UK BRAIN BANK *for* AUTISM
& Related Developmental Research

Welcome to the second Brain Bank for Autism Newsletter - September 2011

A note from the Editor

This edition of the newsletter focuses on the partnerships and collaborations that have developed now that the Brain Bank for Autism (BBA) research programme has been put in place. The generosity and altruism of donors and their families has led to 21 brain donations, the very precious basis on which all the research can build.

The fundamental partnership is between the two autism brain banks, in the UK and the US, which enable approved scientists worldwide to have access to this precious tissue in their research. Daniel Lightfoot, the Director of the US Autism Tissue Program, highlights here the value of this partnership in developing the research. Jane Pickett, the US Program's Director of Resources and Data, gives a fascinating account of recent research findings and Steven Chance, who is part of the BBA team at Oxford, explains in this issue how examination of brain tissue in minute detail can lead to further insights into autism. His project will use brain tissue donated in the US.

We have recently arranged with the National Autistic Society (NAS) that information about brain research is now available through its website on: *http://www.autism.org.uk/brainresearch*. This means that many more people will be able to discover the importance of this research to understanding autism. We include an extract on page 5, where you can also find an open letter from Lorna Wing to the current edition of the NAS Communication magazine. Lorna was a founder member of the NAS and she has had a huge influence on the development of understanding autism. Her letter has influenced some NAS members to register their intention to donate their brain to the BBA. Pledges by family members of people with autism and by members of the general population provide control tissue, which is vitally important to the research.

We also publish a letter from Mike and Julie Lewin, which they have sent to Contact a Family. Their discovery by chance of the existence of the brain bank has led to their letter. They want to inform others about their experience so they have an opportunity to think about what they would want to do themselves in similar circumstances.

The recent agreement by the Board of Fragile X Society that their members should be informed about the work of the BBA is another example of collaborative development. Donations by people who had conditions related to autism, such as Fragile X syndrome, are highly important to enable comparative research. We hope that readers will support this effort by letting others know about this field of research, the contribution it can make and how much it depends on brain donation.

Finally, Christine Swabey, Chief Executive of Autistica, which provides the funding for the Brain Bank for Autism, comments on the importance of this partnership.

Brenda Nally
Outreach Coordinator for the BBA

An International Network of Tissue Based Resources in Autism

United Kingdom & United States

By Daniel Lightfoot, Ph.D.

The differences we see among people with autism raise questions about neurological development that can only be answered by the direct study of human brain tissue. Though new state-of-the-art breakthroughs in neuroimaging allow scientists to peer directly into the brain to study structural changes in discrete brain regions, or from a simple blood sample study the complex genetic foundations that may contribute to autism, it is only with brain tissue that scientists can go far beyond the limits of these technologies and study the brain at both a cellular and molecular level. Tissue research allows scientists to explore the genetic contributions that influence cellular changes within the brain, as well as discovering neurological states, otherwise undetectable through other methods of analysis.

For this, the acquisition of biological tissue for study plays a critical role in research efforts that are focused on finding treatments and cures for many diseases and disorders. Studies of neurological conditions, such as autism, require whole human brains obtained post-mortem. Such acquisitions are exceptionally rare and in great demand by researchers. Additionally, the need for large population based studies, repeatable experimentation, and meticulous comparative scientific studies of both autism and unaffected tissue further increase the demand for this rare commodity. Lacking sufficient quantities of post-mortem brain donations from both individuals diagnosed with autism and those unaffected by any neurological disorders, significantly impedes scientific progress and our understanding of the human brain.

Few organizations worldwide have taken up the effort to collect such tissue in support of scientific discovery. In fact, today only two countries globally are actively collecting and sharing post-mortem autism brains for research: the United States and the United Kingdom. Put another way, two countries in the world provide the global supply for scientific research.

A new way of thinking

Historically, tissue acquisitions have been uncoordinated events by both government-supported and private entities, with each acquiring, storing and distributing tissue independently. These collections were diverse, presenting a patchwork of repositories that each operated independently. With such a rare and

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desirable commodity and very few acquisitions per year, there was a great need for a new approach to stewardship.

