



The Cleft Collective

Closing the Gap in Cleft Research

A Healing Foundation Initiative



University of
BRISTOL



University of the
West of England

Newsletter from the Bristol Research Team

Summer Issue 2012

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The Cleft Collective is Launched!

Welcome to the first issue of The Cleft Collective newsletter brought to you by the Bristol research team. The Cleft Collective is the world's largest cleft lip and palate research programme. The project is an initiative of the UK charity The Healing Foundation, and is supported entirely by voluntary contributions. Funding will extend over the next 5 years from the 1st of May 2012. This funding will provide the opportunity to conduct a much needed long-term research project for children born with a cleft and their families. The Cleft Gene Bank and Birth Cohort Study based in Bristol

will investigate the genetic and environmental causes of cleft, the best treatments for cleft and the impact of cleft on those

University of Manchester, Central Manchester University Hospitals, NHS Foundation Trust and the University of the West of

England. The Bristol team currently has six members. Recent appointments include Research Associates Martin Persson and Nicola Stock. Martin will also continue to work on the Cleft



The Cleft Collective
Bristol research team

Left to right: Jonathan Sandy, Nichola Rumsey, Martin Persson, Nicola Stock and Laura Milne-Day

affected. The UK Clinical Trials Centre based in Manchester will be responsible for coordinating and supporting cleft research within the NHS. Key partners within The Cleft Collective include the University of Bristol, the

Care UK project until its completion. The Genetic Epidemiologist position has recently been offered, with interviews for the Project Manager taking place later this month.

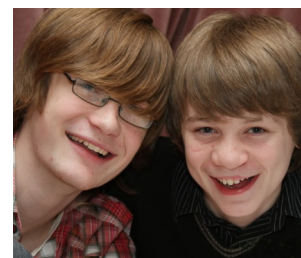


Capturing the Cleft Journey

By engaging with families affected by cleft, the Bristol team has begun to collect photographs in order to create an ongoing Image Bank. The aim is to accurately document the journey in which a family embarks upon when a child is born with a cleft. Many families have already enjoyed contributing to the Image Bank, with

many more fantastic pictures currently being collected. These images are already being used on our website, in conference presentations and in our newsletters. All contributors need to provide written consent and all images are securely stored. We welcome any individuals and families who would like to contribute their pho-

tographs to contact Nicola Stock: Nicola2.Stock@uwe.ac.uk



Spotlight on: Patient and Public Involvement



In collaboration with the Cleft Lip and Palate Association (CLAPA), the Bristol team recently invited individuals and families affected by cleft to attend our first patient and public involvement (PPI) workshop, which took place on the 19th of May 2012 and was held at the M-shed in Bristol. Our key speaker was David Evans from UWE, who advised attendees about how to get involved in research and about what to expect. Other guest speakers included representatives from the

James Lind Alliance, Cleft Talk Online and the Manchester Clinical Trials Unit. The interactive activities generated a positive atmosphere and much constructive feedback was collected. A number of attendees have since expressed their interest in

contributing to future PPI activities. We hope to hold a number of similar events as the project develops.

For more information about PPI, please visit INVOLVE's website: www.invo.org.uk.



The Cleft Collective: Your questions answered

In order to discuss the scientific and pragmatic aspects of The Cleft Collective, the Bristol team are hosting a workshop on the 28th of September, 2012. Nominated representatives from each cleft centre in the U.K will be invited to participate. The workshop will include presentations from each of the key research areas – genetics, psychosocial, speech and 3-D imaging – as well as opportunities to provide feedback and ask questions. The Bristol team aim to disseminate the initial protocols for genetics and psychosocial to each cleft centre in advance of the day. Please direct any enquiries to Jonathan Sandy: Jonathan.Sandy@bristol.ac.uk.



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