



Summer Newsletter 2010

auti?tica

Science in the Service of Autism

**Four men. Four challenges.
One cause.**



Research Focus

'A giant leap forward' in genetic research

Brain Bank for Autism





Welcome to our summer newsletter.

Since we were last in touch, Autistica has been busy supporting exciting UK projects as well as an international collaboration which you can read about in this newsletter.

By the first quarter of this year, Autistica had distributed £0.5m in grants to both new pilot

projects (which were successful last year in our first Call for Proposals), as well as ongoing research projects. One of our funded initiatives, the Brain Bank for Autism and Related Developmental Research is featured in this issue.

It is important for us to stress that none of what we do would be possible without the generosity and dedication of our supporters, who have helped us fund a total of £2.5m in autism projects since our inception, enabling research to accelerate in the UK over the last five years.

Four supporters, Dan Hill, Bernard Abrahamsen, Richard Tucker and Graham White have undertaken a wide range of challenges in support of Autistica and who are featured on here. Everyone at Autistica is in awe of their grit and determination to raise awareness and funds for autism research.

We first met Dan, Bernard and Graham when they chose to run a half marathon for us. The half marathon is certainly a challenge but one that many can achieve with training. The Royal London Half Marathon - a favourite of ours - takes place in the autumn and, because this is such a beautiful and feel-good event, we have increased our number of places. So why not register and be a part of our team - there's still time to train!

I would like to take this opportunity to thank you for the support you have shown Autistica. You might not know that our running costs are funded by the Shirley Foundation, which means that virtually all your donation goes towards important autism research. We are reliant upon the support of individuals, groups, companies, schools and trusts to help us raise income so that we can continue to honour our funding commitments. If you feel you can help us by making a donation, or running for us, by putting on an event or asking your company to support us, we would love to hear from you. You can find our donation form and contact details on the back page.

With best wishes,

Philippa Stannard
Editor

About Autistica

Autistica funds research that investigates better diagnosis, effective treatments and the causes of autism, with the objective of seeking a better quality of life for people living with autism and their families.

Autistica believes that it is the right of everyone affected by autism to have their condition understood, so that adequate and earliest possible care and treatment can be provided. But we cannot truly understand autism if we know only what it looks like, rather than what it is.



Autistica receives partner status with the National Institute of Health Research – the research arm of the NHS

Autistica has received partner status with the National Institute of Health Research, for our funded pilot grants. This will allow the researchers of these grants access to other forms of research support from the NHS that would not otherwise be available.

In order to gain inclusion on the NIHR, Autistica has met eligibility criteria, which includes being of clear value to the NHS. This status is an endorsement of Autistica's research and peer review processes.

Upcoming Events

Lunch at Cliveden House

Tuesday 6th July with Ken Bruce



Celebrated BBC Broadcaster KEN BRUCE will be talking about life with his son who has autism at this year's fundraising lunch. You are invited to join us once again at Cliveden, the historic and sumptuous house set in 400 acres of stunning grounds near Maidenhead.

The day will start with a sparkling champagne reception on the Terrace - before adjourning to the French Dining Room for a delicious summer day luncheon, accompanied by fine wines and good conversation. A raffle of surprise gifts and an auction of delights will follow. A tour of the house and grounds can then be arranged for those who would like a walk, otherwise guests are welcome to relax and simply enjoy the ambience.

Please get in touch with Lynn to secure your ticket on 01491 411569 or at lynn.hart@autistica.org.uk



Fun Day for families of autistic and special needs children Sunday 11 July - Camp Mohawk, Wargrave, Berkshire RG10 8PU

Sensory room, swimming, face painting, tombola, soft play, bouncy castle, BBQ and lots lots more.

11am - 3pm, entry fee £2 per person (under 5s free).

For more details contact kirsty.m.t@hotmail.co.uk or telephone 07731 194230

Thank you Loekie!



'For several years I have organised a garden party for various charities. However, when my grandson Harvey was diagnosed with autism at the age of two I decided that Autistica needed publicity and support. Harvey is almost 6 now and this is the 3rd Garden Party we have held for this worthwhile charity.

For the first time Harvey was present at the party, together with his parents Janine and Nick and 2 year old sister Bea. He soon discovered the joys of throwing stones (the bigger the better!) in the pond and loved the straw hat he found at the bric-a-brac stall.