Just two short years ago, the Autism Tissue Program (ATP), a science program of Autism Speaks, and the Brain Bank for Autism & Related Developmental Research (BBA), supported by Autistica, formed the first international network of tissue banks in support of basic research in autism. The ATP, which houses the world's largest single tissue repository solely dedicated to tissue based resources in autism and the BBA, the UK's only autism brain tissue bank, together provide the bulk of autism brain tissue available worldwide.

By working in partnership, consolidating resources and establishing common methods, these two programs bring continuity to a once fractured field. At the center of this network is a single data resource unparalleled in the field, representing over $0.5 million in capital investment. From this single database, approved researchers worldwide can access all information associated with each bank, explore all scientifically relevant information concerning the brain tissue collections at both banks (medical, genetic, MRI), apply for and track tissue distributions from either bank, and submit experimental results for public sharing of data with peers. This robust digital platform provides a single conduit of entry to the largest pooling of information and resources for tissue based research in autism.

With the success of this international partnership between the US and UK, and the infrastructure now established, the network is currently aiming to expand, adding other banks within North America and Europe. This network is also expanding beyond autism brain tissue in its efforts to create the most biological tissue-based resources in support of autism research. All conditions associated with autism, such as epilepsy and fragile-X syndrome, can provide scientific insight on the underpinning biology influencing neuro-development. The study of how these separate conditions are related and what makes them unique, will provide exceptional insights into how the brain functions and ultimately a broader understanding of each condition.

Significantly, later this year, a unique form of tissue bank will be added to this network - one dedicated to adult stem cells. With the advent of new stem cell technologies, a single skin sample can now be turned into a special type of stem cell termed induced pluripotent cells (iPSC), which can be replicated in mass, creating a near limitless source of tissue for experimental study. These newly created adult stem cells can then be turned into brain cells, enabling scientists in the laboratory to directly study living brain cells! A feat never thought possible just a few years ago. New questions such as how these cells grow, interact and communicate with one another, how target genes affect cell, and many other valuable questions can now be addressed.

The ATP and BBA, with their supporting charitable organizations Autism Speaks US and Autistica, see this network as a key vehicle to scientific discovery in tissue based research in autism and ASD. Through an international approach of scientific collaboration, tissue acquisitions and the creation of non-consumable and replenishable tissue based resources; we hope to facilitate new levels of scientific accomplishment and a better understanding of autism and ASD.

Daniel Lightfoot, Ph.D. is the Director of the Autism Tissue Program in the United States

Jane Pickett, Director of Resources and Data with the US Autism Tissue Program, reports on recent research findings

What is the nature of the cells in the brains of people with autism?

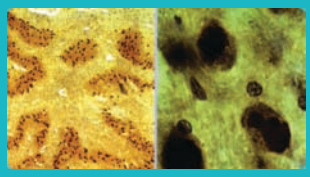
That question dominated the 10th International Meeting for Autism Research (IMFAR, San Diego, May 12-15), the world's largest gathering of researchers and clinicians devoted to a better understanding of autism.

Answers to the question came from a number of researchers exploring post mortem brain tissue in terms of cell number, size, organization, metabolism and genetics. Any of these factors can contribute to the behaviors we observe as autism and can be used to inform and refine treatment and therapeutic strategies.

It might be assumed that these strategies would be new medications but the results of a systematic survey of brain cells of many donors suggest that the brain can be trained to 'behave' differently. An example is a study of the brain region known as the cerebellum, formed during fetal development and maturing through childhood. The brain region is involved in motor coordination as well as language, attention and mental imagery.

Details from the laboratory of Dr. Jerzy Wegiel at the New York Institute for Basic Research show a disorganization of cells in this region that would contribute to an impairment of visual-motor function. The innovative technology and training programmes demonstrated at the conference are aimed at helping children organise their visual and attention systems to engage the brain's remodelling ability (plasticity) to correct faulty cell-to-cell connectivity. That this particular brain area is also connected to the vestibular system would support the use of sensory integration therapies that help to co-ordinate head and trunk movements.

Metabolic abnormalities reported in plasma of children appear to be represented in brain cells, also reported by Dr. Wegiel's group. Secretions of protein in blood called beta-amyloid appear to be related to the severity of autism and aggression in children. Evidence of brain pathology: beta-amyloid fragments stain brown and are shown below in low and hi magnification inside the cells of a brain donor with autism.



