

# autistica

Science in the Service of Autism

Spring 2010



## World Autism Awareness Day



**Stand up for Autism**

2nd April 2010





Welcome to Autistica's first newsletter since our change of name on 1st January.

We are pleased that our name change has been well received and already this year, Autistica has been busy expanding its funding to autism researchers. The research Autistica funds addresses the key questions that will one day improve the quality of life for children, adults and families living with autism.

Autistica funds biomedical research that investigates better diagnosis, effective treatments and the causes of autism. Such research will surely provide better outcomes for people living with this condition.

Our ability to fund this research is due to the generosity of our supporters, for we receive no government funding. Indeed, the government spends a meagre 0.2% of its research budget on autism research - extraordinarily low given that 1% of our population have autism.

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.

Since we formed in 2005, your support has enabled us to allocate over £2million to research projects in the UK and with our forthcoming funding – geared to developing original ideas – Autistica is now the largest UK charity funding autism research. We fill the gap left by other autism charities who work tirelessly in campaigning for change and providing services and education, and we are pleased to have the support and endorsement of many of these charities, including the National Autistic Society, Treehouse and the hundreds of other regional charities who work so hard to provide the best solutions for people with autism.

While fifteen years ago there was only a small number of scientists working on autism research across the world, now there are hundreds. Research is becoming the buzz word in the autism community now. We need to fully understand the science of autism in order to provide better solutions. Autistica is ready to respond to this and will challenge our country's decision makers to do likewise.

We aim to continue funding ground-breaking research, which could provide solutions within ten years. But the speed of this research is reliant on funds available. We can only succeed with the continued generosity of our supporters. Please consider a donation to Autistica - you will find a form on the back page of this newsletter.

Philippa Stannard  
Editor

## New research funding announced

Autistica is pleased to announce awards of new funding for four separate research projects, each of which it believes has the potential to benefit the search for new interventions and therapies to help people with autism.

The four projects were chosen from a field of almost 50 submitted in response to Autistica's first 'call for proposals', an open invitation to researchers across the UK to submit ideas for pilot studies into previously unresearched areas. The total value of the funding is just under £300,000.

Two of the new projects to receive funding explore the role of genes in autism spectrum disorders. One will investigate whether variations in specific small molecules – microRNAs – may play a role in the development of the condition. The other will be concerned with identifying the optimum moment to introduce therapeutic interventions.

Another study will focus on the different responses to sound in children at higher risk of developing autism and the way these reactions might help with early detection and diagnosis. The fourth project will begin the first steps in creating a national register of families with autism as a means of increasing the number of volunteers taking part in research programmes.



## Run-raising for Autistica...

If running is your thing – or if you want it to be your thing – then please, please get in touch. We have some great charity places below and we can provide lots of support. For all the runs below, please contact Lynn Hart on 01491 411569 or at [lynn.hart@autistica.org.uk](mailto:lynn.hart@autistica.org.uk).

### Great North Run 19th September

With 54,000 runners, this is the world's biggest half marathon! If you would like to be a part of it and raise vital funds for autism research, we ask for £25 upfront and that you pledge to raise a minimum of £325.

#### Apply today!

[http://www.autistica.org.uk/runs/great\\_north\\_10.php](http://www.autistica.org.uk/runs/great_north_10.php)

### Individual runners

We are very grateful to our supporters who chose to support Autistica as individual runners in the thousands of runs that take place throughout the UK. If you can support us this way, Lynn would love to hear from you and will provide you with support and of course, our new running vest or t-shirt.

Dan Hill has been a fantastic running supporter – taking part in both the Reading Half Marathon last year and the Royal Parks Half in London. Dan has been accepted to take part in the 2010 Comrades Ultra Marathon in South Africa in May 2010 when he will run an incredible 56 miles!

Dan is married to Caroline (who also ran the Royal Parks last year) and they have a son with autism.

#### If you would like to send a donation to Dan – please go to

<http://www.justgiving.com/56mileUltraMarathon>

### Adidas Ladies Challenge

**5th September - REGISTRATION NOW OPEN!!**

Adidas is extremely proud to be title sponsor of the biggest and best women-only fun run in the UK. Whether you are running to beat last year's PB, running for the very first time or planning to just get round, Autistica will be with you every step of the way to help you achieve your own impossible challenge – and have lots of fun on the way!