I get a lot of support from friends and family and they all help man the various stalls with cakes, crafts, plants, books and bric-a-brac. The Ploughman's lunches are hugely popular as are the cream teas in the afternoon. Like last year, Elise, my 9 year-old next door neighbour, made dried flower bookmarks and this time raised £20! A handmade patchwork quilt, made by four friends and myself, was raffled and raised about £260!! So we shall soon start stitching again for next year. I hope that my experiences will inspire others. Please contact me if you need any tips! And I almost forget to mention that we made £1110.00!'

Loekie Wigmore

Royal Parks Half Marathon

Sunday 10 October



This is our third year at the Royal Parks Half Marathon and our biggest event in the calendar this year! A superb run, it is all on the flat, through the leafy autumnal parks of London. Because of its popularity, we have more places than ever before and they are already getting snapped up!

Register online today

http://www.autistica.org.uk/runs/royal_parks_10.php.
Alternatively, contact Lynn Hart on 01491 411569 or at lynn.hart@autistica.org.uk

£39 entry fee and minimum sponsorship is £325.

Four men. Four challenges. One cause



Dan Hill

56 mile Comrades Ultra Marathon, South Africa, May

My son Ollie was diagnosed with autism in 2007 aged just 2yrs old. He is making enormous strides forward through the intervention Applied Behavioural Analysis. My wife Caroline and I are immeasurably proud of his achievements and are amazed every day by the new and incredible things he can do. Autism is a behavioural disorder that is widely talked about, misunderstood and quickly brushed aside. Its can cause great suffering to those affected, individuals and families alike.

The emotional burden often overwhelming, autism's costs to society and the economy are astronomical and the funding for research into the causes and treatments are minimal. I cannot recall exactly when, but in the last few years I had heard of the Comrades ultra-marathon that takes place every year in South Africa between Pietermaritzburg and Durban and last year, I decided that this would be my challenge for 2010. I was hoping to finish in under the 12 hours permitted and...I can tell you I did it in under 10.5 hours, coming 6470th out of 23,500 – although only 14,000 finished. My wife tells me that I ran 10 miles for 30 mins over mountains which had to be seen to be believed!

I completely under-estimated the severity of the enormous mountain range I had to cross. I am utterly, utterly finished!!!! I would like to send out a huge thank you to everyone without whose support I would have never made it. Especially my amazing wife who has to put up with my stress!!!

Bernard Abrahamsen

Five challenges. One summer!

This summer I have entered five events to raise money for Autistica. It is a charity very close to my heart as it funds research into the causes of Autism.

The first event was the King of the Downs, a tough cycle race of 115 miles with 9000 feet of ascending in warm conditions. After an 8 hour and 34 minute ordeal, I felt like my sponsors had already got value for money! The second event was the Windsor Triathlon (1.5km swim, 42km bike and 10km run) which I completed in 2 hours 39 minutes and 56 seconds - which I am very pleased about, after being concussed after a bike accident the week before!

Just 12 days after Windsor, I will be heading off to Paris in the 550km London to Paris bike ride, followed by the Vitruvian Triathlon (1.9km swim, 85km bike and 21km run) in September. I will complete my summer challenge with the Royal Parks Half Marathon, running with a number of other fund raisers for Autistica.

The total distance covered by my 5 challenges will be 910.4 km and I am hoping to raise £7,000 for this worthy cause.



Graham White

The Three Peaks Challenge, May

Basically the Three Peaks challenge is the hardest challenge I have ever undertaken and made the London Marathon seem like a jog in the park.

We started to climb Ben Nevis at 7-00am and I did not expect to be standing in a blizzard at the top in May! At 12-00pm we were back in the minibus heading for Scafell which we began to climb at 6-30pm I would like to say the scenery from the top was wonderful but I couldn't see a thing! By 12-00 midnight we were back in the minibus and

heading for Snowdon which we started to climb 5 hours later. I have never been so tired, as when I was climbing Snowdon and the relief of reaching the top was unbelievable.

If anyone wants to push their body to the extreme with a mixture of physical effort and sleep deprivation then this is the challenge for you!!

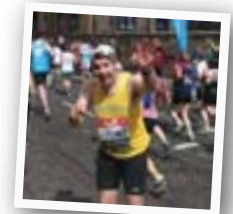
Richard Tucker

The Virgin London Marathon, April

Autism is a subject I really care about. People with autism can have substantial difficulties with communication, relationship building and understanding the world around them. It affects half a million people in the UK. I have two fantastic children. My son who is ten has high functioning autism. He is a lovely, friendly boy who enjoys basketball, Tang Soo Do and playing the keyboard. I feel very blessed to have two wonderful kids. However we have needed a lot of help along the way. With this in mind I chose to run for Autistica.