Evidence of brain pathology: beta-amyloid fragments stain brown and are shown in low and hi magnification inside the cells of a brain donor with autism.

The amyloid protein is a good example of nature's multi-tasking. It is a large protein that can be cleaved to smaller active fragments that affect the brain's development and function, or fragments that indicate a disease process. The abnormal metabolite in the brain cells may involve a particular enzyme that is distinct from the enzymes which

cleave amyloid into fragments that accumulate outside cells in the Alzheimer brain. Dr. Wegiel also showed the importance of comparing brain cells of donors with autism with known medical disorders and chromosome rearrangements.

Epilepsy is a serious problem and present in 39% of brain donors with autism. Autism and epilepsy are prevalent in a group of individuals with duplication of segments of chromosome 15. These children have a high rate of sudden unexpected death and this lab has found a broader spectrum and severity of developmental alterations, degenerative neuronal changes and glial proliferation and activation. Problems relating to defects of migration and dysplastic changes (clusters of cells which are in the wrong place or are immature and disorganized) are most likely to contribute to the high the prevalence of epilepsy.

Dr. Eric Courchesne, San Diego, CA, talked about new revelations in brain tissue research in a dramatic keynote address. He highlighted how important investigating brain tissue is to understanding the early abnormal growth of the brain after birth. His lab's observations of more neurons in the rapidly growing frontal cortex were followed by a closer examination of the 6 layers of the cortex for their respective chemical markers. These markers are localized in cells although some patches of cortex do not show the expected markers. Advanced image processing, devised by post-doctoral research fellow Rich Stoner, generated a three-dimensional microstructure indicating that the cells are present but are not displaying their unique signature.

Young investigators in this lab and others are benefitting from donated brain tissue resources. Those training in neuropathology are rare today and it was so encouraging to see many enthusiastically engaged. One such investigator, Ryan Smith, working in the Ohio State University lab, applied his genetics background to measure allelic expression of a number of genes related to synapse structure and cell-to-cell signaling in human frontopolar cortex tissue from autistic patients and typically-developed controls. Significant and robust expression differences were observed for 11 genes. For some genes, the responsible genetic factors appear to be rare and only seen in brain samples from autistic patients, suggesting rare mutations producing the autistic phenotype.

A central feature of the IMFAR conference was the presence of the National Database for Autism Research team in the US, which leads the National Institute of Mental Health's effort to federate research results. Explorations of the chemistry, genetics, metabolism and organisation of cells, plus cell-to-cell communication and overall brain structure are being integrated into the national database via the Autism Tissue Program informatics portal (give link).

Organizers of the conference gave special recognition to parent advocates who launched the US Autism Tissue Program and emphasized its ever-growing importance in research. They in turn acknowledged the contribution of the families of brain and tissue donors.

Link to IMFAR giving abstracts and programme;

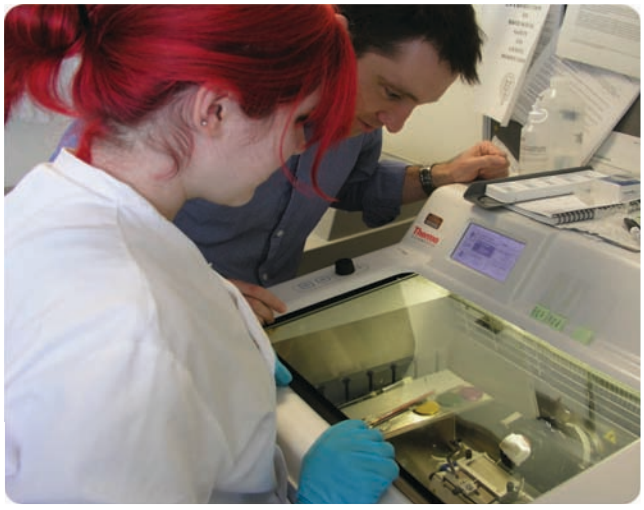
http://www.autism-insar.org/index.php?option=com_content &task= view&id=204&Itemid=172

