

An update on the study

The National Collaborative Usher Study is now in its final phase. We will be concentrating on disseminating information to the 220 individuals with Usher syndrome who have taken part since 2003. Publication of the overall findings together with analysis of the genetic information continues through 2007 and 2008.

The outcomes from the NCUS will have far-reaching consequences both for the families who took part and for families not yet diagnosed. Our understanding of how Usher impacts on the individual and family; clinically, genetically and psychologically has been greatly enhanced as a result of this collaboration between Sense, the scientists from University College London and the families. Sense would like to thank everyone involved in the NCUS, especially the families for their cooperation and support since 2003.

The steering panel which has guided the work of the NCUS since 2002 met finally in July 2007. Panel members included scientists and research officers from the Institutes of Child Health and Ophthalmology, London, Sense staff, a parent and a person with Usher.

Members of the National Collaborative Usher Study steering panel

- Mr Andrew Webster, Moorfields Eye Hospital
- Dr Maria Bitner, Institute of Child Health
- Nigel Marriott, lay member, Sense Trustee
- Prof Tim Atkinson, lay member
- Prof Linda Luxon, Institute of Child Health
- John Trevelyan, Sense
- Melanie Gonsalves, minute secretary, Sense
- Dr Mazal Cohen, University of Manchester
- Liz Cook, Family Coordinator, Sense
- Dr Nell Rangesh, Institute of Child Health
- Mary Guest, NCUS Project Manager, Sense

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