I ran the marathon in 5 hours 17 minutes and 6 seconds - a new "Personal Best" and I really enjoyed the experience. The atmosphere was fantastic - there was lots of music and incredibly enthusiastic crowds. I began by running an 11 minute mile, which seemed ok but got very tired. But I got through it and....bring on the next one!

Massive thanks to everyone who has supported me through this with sponsorship and encouragement. It has really helped.



And saying thank you...

The 3 Peaks Challenge

In May, nine walkers climbed the three highest peaks in Scotland, England and Wales over two gruelling days. Starting with Ben Nevis before heading south for Scafell Pike, they finished at Snowdon.

We are immensely grateful to the SpecSavers Team in Wembley and Graham White for taking part in this challenge, for all the preparation that this entailed and for raising over £4,500 between them. This is a fantastic achievement. If you would like to take part next year, please do get in touch with us. Graham's account is featured on the previous page.

Charity Clay Shoot

The Royal Berkshire Shooting School
Friday 11 June



This was our 4th charity clay shoot and we were delighted that NBC Universal International offered to sponsor the event. Just under 100 attendees – many from the world of TV and media – were in attendance for what was our most successful shoot ever.

A new award for the NBC Best Beginner was won by William Campbell and Top Gun was, once again, won by Phil Blakeway. A fabulous auction included a 5 night stay at the Jamaica Inn in Jamaica, a day's sailing with Dean Richards and a private film screening in London. We are delighted that the day raised nearly £45,000 and want to thank everyone for their support, particularly NBC Universal International.

Walk for Autism Research

The Alnwick Garden, Northumberland
Sunday 13th June



Once again Autistica returned to Northumberland to join our friends in the North East at The Alnwick Garden. Nearly 300 people came and enjoyed their walks, as well as live music, the Gang from H2O Northumbrian Water and an unexpected performance from The Heaton Voices choir! Kirsty Rhodes ran a highly successful Tombola and Taffy Thomas, Laureate Storyteller MBE delighted everyone with his stories in The Roost at the Treehouse. Our thanks to everyone who helped and supported us, all the walkers and a special thank you to Barry and Brenda Taylor our volunteers on Registration.



Cycling events

June was a busy month! This year we decided to get involved with two cycling challenges, the popular four day London to Paris Bike Ride and the novel London Nightrider – an overnight midsummer 100km ride in London! Sincere thanks go to our five cyclists – Fiona Wilson, Bernard Abrahamsen, Chris Gardner, Rob Ward, Eugene Doherty and Duncan Annett.

If you would like to participate in cycling challenges next year, please contact **Philippa on 01189 016876 or at philippa.stannard@autistica.org.uk**.

Research Focus

A giant leap forward for genetic research

Researchers around the world are welcoming what has been described as 'a giant leap forward' in the quest to solve one of medicine's most puzzling questions: what causes autism?

An international team of medical researchers has revealed in the authoritative journal 'Nature' that they are now much closer than before to understanding the genetic mechanisms which underlie autism spectrum disorders (ASDs).

The Autism Genome Project (AGP) which brings together scientists from across the world reports that 'losses and duplications of whole chunks of DNA in an individual are likely to play a role in ASDs'. They found that people with autism had on average 19 percent more 'copy number variants' than the norm.

Earlier research had established that genes play a major role in autism. The latest findings - Phase 2 of the seven year old project - go further in showing how autism appears to result from a combination of genetic variations in the individual.

The latest findings also strongly suggest a link between autism and other developmental disorders such as learning disability and perhaps epilepsy and schizophrenia.



Dr Jenny Longmore, Research Director of Autistica, one the project's funders, said: 'It is a giant leap because it adds to existing knowledge and also verifies and consolidates what was previously known. It pulls together the new and previous findings on genetic variation and make sense of what they actual mean - with the upshot that the genetic variations fall into a number of distinctive biological pathways / mechanisms. Altogether this creates a very strong reliable platform for further work, specifically to figure out what the genetic variations do to these pathways and secondly, provides a roadmap towards a better understanding of the development of improved methods for diagnosis and design of new interventions.'

The British contribution to the project has been led by the Wellcome Trust Centre for Human Genetics at Oxford headed by Professor Tony Monaco.

Professor Monaco emphasised the potential benefits of the research in identifying at an earlier age children at risk for autism.

He also said: 'Just knowing about these genetic changes can help families come to terms with their child's autism.'