Attention to detail – the key to understanding autism

By Dr Steven Chance

There is increasing scientific interest in the basis of autism in the brain. Although autism is a spectrum disorder (ASD) in which the severity of symptoms varies widely, a relatively consistent feature is anomalies in social interaction. In Oxford University we have begun a new research project investigating brain anatomy in the parts of the brain that are involved in social behaviour. We are studying post-mortem brain samples from donors who have contributed their tissues to research as part of the new UK Autism Brain Bank and the Thomas Willis Oxford Brain Bank, both based in Oxford. We have also received tissue from the brain collection in the USA, the Autism Tissue Program. The aim of this project is to investigate how anatomical differences in the brain relate to the symptoms of autism. There are several hypotheses to be investigated that make different predictions of altered anatomy.

Just as a geologist can uncover the processes by which the Earth has formed by examining the rocks around us, so we can study the surface layers of brain structure to reveal how it has developed. The brain's surface is formed by the cerebral cortex (the grey matter) where most of the brain cells (neurons) are found. This is where the connections are made that enable us to think. Thus, while geologists study the Earth's crust to infer lessons for the future regarding climate change, we study the cortex of the brain to better understand how altered development occurs and what consequences it may have for the way we think in later life.



Steven Chance working on the project with Rebecca McKavanagh.

Very early in development, brain cells migrate up to the surface of the brain, forming the cortex by stacking up on top of each other in columns. These are described as "minicolumns". Each minicolumn acts as a miniature circuit to process information. When mature, the horizontal spacing between the minicolumns is only about 0.05mm, however the number of these minicolumns and the spacing between them determines the overall size of the brain surface.

It is well known that humans have relatively large brains with a large number of minicolumns and wide spacing between them, allowing for plentiful connections. In autism, it has been suggested that there are more minicolumns than usual, due to an over-production in early development,

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leaving insufficient space between them for connections to form as they do in the typically developing brain. We are investigating the minicolumns in areas of the brain that perform social processing as this appears to be altered in autism leaving insufficient space between them for connections to form as they do in the typically developing brain.

Understanding social behaviour is considered a complex human function and one hypothesis suggests that autism only involves changes in areas of the brain responsible for "higher functions" such as language and social processing, whereas basic senses may be unaffected in autism. One brain area that will be investigated normally contains a high density of "mirror" neurons. These cells are thought to play a role in understanding the behaviour of others and so may be altered in autism. However, people with ASD also demonstrate other behaviours which are not clearly related to the social sphere, such as unusual fascination with certain sounds, smells and tastes. Sensory abnormalities have been reported in over 90% of children with autism. Fascination with certain sounds may be due to changes in the region responsible for simple sound perception or it may involve regions responsible for more complex functions such as the interpretation or "meaning" of sounds. The regions responsible for sound (auditory cortex) and smell perception (olfactory cortex) have not been studied by our techniques in ASD so we will identify whether or not these areas are altered. Sound and smell perceptions develop early so our findings may provide support for simple tests that could be administered to young children to aid diagnosis. Alternatively, the findings may show that pathology is selective to later developing brain regions or only social brain regions. This will determine whether autism is fundamentally a disorder of the social brain.

Yet brain anatomy in autism indicates an abnormal developmental course not just confined to early brain formation. The brain continues to undergo neuroplastic, structural modification throughout the lifespan. In normal ageing we have found that minicolumn thinning occurs, and in Alzheimer's disease the thinning becomes progressively more severe. The minicolumn method allows investigation of ageing changes in autism. Some of the symptoms associated with autism also show fluctuations in later development; for example, vulnerability to seizures appears to increase during adolescence. It has been suggested that the dense packing of cells in minicolumns causes hyperexcitability of the network, contributing to seizure vulnerability. We are investigating whether altered anatomy in olfactory (smell) or auditory (sound) cortex is associated with greater symptom severity or vulnerability to seizures.

Studies of whole brain volume using brain imaging (MRI) have found that there appears to be early overgrowth of the brain in autism, followed by accelerated ageing effects. We are looking for corresponding effects at the small scale where spacing between minicolumns may change in ASD in a manner different from controls through childhood and adolescence. To investigate ageing effects we are studying post-mortem tissue from twenty autistic patients and age-matched controls ranging from 5 to 50 years of age. This demonstrates that donation of tissues from people of all ages can contribute to the research effort.