#### You can register online now at

[http://www.autistica.org.uk/runs/adidas\\_10.php](http://www.autistica.org.uk/runs/adidas_10.php)

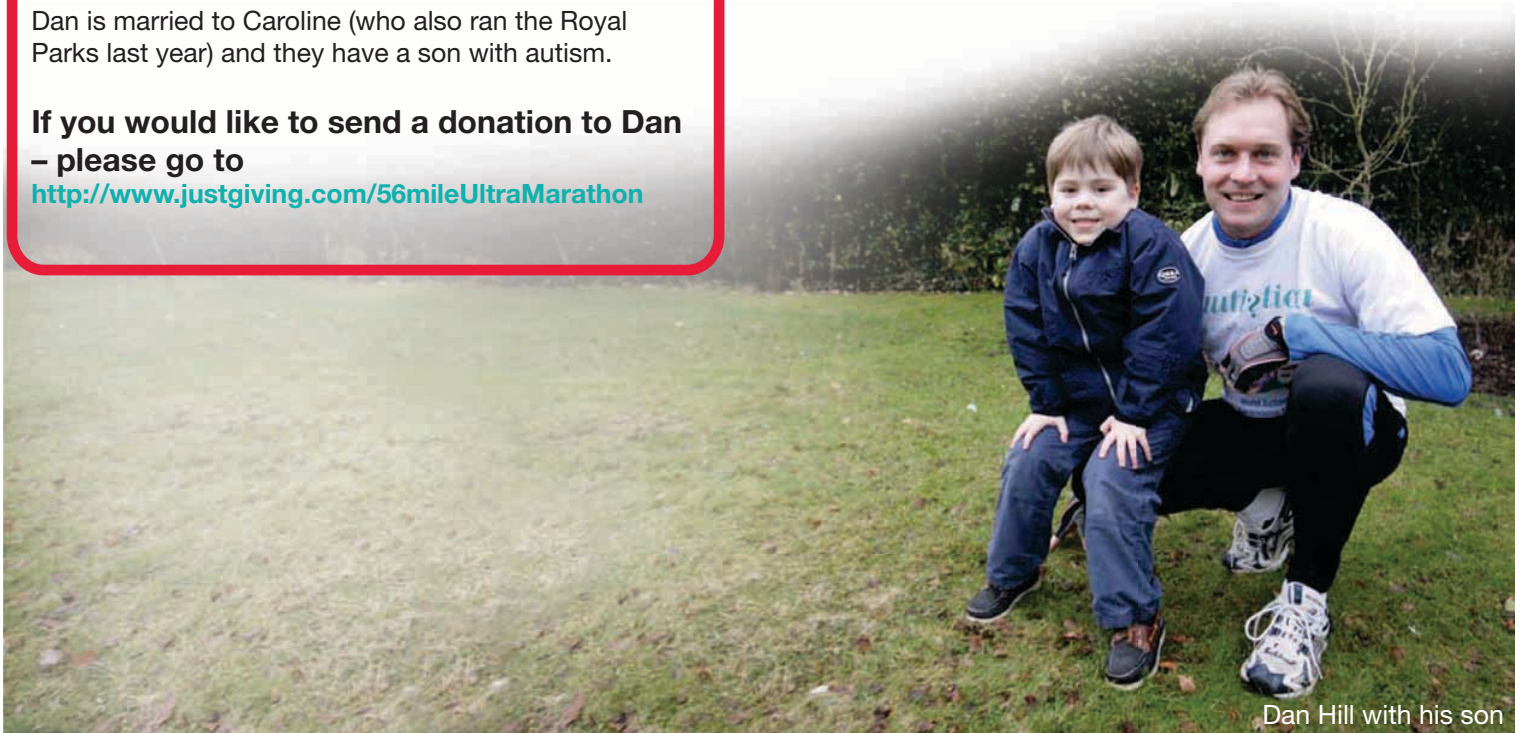
### Royal Parks Half Marathon, 10th October

This is our third year in the Royal Parks Half Marathon and our biggest event in the calendar this year! This is a superb run, all on the flat, through the leafy autumnal parks of London and 2010 promises to be the best and biggest race yet! Because of its popularity, we have more places than ever before but they are already going fast so please get in touch if you would like to take part.

