



Pre-school Autism Communication Trial Newsletter

Recruitment Complete ! Study Update



The PACT Team

We hope that you are enjoying your summer. This is the fourth newsletter to you since the study began in 2006 and the first since we closed recruitment to the study. With 152 families taking part across the UK, this makes PACT one of the largest studies undertaken internationally into the treatment of children with autism. We are delighted at the progress of the study and very pleased to be working with all the families taking part.

We will be able to announce the first results from PACT in the autumn next year. There will be a press release from

our main sponsor the Medical Research Council at this time, and publication of the main findings hopefully shortly afterwards. For families, we will be circulating a special edition of this Newsletter; and there will be other routes of communication to the wider community, for instance through the National Autistic Society website. Further information from the study will continue to emerge in the year or two following the trial finishing: the information we have collected is complex and many aspects of it will take time properly to digest. This further information will appear in

publications when appropriate and we will also circulate further Newsletter updates to you all.

We are also beginning to think about follow-up studies. Autism is of course a long term condition and needs long term solutions to its treatment. We are very interested in following up the families in the PACT study to see how they do into middle childhood and also possibly planning tests of additional models of intervention suitable for a later developmental age; but this is subject to us receiving further funding. If we do, we will be planning to contact you all at a later time to enquire whether you would be interested in joining us in these further studies. (Please note however that you are under absolutely no obligation! Participation with us in the PACT study at this time does not imply your later involvement in later studies.)

On behalf of the whole team I wish you and your family all the best and thank you again for your participation in PACT

Professor Jonathan Green.
Chief Investigator

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New data manager/ study co-ordinator



Following the departure of Dharmi Kapadia from the study, we are pleased to welcome Katy Bourne the new data manager/study co-ordinator to the team. Katy will be responsible for the day to day running of the study office. She is also responsible for the data entry and data management.

"Hi my name is Katy and I am the new Study Co-ordinator. I am the most likely person you will reach if you contact the PACT office in Manchester. I am always available to talk to parents if you would like to discuss anything at all. Originally from Crewe, South Cheshire, I moved to Manchester in 2003 to study Psychology at the University of Manchester and have stayed here ever since as I love the liveliness of the city! My hobbies include floristry, baking and cycling and I really enjoy going to new places and meeting new people. I will sometimes assist Kathy Leadbitter in the filming of assessments so look forward to meeting some of you and your children."

Trial manager



Lydia White is responsible for the day to day management of the study, with a leading role in planning, co-ordinating and completing the study. This includes meeting regularly with all members of the study team, funders and members of the Trial Steering Committee and being responsible for ethics, study materials

and finance of the study. With a degree in Economics, Lydia has been involved with trial management for over 10 years. Lydia is enjoying working on the PACT study and the challenges that it throws at her.

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:

**Behavioural and Brain Sciences Unit
Institute of Child Health
30 Guilford Street
London WC1N 1EH
Telephone: 0207 905 2164**

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

IMFAR

Members of the research team recently attended the International Meeting for Autism Research (IMFAR) in London. This is an annual meeting which is an occasion for ASD specialists and their trainees to meet and discuss the latest findings and to stimulate research progress in understanding the nature, causes and treatments for Autism. It is an occasion to promote the training and development of new scientists and is an opportunity for trainees to interact with established ASD researchers.

The importance of keeping it simple!!!

You may remember completing a questionnaire and an interview with us about your child's language and communication, and also the assessment we carried out on your child using the Preschool Language Scales, when we saw you at the clinic. These measures combine to give us a picture of your children's levels both of understanding of language, and of ability to use language and communication skills to express themselves. Now that all 152 families have been recruited to PACT, we are beginning to look at this information which you provided at your initial research assessment, and are pleased to be able to share with you an early finding from what we have been doing together.

In typically-developing children, understanding of language and communication is usually well ahead of expression and we all know that children usually understand a lot more of what is said to them, than they can say themselves. For example, a typical child who can say 50 words, actually probably understands over 200 words. With your help, we have found that more than 60% of young children with autism have a level of understanding which is the same as (rather than ahead of) their level of expressive communication. So a child with autism, who can say 50 words, might only understand those 50 words. Most people assume that when a child speaks at a certain level, s/he actually understands a lot more, and so we think it is really important for anyone working with children with autism (e.g., teachers, key-workers, clinicians) to be aware that most young children with autism do not actually understand more than they can say.

We have recently presented this information at the 7th annual International Meeting for Autism Research held in London in May and plan to present it more widely.

Dr Kristelle Hudry
Research Associate, London



Please don't forget to let the PACT office or your research associate know if you move house