We are hoping to extend this work in the future by comparing microscopic minicolumn measures with new MRI measures. At the moment MRI technology cannot see brain structure at this very small scale. However, we hope to take the first steps in the development of new MRI techniques for assessing minicolumns which can ultimately be used with living subjects. This would be a major advance, as currently such detailed structure can only be investigated in post mortem tissue, and so it would open up new possibilities for examining microanatomy in both normal development and ASD.

Comment from the BBA Director, Professor Margaret Esiri

The UK Brain Bank for Autism & Related Developmental Research (BBA) is now in its second year and I am very pleased with the progress that has been made. It takes time for a new development like this to take shape and grow

Now, with the generous help of donors, it has acquired an invaluable collection of samples which we are able to make available for research. It is not possible to carry out good, tissue-based, research on only a handful of cases so we have needed to build up more than this before offering the tissue to scientists to use. Now we can make tissue available as our first contribution to a research project – quite a milestone.

Research on the brain in autism is fast gathering pace. Steven Chance writes here about his work, and many other scientists in various parts of the world are all making contributions. The genetic advances of the last 20 years or so have laid the foundation that can now be built on with studies of many parts of the brain.

A major aim is to investigate how the genetic changes detected from blood or saliva samples are influencing brain structure and function.

Surprising though it may seem, much can be learnt from studying brain tissue after death. Because the brain is so complex it will take much work to determine what changes there are in different areas and the possible influence these may have in creating difficulties that people on the autism spectrum experience. The resulting knowledge should enable us to deliver improved ways to assist with dealing with these problems. We also lack understanding of changes that occur in typical brain development. By comparing brains from people on the autism spectrum with those of normal subjects we can expect to gain enlightenment about both.

Brain imaging in life has also made much progress and taught us about brain changes there are in autism. To assist in understanding those changes we are carrying out a pilot investigation with Karla Miller in Oxford and Derek Jones, an imaging expert in Cardiff, to examine images of the brain taken after death. In this way we eventually hope to be able to link up imaging changes with microscopic structural changes and thus enhance understanding of what the images are able to tell us in life.

Daniel Lightfoot's article in this edition shows how the US Autism Tissue Program collaborates with the BBA to distribute tissue to the most scientifically deserving researchers. He explains just how pioneering the US and UK autism brain banks are and how they are helping to advance understanding of this developmental condition. None of this work could be done without the generous support of those who donate tissue for research and we are enormously grateful to them.

Lorna Wing's letter in the current edition of 'Communication', the magazine of the National Autistic Society, is reprinted below.

Brain research: a personal view

In September 2005, my husband John and I lost our daughter Susan. She was 49 years old and had been diagnosed as having autism at the age of three. We wanted her brain to be donated for research and arranged for its safekeeping by scientists, until it could be used in this way. It is now in the care of the Brain Bank for Autism and Related Developmental Research at Oxford University.

In April this year, John died. He pledged to donate his brain to research in his will. I have done the same. I will always miss and mourn Susan and John, but I will always be glad that their gifts and mine may benefit others.

I believe that it is only through research on the brain – with brain imaging and electroencephalograms that record electrical activity in the brain – in life, or post-mortem examinations after death – that we can develop understanding of the neurology underlying any aspect of human life. Autism is particularly complicated. The whole spectrum includes people of all levels of cognitive ability from those who are profoundly disabled up to those of 'genius' level.

The aim of brain research is to identify the causes of the specific disabilities affecting social interaction, social communication and social imagination in all cases, and other aspects of cognitive and motor skills in many. It will also shed light on the special positive skills. These may be shown in, for example, remarkable memory, mathematical ability, visuospatial skills and musical talent.

Some people may have remarkable vocabularies, even if other aspects of language are not so good.

