



Research Update

Improving quality of life for individuals with Lowe syndrome - the behaviours that matter most

Until now there have been no detailed studies of behaviour in Lowe syndrome. At best research studies have used questionnaire measures to describe behaviour, and few researchers have met with individuals with Lowe syndrome to try and learn more about behaviour. This is despite the fact that **8 out of 10 individuals** with Lowe syndrome experience troublesome behaviours such as self injury and temper outbursts during their lives; a far greater number in comparison to individuals with intellectual disability without Lowe syndrome.

These behaviours impact on the quality of life of individuals as they have the potential to interfere with development and the typical day to day activities people enjoy.

Professor Chris Oliver's team at the University of Birmingham is starting a two year project to explore why these behaviours develop so frequently in Lowe syndrome. The study has three stages; firstly a clinical psychologist from the team (Jane Waite) will conduct a telephone interview with families to learn about specific behaviours of concern. This will be followed by a brief questionnaire prior to a full face to face clinical assessment. Families can take part in one stage or all stages depending on their preference.

A behaviour profile for each participant will be created and the team will look for patterns across participants. These patterns will give clues to the causes of behavioural difficulties.

In addition to understanding more about behaviour and its development overtime, each participant's **strengths and weaknesses** will be described. Families will receive an individualised feedback report for their child.

Chris Oliver's team is an experienced team made up of Clinical Psychologists and Research Fellows with knowledge in genetic syndromes. It is important to the team that the assessments are not burdensome for families and that the location of the assessment is flexible. A lot of thought goes in to ensuring that the assessment suits the individual. We would like to make taking part in research as easy as possible for families so if there is anything we can do to help with this please let us know.

Prof Oliver's team are interested in speaking to any families of children and adults with Lowe syndrome. This also includes families of individuals who do not have behavioural difficulties as these families may be the key to understanding the factors that protect against the development of these difficulties. The more families who take part, the more likely the results will be meaningful and helpful to other families in the future. If you would like more details please contact Jane Waite, j.e.waite@bham.ac.uk; 07846394511.



Left: Prof Chris Oliver; Right: Dr Jane Waite