

## ASD-UK and Dasl<sup>n</sup>e Research Newsletter Winter 2017/18

### Almost 4500 families have now registered with ASD-UK and Dasl<sup>n</sup>e!

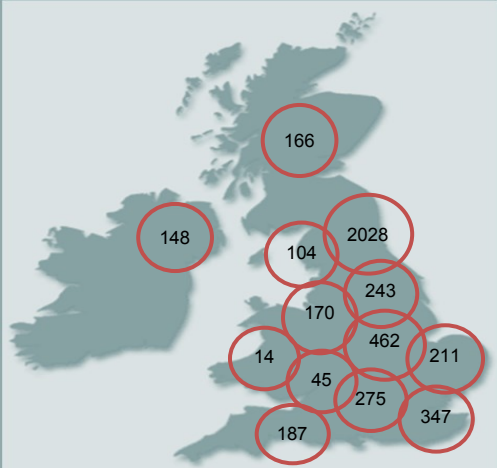
ASD-UK is the national research database of children with ASD across the UK. Dasl<sup>n</sup>e is the research database of children with ASD living in the North East of England. These are two separate but linked databases - families join one or the other, based on their location. We are delighted that almost **4500 families** of children with ASD have the opportunity to take part in research that aims to answer important questions about ASD, and which has the potential to lead to significant advances in the care and treatment of children with ASD.

### ASD-UK and Dasl<sup>n</sup>e Update

⇒ **Around 2400 families** from across the UK have registered and consented to take part in **ASD-UK**

⇒ **Over 2000 families** from Northumberland, Tyne and Wear have registered and consented to take part in **Dasl<sup>n</sup>e**

This map shows you the number of families taking part in ASD-UK and Dasl<sup>n</sup>e in different regions across the UK.



### Autistica Launch the Discover Network

The UK is a world leader in autism research. Yet barriers remain which mean too little progress is being made at too slow a pace. So that more research leads to better lives for all autistic people, Autistica has launched the UK's first national autism research network, Discover. Discover will link autism research centres with autistic people, their families and anyone who is either involved in, or supportive of, autism research. Charities, NHS Trusts, hospitals and care providers will also be able to join and participate. Through the Discover Network, Autistica aim to achieve longer, happier, healthier lives for everyone affected by autism.

Discover will speed up autism research progress and change lives by:

- involving more autistic people in research studies
- focusing research on areas chosen by autistic people and their families
- supporting researchers to work together on bigger and better studies
- helping everyone to understand the impact of research
- ensuring services are evidence-based
- enabling effective campaigning for better Government support

Join Discover at [autistica.org.uk/take-part](http://autistica.org.uk/take-part)

## Studies recruiting participants

### What could help children with eating, drinking and swallowing difficulties?

#### FEEDS: Focus on Early Eating, Drinking and Swallowing review

*Dr Helen Taylor, Dr Lindsay Pennington and Dr Jeremy Parr, Newcastle University*

Children's feeding is a challenge for many families of children with neurodevelopmental difficulties and has a big impact on family life. The National Institute of Health Research (NIHR) is funding a research study to investigate what strategies are offered to parents regarding their children's eating, drinking and swallowing difficulties and how effective these strategies are.



This study will gather information from parents, clinicians, educational staff and young people through group discussions and surveys. The information gathered will help to identify strategies for feeding difficulties that could be explored in future research. The study is being carried out by a research team led by Dr Jeremy Parr and Dr Lindsay Pennington at Newcastle University, together with colleagues from Exeter, Sussex and London.

A parent/carer survey will be sent out through ASD-UK/DaSl<sup>o</sup>e in early 2018. We hope you will be interested in participating!

For more information about the study, please visit:

[research.ncl.ac.uk/neurodisability/ourstudies/feedsreview](http://research.ncl.ac.uk/neurodisability/ourstudies/feedsreview) or email [FEEDS@ncl.ac.uk](mailto:FEEDS@ncl.ac.uk)

### How well does your baby sleep?

#### BabySleep

*Dr Victoria Knowland, University of York*

ASD-UK is supporting Victoria Knowland to recruit infants who are under 2 years old and have an older sibling on the autism spectrum. The purpose of the study is to track the early sleep patterns of children who have an older sibling on the autism spectrum. Many children on the autism spectrum have chronic sleep difficulties, including trouble falling asleep and trouble staying asleep. However, it's not yet known how early those difficult sleep patterns develop, or indeed if sleep is involved somehow in the emergence of symptoms of autism. Working with the siblings of children with diagnoses can be very informative as they have a higher chance of going on to show symptoms, though the majority do not. By measuring changes in sleep patterns over the second year of life, the researchers hope to understand more about how sleep relates to early development.



The researchers will give families a MonBaby button (a commercially available device that clips onto your baby's pyjamas to measure their movement) and ask families to use this for five consecutive nights each month for five months, or as long as they can manage, as well as filling in a short sleep diary. At the start and end of the period of sleep monitoring, or when your infant turns two, the researchers will complete an assessment of your infant's development, which will involve a short play session with them, and ask parents to fill in some questionnaires.



For more information about the study or if you would like to take part, please contact Victoria Knowland ([victoria.knowland@york.ac.uk](mailto:victoria.knowland@york.ac.uk)). **Currently recruiting in Yorkshire, Greater London and the North East.**

## Further studies recruiting participants

### Does your child have communication difficulties?

#### **PACT-G: Paediatric Autism Communication Trial-Generalised**

*Dr Heather Moore and Prof Ann Le Couteur, Newcastle University*

The Paediatric Autism Communication Trial-Generalised (PACT-G) is a research study that will test whether the PACT-G therapy improves social communication in children with autism. PACT-G is running in the North East, North West, and London and will be continuing to recruit until the end of March 2018.



