



Many people are involved in the Brain Bank for Autism and the precious tissue donated to it supports worldwide research. Here some of the researchers, whose work has been significant in furthering our understanding of autism, explain why they support the brain bank and ask people to consider whether they too would want to support this work through brain donation. So do some of those who are most centrally affected: people with an ASD and their families.

James Cusack



“As an individual with autism and an academic researcher studying autism, one of my central life aims is to further our understanding of autism. By donating my brain when I die, I can leave a lasting legacy, and make a significant contribution that will help contribute to this aim. For these reasons, I wholeheartedly support the Brain Bank for Autism.”

Lorna Wing



“I am happy to give my support to the Brain Bank for Autism. My long experience, first as a parent and later as a clinician and researcher, has shown me that autism is a developmental condition affecting brain function and that its wide spectrum ranges from very severe generalized disabilities up to very high ability. My daughter Suzie, who was diagnosed as having autism at the age of 3 years, died unexpectedly aged 49 years. One consolation for my husband and myself was to donate her brain for research into autism and to pledge to donate our own”.

Lorna is a leading pioneer in clinical practice and research relating to autism. She arranged Suzie’s donation after her death and she has pledged to donate her own brain to the Brain Bank for Autism.

Jean Bradbery



“I have pledged to donate my brain to the Brain Bank for Autism at Oxford University. Having done this, I’m surprised by how much this means to me. All the confusion and difficulties of my life – I wasn’t diagnosed with Asperger’s syndrome until the age of 69 – are now set in a much broader context, the enquiry into what autism is rather than just what it looks like. I feel I am now able to play a constructive part in something very worthwhile, which will go on long after my death. I am now part of the solution, not just part of the problem.

I would encourage anyone concerned to think about making a similar pledge to mine.”

Uta Frith



"To understand how the brain works, looking at the brain under the microscope is just as vital as looking at the brain in a scanner, if not more so. But tissue needs to be collected from kind people who donate their brains after death. This is a noble and generous deed. We need to understand how the brain works to understand autism. Brains are needed for this".

Uta Frith, DBE, FRS, FBA, FmedSci
Emeritus Professor of Cognitive Development
Institute of Cognitive Neuroscience
UCL, London

Michael Rutter



"Brain tissue research continues to be a crucially important element in mainstream science that is seeking to understand the nature of the brain processes underlying autism. My experience is that most families are very positive about this research and are very willing to sign up to contributing the brain of their child with autism if, sadly, he/she dies unexpectedly. It is necessary for professionals to realise that families need to be aware of how to contact the Brain Bank for Autism and that if the topic is tactfully raised, they need not be uneasy about discussing the possibility when the child is still alive."

Professor Sir Michael Rutter
Institute of Psychiatry, London

Sam Lewin



"Sam's passing has left a massive space in all our lives but the comforting thought is that he had a very happy life. It is equally comforting to know he is helping in this very special way for the benefit of this special research. The Oxford team are the world leaders in this field. Many people don't want to think of this happening to them or are maybe against this type of donation for many reasons. We assure you and them that it is a brilliant thing to do."

Mike and Julie Lewin

Simon Baron-Cohen



"The work of the UK Brain Bank for Autism is absolutely vital for scientific progress in understanding this complex set of conditions. We recognise how hard it is for families of someone with autism to think about tissue donation as an intention during their relative's lifetime, let alone at a time of bereavement, and we thank families for thinking of this invaluable and selfless step."

Professor Simon Baron-Cohen, FBA
Autism Research Centre, Cambridge University

Declan Murphy



“The work that BBA does is essential to our understanding the cause(s) of autism, and to identifying new treatment targets. Brain donations are currently the only way that we can directly examine the causes, and consequences, of having autism. I very strongly support this work, and find that when individuals with autism (and/or their families) are approached about this they are very receptive to the idea.”

Declan Murphy

Professor of Psychiatry and Brain Maturation

Head of Department of Forensic and Neurodevelopmental Sciences

Institute of Psychiatry, London

Richard Mills



“Despite our progress in techniques of brain scanning, we still rely on post-mortem studies to provide detailed information on the nature of the brain. For this reason, brain donation is of critical importance as our research is at present significantly hampered by a shortage of autistic and non-autistic brains for study. An understanding of the structures of the brain and how it works is critical to our understanding of the nature of autism and I hope that the importance of this project is recognised and supported by all with an interest in developing a better understanding of autism. That will lead to more appropriate interventions where they are needed.”

Richard Mills

Director of Research, The National Autistic Society

Research Director, Research Autism

Sean



Sean had Asperger’s syndrome and epilepsy. His parents remember: “He was our beautiful boy. He was taken from us at the age of 21, suddenly and without warning. The decision to donate his brain – that magnificent, defining part of him – was not easily made. However, it will always be a comfort to us to think that something exceptionally important may result from the study of our exceptional son. We are so very proud that Sean’s brain will be part of the Brain Bank for Autism. He would have made a difference, had he lived and - through his donation - we are sure he still will.”

Tony Bailey



“I support this programme wholeheartedly. The only way we can study the fine structure of the brain is by direct examination of brain tissue, which is essential to better our understanding of autism. To make progress in this sensitive but important area of clinical research, we depend heavily on the donation of autopsy brain tissue.”

Professor Anthony Bailey

Department of Psychiatry, University of British Columbia

Valentino



Emily Adams says: "I had cared for my grandson Valentino, who had autism, throughout his life and was his next of kin. A few days before he died, I read an article about the new Brain Bank for Autism in the National Autistic Society's Communication magazine and I decided to donate his brain for research into the causes of autism. When a loved one dies, it is the worst time to try to make decisions but this has proved to be my one positive way forward after his death."

Evelyn



Charlotte, her mother, says: "Evelyn, who had Asperger's syndrome, had great courage. After she realised that she had a terminal illness, she did some research on the internet and then she said one day, 'Mum, you may think that this is a terrible idea but, when I die, I want to give my brain to the Brain Bank for Autism at Oxford University.' However, my reaction was, and still is, that it was a wonderful thing to do."

Lorna Hall



"As the sister of someone with autism, it is important to me that I contribute to autism research in any way I can. Donations from close relatives of people with autism are so important. This is why I have made a pledge to donate my brain to the Brain Bank for Autism."

The success of the research done through the brain bank depends on the willingness of just a small proportion of autistic people and their relatives to donate their brain. No-one should feel under pressure to participate in this way. It is also far better to have considered whether donation is a decision that the donor and family want to take, at a time when there is not the pressure of an impending death in the family.

For more information, please visit www.brainbankforautism.org.uk

Or phone 0800 089 0707

Or email Brenda.Nally@ndcn.ox.ac.uk