I hope that everyone involved – people with autism, their families and professionals – can appreciate how research into brains, in life and in death, might lead to ways of encouraging positive skills, as well as ways of overcoming disabilities. Those of us, like me, who are happy to donate their brains for post-mortem research, are making a positive contribution. I do understand that some may have emotional objections to this type of research but hope that what I have written does help you to understand my point of view. There is certainly no pressure to donate on anyonewho feels uncomfortable about doing so, but the main barrier to developing understanding of autism through this research is the lack of donated brain tissue. So I hope that everyone in the autism community will give this issue their consideration. **Dr Lorna Wing**

For more information, call free on 0800 089 0707, email brenda.nally@clneuro.ox.ac.uk or visit www.brainbankforautism.org.uk or write to The UK Brain Bank for Autism & Related Developmental Research, Neuropathology Department, Oxford University, Level 1, West Wing, John Radcliffe Hospital, Oxford OX3 9DU.

Lorna Wing has had a seminal influence on the understanding of autism and a long association with the NAS. She was a founder member and, although officially retired, Dr Wing continues to act as Consultant to the NAS Lorna Wing Centre for Autism.

National Autistic Society Information Sheet

The National Autistic Society has published an information sheet about brain research which is published on their website.

Following is an excerpt from the document.

Why study the brain?

Finding out how the brain works is extremely difficult as the brain is so complex. Brain research is important as it helps us understand how the average brain functions and what we can do when things go wrong (for example, after a head injury).

Understanding how the brain works in different people is important, too. Many features of ASD - such as difficulties with social interaction, the use and understanding of language, or repetitive behaviours - are a result of how the brain is structured, and how it works. If we find out more about brain structure and function, we will better understand the difficulties faced by people with an ASD - but also their strengths. We will also be able to develop better support and treatments.

Post-mortem brain study

Brain imaging and MEG and EEG research have greatly increased our understanding of the subtle differences in the brains of people with an ASD. However, they can't tell us everything. We can't see individual brain cells or very small, but important, molecular structures or fully understand the effects genetic differences have on brain tissue.

The only way to study brain cells and molecular structure is to examine the brain after death. It was post-mortem studies that showed how a brain chemical called dopamine was reduced in people who had Parkinson's disease. This led to the development of quite an effective treatment to replace lost dopamine.

To read more about brain research on the NAS website go to: *http://www.autism.org.uk/brainresearch*,

The National Autistic Society

In this letter, Mike and Julie Lewin describe how earlier this year after the sad death of their son, Sam, they decided to consent to his donation to the BBA. They discovered by chance, when he died, that the BBA had been established at Oxford University and that Sam's donation would be of immense value in its work. They want to inform others about their experience so they have an opportunity to think about what they would want to do themselves in similar circumstances.

Until quite recently we were the parents of Sam, an adult with autism. Sam died back in February this year at the age of 22yrs. He is sadly missed by his family and by the staff and residents at Peldon, the residential home he lived at, near Colchester.

We are always keen to support the tissue donation service (donor card system) and wanted Sam's passing to mean something. With that in mind we asked that, as soon as possible after his death, he should be seen as a multiple donor. The very supportive staff from Peldon and Autism Anglia head office asked us if we had heard of the Oxford Brain Bank. We hadn't and were then told of their work in the field of research into autism and epilepsy.

We instantly thought this to be a fantastic opportunity for Sam to contribute towards this research and quickly gave our permission for the Oxford team to proceed. We have been supported throughout by the team, who have kept us fully informed of their work and how donations such as Sam's would benefit their research.

Sam's passing has left a massive space in all our lives but the comforting thought is that he had a very happy life at home, at Peldon recently and other schools prior to that. 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
Peterborough.

Christine Swabey is the new Chief Executive of Autistica, the charity which funds the work of the Brain Bank for Autism. She comments:

"Autistica was founded six years ago by Dame Stephanie Shirley, who recognised that despite the growth in direct services for people with autism over the past 50 years, there was no one organisation devoted to establishing the cause and true nature of this complex disability. We are now the leading charitable funder exclusively focused on supporting research into the causes of autism, with a view to making diagnosis easier, more accurate and supporting the development of treatments and interventions that will enable individuals with autism to lead more fulfilled and productive lives.

We are really proud to be funding the Brain Bank for Autism at Oxford University. I was privileged to visit the Brain Bank just recently with some colleagues from Autistica. We met with the team who are responsible for everything, from working with families who are interested in brain donation, to preparing brain tissue for research and storing all the material, so that scientists of the future can access this precious resource as required and as scientific knowledge progresses.

