

Asking people with autism and their families to consider donating brain tissue for research is contentious. Here, **Brenda Nally**, of Autism Speaks, tells us why the charity backs the parent-led post-mortem brain tissue donation programme.

Brain donation

“The causes of autism are not well understood. Although body systems such as the gut may be involved, the behaviours we see are most likely to be driven by the brain, so the brain is a good place to focus research.

Scientists using imaging techniques can see inside the brain of living individuals, showing the ‘big picture’. Examining the fine detail is only possible using post-mortem brain tissue. Early findings need further investigation, but potentially point to new ways of detecting and intervening in autism.

The scarcity of post-mortem brain tissue for scientific study is the major barrier to this research. To address this problem, the Brain Bank for Autism and Related Developmental Research is working, in collaboration with the Autism Tissue Programme in the US, to provide brain material as a resource for bona-fide autism researchers worldwide. Since 1997, the Autism Tissue Programme has received 150 brain donations and supported 75 research projects.

Scientists compare the brains of people with autism with brains from the ‘neurotypical’ population, who also are free of any other neurological or psychiatric condition. Since epilepsy often occurs alongside autism, it is also necessary to study brains from people with epilepsy but no autism. In this way, it is possible to shed light on the underlying biological and structural differences, which are vital to our understanding. For this reason, brain donation is needed from across the whole community.

© www.istockphoto.com/Vasilij



It is important that the autism community takes the lead

Donation of a brain must occur very soon after death and often relies on the next-of-kin giving informed consent. The complex emotions and attitudes aroused, especially when children are being considered as donors, are largely unexplored. Our mission at the Brain Bank for Autism is to open up the debate so families feel able to discuss their views and feelings at a time when they are neither anticipating nor experiencing the loss of a loved family member. Autism is the focus of the research and so it is important that the autism community takes the lead.

The Brain Bank operates with transparency about donation and research outcomes. Some people

already know what they want to do; others want to consider it further or are just interested in knowing more. We always fully inform and support families in making their decisions and, when a donation has been received, we work closely with the family to build a profile (medical, social and educational) of the donor, which allows the fullest interpretation of research findings.

Last word goes to veteran autism clinician, researcher and parent, Lorna Wing. “My long experience has shown me that autism is a developmental condition affecting brain function. We need to understand how the brain works so that we have a clear insight into how best to help and guide our children to ensure they have the highest quality of life possible for them. Our beloved daughter, Susie, diagnosed with autism at the age of three, died unexpectedly two years ago, aged 49 years. My husband and I still mourn her loss. One consolation for us is that we donated her brain for research and are donating ours in our wills.”

The NAS has been part of the steering group discussing the important ethical issues around this research for a number of years. While we are keen that our members are aware of this and other research being undertaken in this area, we also wish to make clear that the NAS does not make any recommendations as to whether our members take part in such research or not.

→ For more information, with no obligation, call 0800 089 0707 (freephone), email info@brainbankforautism.org.uk or visit www.brainbankforautism.org.uk