

Autumn Newsletter 2010

autistica

Science in the Service of Autism

**Autistica welcomes a new
Chief Executive**

**Look out for Authors for Autistica eBay
Character Auction this November!**



**Autistica funds pioneering
new project - iBASIS**



Welcome to our autumn newsletter.

Welcome to our autumn newsletter where we find ourselves at a most significant time of Autistica's evolution.

It is five years ago since Dame Stephanie 'Steve' Shirley formed this charity; her mission to raise funds to discover the causes of autism.

In this edition, Steve has written a piece about what moved her to establish our charity.

Lynn Hart, Head of Events at Autistica is the only member of staff who has been with us from the onset. Lynn has written here about how Autistica has developed over these five years.

This autumn also marks a sad departure of our Chief Executive, Hilary Gilfoy, who has steered the charity with incredible vision to where we are now – a charity highly respected amongst world class autism researchers, politicians and most

importantly, people with autism. Hilary needs to step down due to health issues, but will continue to support Autistica.

With Hilary's departure comes a new Chief Executive and everyone at Autistica is delighted to welcome Christine Swabey in this role. Christine has written a message over the page and I hope reading this will leave you as excited about our new chapter as we are!

Professor Jonathan Green contributes to our Research Focus. We are pleased to be able to fund his pioneering work in 2011, thanks to a generous corporate donation. You can read about this project on page 7.

Please also look out for the return of our Authors for Autistica eBay Character Auction in November – just in time for Christmas shopping!

I hope you enjoy this newsletter. With best wishes,

Philippa Stannard
Editor

What is autism?

- Autism is a life-long brain disorder that is normally diagnosed in early childhood.
- People with autism have difficulties communicating, forming relationships with others and find it hard to make sense of the world around them.
- Autism is a spectrum disorder varying in severity and impact from individual to individual, ranging from those with no speech and severe learning disabilities to people with IQs in the average range who are able to hold down a job or start a family. People with autism may also have unusual patterns of language development, narrow interests and engage in repetitive and sometimes challenging behaviours.
- Asperger's Syndrome is a form of autism in which speech development and IQ are normal, but in which social disability can be compounded by depression and mental health problems.
- Some people with autism demonstrate significantly challenging behaviours; most need specialist support and care.
- Autism affects half a million people in the UK – tens of millions worldwide - and is one of the most common developmental disorders.
- Boys are four times more likely to be diagnosed with autism than girls.
- Autism affects people of all racial, ethnic and socio-economic backgrounds.

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.



Make a donation online

autistica



A message from our new Chief Executive

Dear Supporter,

I am absolutely delighted to be joining Autistica as its new Chief Executive, and am really looking forward to getting to know everyone. I hope to meet as many of you as possible in person, to hear about your involvement with Autistica and listen to your ideas for how we can build on the charity's successes to date.

Like so many people, I had heard of autism but had relatively little understanding of the condition, and of how many people are affected by it. That all changed when I joined Treehouse as a Trustee in 2001 and came face to face with the realities faced by parents who have an autistic child or children. To this day, I remain inspired by the dedication, dignity and resilience of all those who devote themselves to providing their loved ones with the best possible opportunities in life. However, I am equally conscious how far we as a society still have to go to fulfil our obligations to support those in need of help.

After time spent working within the NHS and education sectors, I have been struck by how much our knowledge and understanding of autism have increased. Under Hilary Gilfoy's excellent leadership, Autistica has played an important part in this progress; both through direct funding of research and in encouraging others to support an increase in research funding. Our challenge now is to maintain and further this momentum so that we can, through better understanding, make a real contribution to improving the lives of all those affected.

As you know, we are totally reliant on donations and voluntary income to carry out the scientific research we fund. We are therefore fortunate to have so many friends and supporters who give so generously and in so many ways. I am acutely aware of how challenging fundraising can be, particularly in difficult economic times, but I'm looking forward to making a contribution to our fundraising activities. As a start, my son Charles and I will be running in the Royal Parks Half-Marathon, as well as my nephew and a friend. This is proving to be a big personal challenge, but I can't think of a better incentive to keep me going than our shared ambitions to understand more about autism spectrum disorders, so that all those with autism can one day have the life chances they deserve.

My best wishes,

Christine Swabey

Autistica Events



Authors for Autistica

We are back with another exciting eBay Character Auction in November – perfect timing for a fabulously unique Christmas gift!

Our flagship character auction – where you have your own or your chosen name immortalised in print by bidding to be in one of our authors' next books - returns this autumn. We are delighted that Ken Follett, Darren Shan, Susan Lewis and Melissa Hill are involved again and we welcome A L Kennedy and David Mitchell who have also agreed to donate a character.

