities. These visits took place all over the UK. We are currently working on analysis of the information collected during this research project.

Thank you to all the families who were so willing to participate in this study!

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