My overwhelming impression was of a highly professional team who were absolutely focussed on delivering an excellent service, so that all those who so generously consider brain donation can be sure that their contribution is valued and respected. This is such an exciting and productive area of research and one that we believe will make a real difference to fulfilling our aims and ambitions over the coming years.

We at Autistica, share many of the same hopes and aspirations as the BBA and hope to develop our collaborative relationship in the future. Raising awareness of the need for more research into autism is central to Autistica's future plans. Medical research is costly, but with 1 in a 100 people now thought to be effected, so is the impact on society and most importantly on individuals. We talk to so many families with whom we are very keen to engage, both to share new knowledge as our understanding progresses and to make sure their voices are heard when setting research priorities.

Of course we can only support this type of vital research because of the generosity of our supporters. There are many ways to get involved with Autistica and we'd love to hear about your ideas for raising funds as well as feedback about the work we do. Please take a moment to visit our website and get in touch with us. ***www.autistica.org.uk*** *Together we can all make a real difference and with the accelerating pace of discovery the time for action is now".*

autistica
Science in the Service of Autism

Some tributes by their family to those who have donated to the Brain Bank for Autism

Evelyn

Evelyn, who died when she was aged 44, had Asperger's syndrome. Her mother, Charlotte, writes:

"Evelyn had great courage. After she realised that she had a terminal illness, she did some research on the internet and 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 that it was a wonderful thing to do.

Since then, I've supported her in carrying out her decision in every way I can. She felt that making this donation gave her life more purpose and she died with such grace and dignity, knowing that her gift could help future generations."

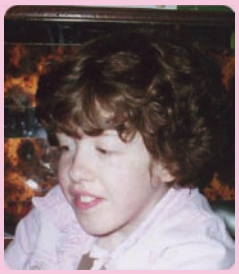
Valentino

"My grandson Valentino (or 'Duke' as he was known within the family), had autism and sadly he died in September 2008.

I have cared for him throughout his life and was his next of kin. At the time of his death, I read an article about the new Brain Bank for Autism in the National Autistic Society's Communication magazine and I decided to donate Duke's 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. For me, he shone as a lovely cherished human being and I have been devastated to lose him. But I believe that my donation, and the others which are made, will provide hope that in future years there will be a much better understanding of autism and of children like Duke."

Emily Adams

Alice



Alice, who died aged 13, had a rare chromosomal disorder and autism.

Her donation was the first to be made to the Brain Bank for Autism & Related Developmental Research when it was set up at Oxford University. During her short life her parents always tried, in whatever way they could, to help her to have as good a quality of life as possible. At the time of her death, her parents said that, although they had lost their beloved Alice, they found some consolation in being able to help others by donating brain tissue to further research into autism and related conditions.

Four years after her death, Alice's mother now adds, *"It may help others who are considering brain donation to know that, for us, it was very positive, at a time of tragedy in our lives, to be able to make this contribution to scientific research. As our lives have moved on, we look back on the decision we made then as clearly the right one."*

Sean

"Our son Sean was, and always will be, our beautiful boy. He was taken from us at the age of 21, suddenly, without any warning.

He was in the final year of his aerospace engineering degree but had already been accepted onto the Masters' course. He learned to read at the age of three - or should I say he started reading at the age of three because he never really 'learned'. One day he just knew how to do it. That's how it was with him - his brain was like a sponge - he absorbed anything and everything. He was witty and wise. Those who were lucky enough to be his friend were blessed to have someone they could always rely upon.

The decision to donate his brain - that magnificent, defining part of him - was not easily made. It is not the discussion you have with a healthy young man. 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."

To learn more about how you can help and for further information:

Brain Bank for Autism & Related Developmental Research (BBA): *http://www.brainbankforautism.org.uk*

Autism Tissue Program (ATP): *http://www.autismtissueprogram.org*

The Brain Bank for Autism & Related Developmental Research
Neuropathology Department
Level 1, West Wing, John Radcliffe Hospital
Headley Way, Headington
Oxford OX3 9DU

Tel: 08900 608 205

Helpline: 0800 089 0707

http://www.brainbankforautism.org.uk