In addition to the Character Auction, a number of authors have chosen to give a helping hand to budding novelists. Jim Sallis, R J Ellory and Patricia Wood have agreed to take part in auctions where the winner will have a section of their unpublished work appraised by them.

Look out for more information on our eBay page - [click here.](#)

The annual Autistica Cliveden House Lunch, Berkshire

Autistica held a magical and poignant fundraising lunch at Cliveden House in July. Guest speaker, BBC broadcaster Ken Bruce, captured the audience with his honest and heart-warming speech about his autistic son Murray.

With the sun shining, our guests enjoyed champagne on the terrace overlooking the magnificent formal gardens of Cliveden, which was followed by a delicious lunch in the French dining room.

A further speech was made by Caroline Hill, an ardent supporter who spoke movingly of her experiences as a mother of a son with autism and her reasons for supporting Autistica.

The auction that followed included a night's stay at the luxury 5* Landmark Hotel in London, a bottle of Krug Grande Cuvee and a day's golf at Sunningdale on the Old Course.

Our guests had a wonderful time and raised nearly £12,000 which will go towards supporting the charity's latest research, including key projects designed to secure earlier diagnosis and treatment of autism.

Head of Events, Lynn Hart said it had been a great success. "Ken Bruce is a wonderful speaker and we were thrilled to have him attend our event. I have received a huge amount of local support and would like to thank everyone who helped so freely. Special mentions must go to Mark our chauffeur for the day; Charlotte Snowden, our photographer and Candy Gilbert-Smith who did the flowers. Without these people and the help/support of many others, we would not have been able to have such a super day. Thank you."



Autistica Events

Garden Party

Hennerton House, Wargrave, Berks, Sunday 12th September

Local supporters are invited to attend Afternoon Tea at a Garden Party on Sunday 12th September at the home of one of our trustees in Wargrave.

If you would like to come along and learn more about our work, please email lynn.hart@autistica.org.uk

An evening with Peter and Dan Snow

London, Wednesday 24th November

The evening of Wednesday, 24th November is the date of our biggest fundraising event for 2010: a champagne reception, black tie dinner and cabaret at Lady Rosa Lipworth's home in North London.

Peter and Dan Snow are providing the after-dinner entertainment at this private and highly-sought after charity venue. They will be giving their own amusing and very personal account of their careers, journalism, TV presenting as well as touching on the many fascinating history programmes and books with which they have been involved. The evening will include a stunning raffle and an auction of fabulous lots.

Please contact lynn.hart@autistica.org.uk or telephone **01491 412311 for tickets.**



Runs and Marathons

We are delighted with the support and interest shown in the runs and marathons this year - a huge thank you to each and every one of you, who have trained and worked so hard in raising funds for Autistica.

People are already signing up for our 2011 marathons - if you are interested please email lynn.hart@autistica.org.uk for the following runs:

- Reading Half Marathon, 20th March
- BUPA 10,000 in London, 30th May
www.autistica.org.uk/runs/bupa_11.php

Please keep an eye on our website - we will post details of next year's runs as soon as they are available.



Autistica – five years on



Founder & President of Autistica, Dame Stephanie Shirley, describes what inspired her to create an autism research charity

Five years! Autistica has made fantastic strides and – more importantly – has already made a real difference to the quality and quantity of the medical research carried out into the causes of the different autisms. A big THANK YOU to everyone involved.

I've been asked to sketch the genesis of Autistica. It all started back in 2001 following on from other pioneering projects my foundation, The Shirley Foundation, had funded including the Kingwood support charity (formally inaugurated 1994), Prior's Court School (1997), the study of the economic impact of autism spectrum disorders (also 1997) and Autism Cymru (1999).

Research was at a point where the overall conclusion was that although we were beginning to understand what autism looked like, no-one knew what it was. At this point The Shirley Foundation was interested in the concept of electronically linked medical research units.

Then in 2003, we co-founded a project called the Kaspar project with Chuck Gardner Jnr, the visionary behind the UC Davis MIND Institute in the USA and who, like me, had a son with autism and was passionately involved with a school for pupils with autism. The Kaspar Steering Group included Seattle's Professor Geri Dawson (now Autism Speaks' Research Director), Professor Simon Baron-Cohen from Cambridge and Consultant Peter Galsworthy.

The mission was simple: "What do we have to do to understand the causes of autism and halve its global cost?"

However, when we started costing the first draft of the Scientific Research Plan it came out at £0.4 billion - way outside my capability! So I began to look for partners and found the National Alliance for Autism Research (NAAR) in America and, with their help, founded NAAR (UK). This morphed into Autism Speaks (UK) and, on 1st January last year, Autistica. I am enormously proud of it.