The research team would like to hear from parents of children aged 2-4 years (under 5), who have a formal diagnosis of autism, with limited speech (i.e. no speech up to phrases and simple sentences). English must be spoken in the home. All families who take part will receive comprehensive assessments. To test whether the therapy works, half of children will continue with their usual services, treatments, and interventions, and the other half will receive the PACT-G therapy in addition. This is decided randomly by a computer. Therapy will take place at home and in nursery/school.

If you are interested in learning more, please contact the PACT-G research team ([pact.g@ncl.ac.uk](mailto:pact.g@ncl.ac.uk), 0191 282 5963). **Currently recruiting in Newcastle and the surrounding areas.**

## Summaries of findings: Studies which recruited from ASD-UK and Dasl<sup>n</sup>e

### **Stigma Autism Listening Questionnaire**

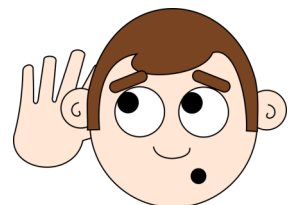
*Dr Chris Papadopoulos, University of Bedfordshire*



With help from ASD-UK, academics at the University of Bedfordshire led by Dr Chris Papadopoulos carried out an online listening exercise survey to explore autism stigma. 198 people participated with the large majority stating they had experienced some form of stigma, with a wide range of detailed examples provided. For example, parents described accounts of their child being unfairly excluded by schools and bullied by peers, wider family members refusing to accept or understand the diagnosis, perceiving "stares and being tutted at" by members of the community, and receiving negative comments about their parenting style.

Autistic adults reported similar themes as well as describing the hurtful, stigmatising language in every day conversations such as "everyone is little autistic." Half of the respondents stated that they tried to cope with stigma by developing thick skins, ignoring the public, or admitted they had no idea how to deal with it. Others stated that consciously recognising that stigma arises from lack of public understanding helped them to cope when encountering negative attitudes towards them.

A wide range of ideas about how we can help tackle autism stigma were described including not hiding a diagnosis, education and, for family carers, having some ready made responses when encountering stigma. Dr Papadopoulos and colleagues are immensely grateful to all that participated and will be using the learning from this exercise to inform the development of a stigma protection intervention. The full results from the study will be published later this year.



## The ASD-UK and Dasl<sup>ne</sup> Team



### Back row, from left

Mrs Alison Mulvenna (Dasl<sup>ne</sup> Co-ordinator)  
Dr Marc Woodbury-Smith  
Dr Faye Wolstenhulme (ASD-UK Programme Administrator)  
Dr Jeremy Parr (ASD-UK/Dasl<sup>ne</sup> Lead)

### Front row, from left

Dr Alex Petrou (ASD-UK Co-ordinator)  
Mrs Ann Payne (ASD-UK Administrator)

## Thank you Helen! Welcome Marc!



After 14 marvellous years as director of Dasl<sup>ne</sup>, Prof Helen McConachie (pictured left) is leaving to take a well deserved retirement. In addition to leading Dasl<sup>ne</sup>, Helen has worked for 38 years in multidisciplinary child health and mental health teams and will be greatly missed by all of her colleagues. Thank you Helen for all of your hard work! We wish you all the best for your retirement. Dr Jeremy Parr (pictured above) is taking over as Dasl<sup>ne</sup> director.



We are delighted that Dr Marc Woodbury-Smith (pictured right) has recently joined the team from McMaster University in Canada. Marc is a clinical senior lecturer and honorary consultant psychiatrist who specialises in autism spectrum disorder. Welcome Marc!

### Joining ASD-UK or Dasl<sup>ne</sup>

If you have not yet had a chance to complete your consent form & questionnaires so you can take part in either ASD-UK or Dasl<sup>ne</sup>, please contact us if you need another pack, or join online at:

**www.asd-uk.com** (for families across the UK)  
or  
**www.daslne.org** (for families in NE England)

If you would prefer not to take part, or receive newsletters, please let us know and we will remove your details from the list of families who have contacted us. If you would like to take part in the future, please do contact us. We would like to hear from you.

### Contact ASD-UK

Institute of Neuroscience  
Henry Wellcome Building  
Newcastle University  
Framlington Place  
Newcastle upon Tyne  
NE2 4HH


**Tel:** 0191 282 5965 **Email:** [asd-uk@ncl.ac.uk](mailto:asd-uk@ncl.ac.uk)

### Contact Dasl<sup>ne</sup>

Institute of Health and Society  
Newcastle University  
Sir James Spence Institute  
Royal Victoria Infirmary  
Newcastle upon Tyne  
NE1 4LP

**Tel:** 0191 282 1400 **Email:** [daslne@ncl.ac.uk](mailto:daslne@ncl.ac.uk)

 Autism Spectrum Database—UK

 @asd\_uk2011 #asduk

 Dasl<sup>ne</sup>



**Moving House? Have you changed your email address recently? Please help us make sure we have the correct contact details for you, otherwise we can't easily get in touch with you about research. Please fill in the form below and send it to us, or email [asd-uk@ncl.ac.uk](mailto:asd-uk@ncl.ac.uk) or [daslne@ncl.ac.uk](mailto:daslne@ncl.ac.uk)**

**Child's Name:** \_\_\_\_\_ **Telephone No:** \_\_\_\_\_

**Address:** \_\_\_\_\_ **Postcode:** \_\_\_\_\_

**Email:** \_\_\_\_\_