



Pre-school Autism Communication Trial Newsletter

Thank you for your continued support and commitment to the PACT study!!

The Pre-school Autism Communication Trial (PACT) is the largest autism study internationally, to date. This study is at the forefront of autism research and is a fantastic opportunity to prove the value of early autism specific intervention which embraces parents as co-therapists. The study involves families in London, Greater Manchester and North-East England and will continue until October 2009. The intervention being tested is an approach to help parents understand and communicate with children with autism. All participants entering the study continue with whatever treatments they are already receiving with half the families receiving the PACT intervention. All families meet with our research associate on three occasions to complete assessments over a 12 month period. The first of these assessments act as a baseline against which we can measure later change. Following the research assessments, all families receive two detailed written reports about their child, one at the beginning of the year and the second at the end. For the duration of the study all families continue to be cared for by their local services as usual.

Study update

The **PACT** study has now randomised 89 participants which means that we are more than half way towards our target of 144. Many thanks go to all our families who have agreed to take part and continue to show support by attending treatment sessions and by attending research assessments with our researchers. Your continued involvement is very much appreciated.

Trial Steering Committee and Data Monitoring and Ethics Committee

Recently, the Data Monitoring and Ethics Committee and the Trial Steering Committee met. These are two committees with members independent of the study and consist of psychiatrists, statisticians, parent representatives and representatives from the National Autistic Society. These two committees oversee the working of the study and ensure that any problems are identified and acted upon. We are pleased to report that both committees returned reports that were positive and supportive – with compliments all round about what is perceived as excellent overall progress to date.



Tony Charman

is the Principal Investigator for the London site. He is Professor of Neurodevelopmental Disorders at University College London. He is an Honorary Clinical

Psychologist at Great Ormond Street Hospital where he works in a diagnostic service for children with complex neurodevelopmental conditions. His main research interest is the investigation of early social cognitive development in children with autism and the clinical application of this work via screening, early intervention and epidemiological studies. He has served on a number of expert panels for the Medical Research Council in the UK and NIH in the USA. He is a scientific member of the Advisory Group to the All Party Parliamentary Group on Autism.

"Give it a Whirl"



Julie Cornell

In January 2006, my husband and I attended a National Autistic Society Help! Course for parents of primary school-age autistic children, my middle son having been given a diagnosis of Autistic Spectrum Disorder the previous year. Subsequently, parents from the course were

contacted by the NAS, seeking a volunteer to sit as a parent representative on the Steering Committee of the Newcastle part of the Pre-school Autism Communication Trial.

It is difficult to explain what motivated me to volunteer. My only previous experience of any kind of research trial was recording whether my boys preferred the brown or white bread of a well known baker, (they liked neither!) My own son's case did not directly reflect the trial, as he was not diagnosed until after starting school and his pre-school communication problems were thought to be solely the result of glue ear.

However, I know how much my son's condition, though comparatively minor, has affected both his own and our family's life and continues to do so, and I very much felt that anything I could do to help other families would be worthwhile. I didn't really have any pre-conceptions of what a meeting would be like. I have attended two committee meetings so far and have found all the other members to be

friendly and welcoming. In truth, the part I play is very minor, occasionally expressing how I would feel as a parent within the trial.

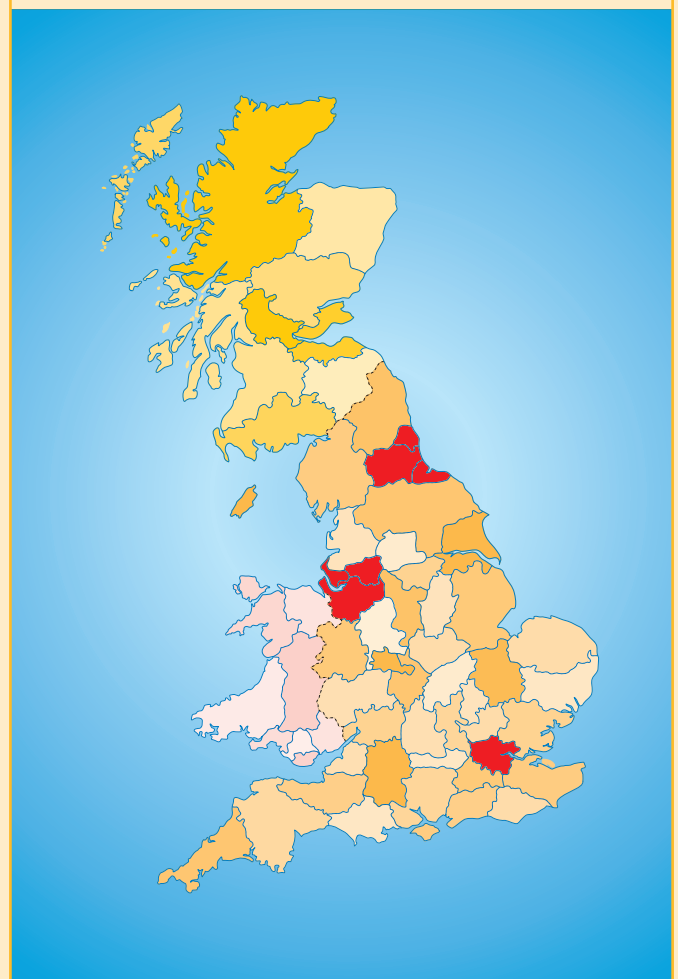
As with any new situation, it is sometimes difficult to understand jargon and in particular acronyms, a glossary of terms would sometimes be helpful. However, I now feel confident to ask if I don't understand something.

I have found the meetings to be extremely interesting and am staggered to realize just how much thought and planning goes into a trial of this kind. It is very easy to read reports in the newspapers without wondering exactly how the information was gathered. I feel reassured to know that trials are so closely scrutinized for their efficacy.

I would urge other parents who are approached to sit on committees to "give it a whirl", there is nothing to be intimidated by and much satisfaction to be gained.

Julie Cornell

Referral Sites across Britain



If at any stage you wish to contact the PACT team please email us at pact@manchester.ac.uk

Further details of the study are available on the PACT website:

<http://www.medicine.manchester.ac.uk/pact/>

You can also contact your local PACT office at:

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If you have any comments on this newsletter or would like to contribute an article please contact the PACT team