What of the future? Some of the causes of autism should be understood well within the next few years. I'm also hopeful that researchers worldwide will be working collaboratively towards the common objective of helping people affected by autism. Watch this space!

Dame Stephanie Shirley



Lynn Hart
Head of Events

It all began with a small ad in the local paper in July 2004 – part-time help needed to organise sponsored walk in Windsor Great Park.

I was running my own business at the time, Henley Concierge, and a long term-client had just moved on. I met one of the new charity's Trustees, Hugh Lake and immediately knew I wanted the job and I was lucky enough to get it!

At the time there were just three of us working, including Steve Shirley - although Hilary Gilfoy was soon to join as Chief Executive. I worked with a committee of 10 volunteers in organising the first Walk for Autism Research held on a very hot day in July 2005. Over 400 people came and we raised an amazing £32,000.

The charity grew very quickly - it was like starting a new company. I was involved in everything from sending out information to setting up the first website and loved it from the word go. Before long, with the hours growing by the week, I became a full-time member of staff.

During the second year our events developed, more people got involved and the number of staff increased. We worked hard to spread the word - the database grew too big for my little computer and we installed a professional charity database, which we still use today.

I can't believe it is 5 years since that first walk in Windsor and the nice thing is that there are so many people who came on-board then and still involved with the charity today.

Jane Westley - whose husband Richard presented a cheque at that first Walk is now our Trusts and Foundations Fundraiser.

Victoria Sanvitale - one of our very first volunteers - has been to almost every event as a volunteer since. She took part in the sponsored row we did one year at Dorney Lake, has been twice to our Alnwick walk in Northumberland and is even running her first half marathon at the Royal Parks in support of Autistica. Victoria is one in a million.



It is the commitment and enthusiasm of the volunteers, staff and supporters that is my real reward for working with Autistica. I've met so many amazing people - people who never give up and who lead lives that no one would believe could be so tough, yet they still manage to keep smiling.

I feel incredibly lucky - I absolutely love my job, it isn't like work. Sir Richard Branson once said - he didn't think of work as work and play as play. It's all living. I agree!

Autistica is included in the History of Autism – Conversations with the Pioneers commissioned in 2007 and published by Wiley/Blackwell earlier this year.



Supporting Autistica

We are immensely grateful for the ongoing support of Kirsty Thompson.

Kirsty has a son with autism and found out about us while volunteering for an autism research project at Oxford University a few years ago. Since then, Kirsty has chaired the Autistica local group in Berkshire, has sky dived, shaken lots of buckets and this July organised a Family Fun Day at Camp Mohawk in Berkshire.

The day was blessed with the last of the English summer weather and was a fantastic success. Over one hundred families arrived for a day of swimming, face-painting, barbeque, a host of stalls and even a goody bag to take away! The event raised over £1,500 and left everyone with a smile on their face!



Research Focus – *i*BASIS

Autistica is delighted to announce the funding of a new ground-breaking research project in 2011.

***i*-BASIS – Intervention within the BRITISH AUTISM STUDY OF INFANT SIBLINGS (BASIS)**



The British Autism Study of Infant Siblings (BASIS) uses newly developed techniques for studying brain and behaviour in infants, to investigate whether there are any differences in development between infants who have brothers or sisters with autism and those who do not.

Following on from their research, Professor Jonathan Green and his team at Manchester University will research very early intervention for infants at high risk of developing autism. It is thought that some aspects of brain and genetic functioning may be responsive to intervention during the one to one social interaction in the first year with parents & caregivers.

Their hypothesis is that this intervention will shift aspects of behaviour, brain function and genetic expression towards a more usual developmental path.

The research will aim to deliver an intervention that works with parents to help them understand their infant's particular communication style and adapt best to it in ways that theory suggests will promote optimal social and communicative development.

The team will select a group of 8-10 month-old infants at high genetic risk of autism, of whom 25 will be allocated into an intervention lasting 5 months. An equivalent group of infants will be allocated to no intervention. Both groups will be assessed both before and after the intervention using measures of relevant infant behaviours and brain functioning.

The study will give important information about the impact of the intervention on: patterns of attention shifting, visual preference for faces, brain processing of face information and behavioural markers of autism.

This study is the first of its kind - not only looking at the impact of such intervention on behaviours that are believed to signal risk for ASD, but also at the impact of intervention to a more 'biological' level, i.e., brain functioning. The effect of intervention on these different areas of functioning will give early indication of the malleability of early developmental pathways in autism spectrum disorders and on the prospects for alteration of their later developmental course.

