

Sleep Apnoea Research Update

Obstructive Sleep Apnoea in Children with Down Syndrome

July 2014



Firstly we'd like to thank all of you who have helped with the study so far.

Message from Dr Cathy Hill Chief Investigator:

This is an exciting time in our study as we have seen the numbers of children taking part pass the 100 mark! THANKS to all of you who have given your time. We have been bowled over by the enthusiasm of families across the country to help with this research. We have enjoyed meeting you and your children and hope you have all, in different ways, found some benefit from taking part. It may be that we helped your child towards a diagnosis of sleep apnoea, or it may be that we were able to reassure you. Many of you, I know, are simply keen to help us to learn more about this condition.

Whatever your experiences and reasons for taking part we are enormously grateful. We know you have busy lives already full of appointments and demands and that makes your help even more precious.

THANK YOU

SOUTHAMPTON have recruited 58



Southampton 023 8120 4989

Email: Jane.martin@uhs.nhs.uk

LONDON have recruited 29



London 020 7188 7188 ext 53286

Email: ChildrensSleepResearch@gstt.nhs.uk

SHEFFIELD have recruited 28



Sheffield 07425548039

Email: Janine.Reynolds@sch.nhs.uk

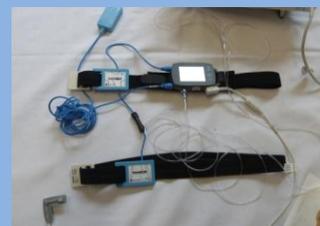
RECRUITMENT

Recruitment so far has been amazing and is on target with a total of 115 children participating over the three sites so far.

The age range & gender of participants is evenly distributed (49% aged 6 months-3 years and 51% aged \geq 3 years)

Recruitment has been by community paediatricians, cardiac clinics, self referral following posters, social media & visiting support groups. News of the study has spread far and wide and the Southampton site is looking to expand into Exeter and the South-West.

Parents are sleep professionals too!



Most children have had successful studies at home. This is an amazing result and a testament to your skill and commitment as parents.

PARENT FEEDBACK

Feedback was positive, participating families expressed willingness to return for similar assessments in the future. Families had little awareness of OSA prior to the study & they valued the new knowledge about their child achieved through the study

'So now after a few weeks we have taken part in the study, he has had an operation and is recovering'

'He has had an amazing level of care'

Jane has been very informative and supportive and we feel that he has had someone on his side'

Participant No. 143

PARTICIPANT NO.316



'He was a little monkey last night it took 45 minutes to go to sleep and then was up at 4.35, but it all went well, Aww send our best to Dr Elphick we love her!'

Having you on mobile access was brilliant.

Participant No. 118

So far so good! She was very hesitant to putting it on. She's a good girl x

PARTICIPANT No.317



FEATURE STORY

PARTICIPANT 119 wrote:

Here goes....

It feels like a life time ago when we were experiencing horrendous sleep issues with our baby. I had an inkling that our daughter was experiencing some form of sleep apnoea and had tried to video her sleeping at night to evidence the fact, in between her waking several times throughout the night! Trying to function with family and work life with very disturbed sleep night after night is torture! Let alone the impact it potentially could have on a baby.

Her Consultant directed us to participate in the sleep study through the Southampton hospital to help identify if this was the case and so we signed up! Initially I was a little overwhelmed by the equipment and although we were given excellent instruction I wondered if I would get it right!

There was nothing to fear and it was incredibly reassuring and helpful to know that Jane our research nurse was available at the end of a phone to advise at anytime! And help she did, I think it was more of a reassurance for us as sleep deprived parents that we weren't making a hash of anything and getting it wrong! No question was too silly and Jane was just so patient and understanding with us.

The small part we played was actually over very quickly within two nights and by the second we gained a perverse sense of humour that our daughter looked like she was set up as a terrorist with the equipment. She was incredibly compliant and uncomplaining each evening which I think helped make the experience a good one!

The equipment and data was collected by a courier and so there was no inconvenience to us and our schedules. The feedback we received via Jane was invaluable and clear for us to understand and has helped enormously towards informing us and working towards rectifying Poppy's mild sleep apnoea, for which as a parent who needs her sleep I am very grateful!

Our first night went well - it's tonight that's the tester - it was so lovely to meet you and I really hope you do well with all the research you are so passionate about - we're lucky and honoured we can play a small part in your hard work.

PARTICIPANT NO. 328

DOWNING STREET RECEPTION 25th March 2014

We were honoured to be asked by our funders, Action Medical Research, to talk about the study at a Downing Street reception. We were one of only four studies presented & Dr Hazel Evans, Southampton principal investigator represented the study and is pictured right.



Dr Hazel Evans showcases study at Downing Street



Fiona Bruce, Samantha Cameron & Davina McCall pose for photo at Downing Street Reception

PHASE 2 NEWS

We are pleased that everyone has been happy to join our research database. This will make it much easier for us to contact you in the future to let you know about the next phase of our research. You may be interested to hear a little bit about what we are planning...When this study is complete we will know how common sleep apnoea is in young children with Down syndrome and what is the best way to test for this. But there is still a lot we don't know! Importantly we are not sure what happens over time. For example, do children who don't have sleep apnoea now develop it later on? Equally do children who have it now improve over time? For those children in our study who have had treatment such as surgery for their tonsils and adenoids, do they get better? Importantly we want to run a treatment study to answer the really important question: 'What can we do to make this condition better'? We are currently working hard to apply for money to run this study. If we are successful we may be able to start the follow-up study towards the end of the 2015. We are really grateful to Francesca and a local PPI representative from the Southampton research patient participation group who has been working with us to help design the next phase - your input is really critical.

Once again on behalf of all the research teams thank you for your participation. Without you this would not have been possible.

Dr Cathy Hill

**CONGRATULATIONS TO THE PARENTS
OF PARTICIPANTS 134 & 140
ON THE BIRTH OF THEIR NEW
BABIES.**



AND FINALLY

The study has really shown us the power of your networks. Many of you have come to us through word of mouth or through online social networks. Do keep spreading the word amongst your friends. We are always happy to hear from you and are still recruiting in centres around the country to the end of 2014.

REMEMBER



Get in touch with your local research centre if you change your contact details