Mentor Based Fellowships



Autistica, in collaboration with the Prince Salman Center for Disability Research - PSCDR (Riyadh, Saudi Arabia) are delighted to announce a Call for Mentor Based Fellowships. Both Autistica and the PSCDR recognise the need to create training opportunities for young scientists at an early stage of their careers, in order to nurture and develop expertise and knowledge in the field of autism research. The Mentor Based Fellowship programme will identify mentors (UK based) who can provide strong professional guidance and research opportunities for young talented researchers holding Saudi nationality and thereby support early career development, foster the next generation of autism experts and strengthen the international research links between the UK and Saudi Arabia.

Donate to Autistica

There are several ways you can give to Autistica. Our running costs are funded by the Shirley Foundation so you can rest assured that anything you can donate will go directly to help pay for the essential research into the causes of autism.

Please visit our website to see how you can give to Autistica. www.autistica.org.uk/donate

In 2009, Autistica funded the establishment of The Brain Bank for Autism and Other Developmental Research. Here, the Director Professor Margaret Esiri explains what we can expect to learn from studies made possible by this vital resource.



The Brain Bank for Autism and Related Developmental Research

Recent research on living people with autism or Asperger's Syndrome has provided much information about the biological basis of these conditions. Two approaches, the study of DNA and the study of structural and functional brain scans – or imaging - have been particularly revealing.

However, what is not possible in living people is the direct study of brain tissue – the cells and molecules that actually constitute the brain, since the brain is far too vital an organ to be sampled in its living state. It is perhaps surprising, but nevertheless true, there is a great deal that can be learnt about the cells and molecules of the brain, after someone has died, when their brain is no longer of use to them.

The brain bank is a carefully preserved collection of brain samples removed from someone who has recently died (with full consent of that person, recorded while they were alive if they were capable, or by their next-of-kin.) It is of course the case that the brain bank needs samples from people who were unaffected by autism as well as those that were, so that comparisons between the two types of samples can be made.

Genetics and brain tissue

The DNA that is present in almost all cells in your body is the same. Large scale studies of DNA of people with autism has shown some variations in certain genes that influence the way nerve cells connect with one another at the points where communication between them takes place by chemical means (synapses). If we wish to understand exactly what influence these genes have on nerve cell communication we need to examine brain tissue microscopically, chemically and using genetic techniques.

But there are many people with autism who do not have these obvious genetic changes. In these people there may be differences in how the genetic material in brain nerve cells functions – that rather than being 'switched on', they are actively 'silenced' by control mechanisms. This is not yet entirely understood, although one control mechanism group that effectively turns off a gene 'switch' has been identified. It is possible that this may account for some brain changes in autism and one possible intervention in the future might be to influence this. This is an aspect of gene function that can be investigated in brain tissue.

Brains imaging and brain tissue

Brain imaging on living brains can now provide amazingly accurate pictures of brain structure. However, to interpret the signals that imaging provides, it is necessary to understand the cellular and molecular differences at microscopic levels. It is possible that studying different brain regions and the connections between them can give clues to subtle differences in wiring of brain connections in autism.

Genetic and imaging studies are just two ways in which brain samples donated for research from people who have recently died can help us understand how brain structure and function in autism may differ slightly from other brains. This understanding, in turn, offers the possibility of devising more effective interventions to help overcome difficulties experienced in autism. People who have contributed to efforts to understand autism by consenting to brain donation often say that this generous act has given them comfort and satisfaction in that it can help future efforts to improve the lives of those with autism, Asperger's and their families.



If you would like to donate your brain to the Brain Bank for Autism and Related Developmental Research, please call 0800 089 0707

We hope you will agree that Autistica is a charity worthy of support. Every donation to Autistica is greatly appreciated and brings us a little but closer to finding the causes of autism and a better quality of life for autistic people.



Supporting Autistica

Putting on an event

Our supporters have raised thousands of pounds by organising events to benefit Autistica. We can provide ideas, support, advice and literature. If this is of interest, please contact **Lynn Hart on 01491 411569** or at lynn.hart@autistica.org.uk

Company fundraising

If you would like to discuss how your company might support us, please contact **Philippa Stannard on 01189 016876** or at philippa.stannard@autistica.org.uk.

Volunteers

Can you help us?

We are looking for volunteers to help us at our events.

Please email lynn.hart@autistica.org.uk if you feel you can support us this way. Thank you.

Why not join our growing running team?



Whatever your level of fitness, there is a run to suit you!

We will support you every step of the way with fundraising packs, t-shirts or running vests and be with you on the day.

If you would like to run for Autistica please contact **Lynn Hart on 01491 411569** or at lynn.hart@autistica.org.uk

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