What is the BINGO project?

BINGO stands for Brain and Behaviour in Neurodevelopmental Disorders of Genetic Origin.

We are a group of researchers based at the MRC Cognition and Brain Sciences Unit (MRC CBU), University of Cambridge. We are particularly interested in understanding the strengths and difficulties of children with rare genetic conditions, and how different types of genetic conditions influence cognitive abilities and brain function.

Behind the BINGO project – A message from Dr Kate Baker (Lead Investigator)

I started the BINGO project back in 2010. I wanted to follow-on from the amazing work done by Lucy Raymond in the Department of Medical Genetics who discovered lots of new genetic causes of intellectual disability.

For the first five years, the BINGO project was just me. It included a lot of paperwork, setting-up the project and persuading people to give me time and money to carry it out. After a lot of thinking of what the project should focus on, I travelled around the UK to meet participants and families who received these genetic diagnoses. I remember every single visit. Some of them were very emotional and sometimes difficult but I am very grateful for those experiences and the generosity of families who welcomed me into their homes. It was also very exciting, as I started to discover similarities between small groups of participants who shared the same diagnoses. These results led me toward new questions about the links between genetic diagnoses, brain development, cognition, and mental health which I think are fascinating and also really important.

I am extremely lucky that I now have the opportunity to lead a research group and there is a BINGO team – currently there are 10 of us working together! There is a lot of communication and co-ordination involved to make sure we are asking the most important questions and have the most positive impact for participants and families. I am even more confident than I was in 2010 that we need to focus on rare conditions and mental health. More and more families are receiving diagnoses every day. The challenge now is to improve our knowledge of these conditions, so that genetic diagnosis can make a positive difference over the long-term. That is going to take a lot more work...

Some of our previous research activities

In the past, we have designed and developed FarmApp – a gamified tablet-based app that measures everyday learning and memory to better understand the cognitive abilities of children and young people with neurodevelopmental difficulties of genetic origin. We have also explored the range of social, emotional and neurological characteristics of children and young people with a particular focus on SYT1, DDX3X, CACNA1A and STXBP1 genetic conditions.

To find out more about our research, you can read summaries of our findings on the BINGO website! Find specific information about SYT1-associated neurodevelopmental disorder on the BINGO website.

What are we doing now?

Since April 2023, 127 new BINGO families have registered to take part. These families are in the process of completing online questionnaires and an interview, where

we ask about children's medical background, learning, behaviour, and emotions. We also started home-based sessions with children aged 3-7 years old in the UK, where we try out some play-based activities. During these activities, we measure children's heart rate and physical activity to understand more about their feelings.

What families say about their experience?

Why did you decide to take part in BINGO?

"I decided to participate in the BINGO project to educate myself and others about my son's rare genetic disorder. With few papers and research into his specific gene disorder, I want to learn and raise as much awareness as possible." – Chantelle, Zach's mum

"I was excited by the prospect of [genetic conditions] being studied from an angle of behaviour and emotion, since it is something that has never been researched." – Laura, Sarah's mum

How did you find your experience of the BINGO project?

"The team were professional and made myself and Zach feel comfortable. They explained step by step the process and were flexible if Zach was not comfortable with a particular activity." – Chantelle, Zach's mum

"The members of the BINGO team were incredibly friendly, and it was really fun to have them come to our house and play with my daughter. They were also very supportive during the interview if I found it difficult to answer certain questions." – Laura, Sarah's mum

What would you say to families considering taking part in research?

"I would 100% participate in further research. We are really lucky to have these opportunities and the more we participate in research now, the more we can understand for the future." – Chantelle, Zach's mum

"I would recommend any family who would like more support going forwards to take part in the BINGO project. From feeling very isolated and unsupported to having a whole research team wanting to understand my child better was a very positive journey." – Laura, Sarah's mum

How can I take part?

Currently, we are inviting children and adolescents (3–18 years old) with any single gene disorder (a change to a specific gene sequence that alters the gene) to take part. You can take part from anywhere in the world, as long as you have working knowledge of English. Activities that might be offered include (1) online questionnaires and interviews, (2) play-based activities at home, and (3) brain scans either at home or at the MRC CBU in Cambridge (depending on child's age, ability level, and whether you live in the UK).

If you'd like to find out more or have any questions, please get in touch now – we'd love to hear from you! You can visit our website **(www.mrc-cbu.cam.ac.uk/bingo)** and fill in our contact form or contact the BINGO team via email **(bingo@mrc-cbu.cam.ac.uk)**.