**Entry Fee:** £39; **minimum sponsorship** £325.

#### Register online today -

[http://www.autistica.org.uk/runs/royal\\_parks\\_10.php](http://www.autistica.org.uk/runs/royal_parks_10.php)



Dan Hill with his son

## Autism research up close

In each issue we will attempt to bring you closer to the research we support and illustrate how all Autistica funded research will aim to bring real benefits for people living with autism.

British Autism  
Study of Infant Siblings



### The British Autism Study of Infant Siblings (BASIS)

The main aim of BASIS is to follow the development of the baby brothers and sisters of children diagnosed with autism, compared to babies who have older siblings with no family history of autism. It is hoped that in the long term this will help identify the early signs of the disorder, allowing for earlier and more effective intervention aimed at improving the quality of life of children with autism.

BASIS now has enrolled over 150 families who have a child with autism, in addition to families who don't have a family history of autism as a "comparison" group. Families are asked to visit the lab regularly from the time the babies are around 4-6 months until they reach three years. It has been wonderful to see these little ones grow from babies to toddlers! Families usually spend a whole day at our 'Babylab', with their child taking part in several fun short computer tasks such as watching faces and colourful animations as well as taking part in interactive games with the researcher.

### BASIS – a UK wide Network

Since its launch in 2008, the BASIS project has grown substantially. In addition to the ongoing work at the Babylab, BASIS scientists are now setting up projects on genetics, brain imaging, and intervention. Collaborating centres include Birkbeck, University of London, Institute of Education, Institute of Psychiatry, Cambridge University, Oxford University, and University of Manchester. We hope BASIS will continue to be a platform for some very fruitful collaboration across different teams in the UK.

### Adult Autism Strategy published

At a packed House of Commons reception, hosted by Autistica, Phil Hope, Care Services Minister announced the newly published Adult Services Strategy 'Fulfilling and rewarding lives'. Autistica welcomes the raft of new measures in this landmark strategy aimed at tackling the isolation, ignorance and inequality, routinely experienced by the over 300,000 adults with autism in England. The strategy is expected to drive a dramatic improvement in the quality of health, social care and other public services for people with autism.



Phil Hope  
Care Services Minister



Hilary Gilfoy of  
Autistica

### More Families needed!

If you are interested in getting involved in research and are pregnant or have a baby up to 9 months old who has a full sibling diagnosed with an autism spectrum disorder, the Babylab team would love to hear from you. Travel costs to central London (WC1) are reimbursed and special arrangements are made for families who live further away.

Please contact:

Janice Fernandes  
Tel: 020 7079 0761  
E-mail: [basis@bbk.ac.uk](mailto:basis@bbk.ac.uk)

## Daily life can be a major challenge for people with autism

Why not give yourself a challenge and raise money for autism research – research that will lead to a better quality of life for autistic people.

Autistica is involved with a number of bike and trek fundraising challenges this year and would be delighted if you would join us for one. Please contact Philippa on 01189 016876 or at [philippa.stannard@autistica.org.uk](mailto:philippa.stannard@autistica.org.uk) for more details.



### The 3 Peaks Challenge 14 - 15 May

Climbing the three Highest Peaks in the home nations: Scotland, England and Wales. Starting with Ben Nevis before heading south for Scafell Pike and then finishing at Snowdon. The challenge is all the more tough as we complete the whole lot in 24 hrs.

### Scotland Coast to Coast Eco Challenge 21 May - 1 June

This amazing trek from the East to West Coast of Scotland winds through remote areas of the Highlands. The spectacular landscape of glens and hill lochs provide a dramatic backdrop to this wilderness challenge. A strong emphasis on the preservation of the environment through camping and trekking means you take part in a really responsible challenge.

### Vietnam Hill Tribe Trek 2 - 12 Sept

The Sapa Hill Tribe Trek will start in the capital city Hanoi and then head further north to Sapa on the luxury Victoria Express Train. Sapa is a typical rugged northern Vietnamese area with lots of terraces, large rolling hills, deep valleys and rice fields. Unlike other treks passing over similar terrain this expedition has the essence of a challenge without the discomfort, making culture shock less 'shocking' and the enjoyment factor higher!

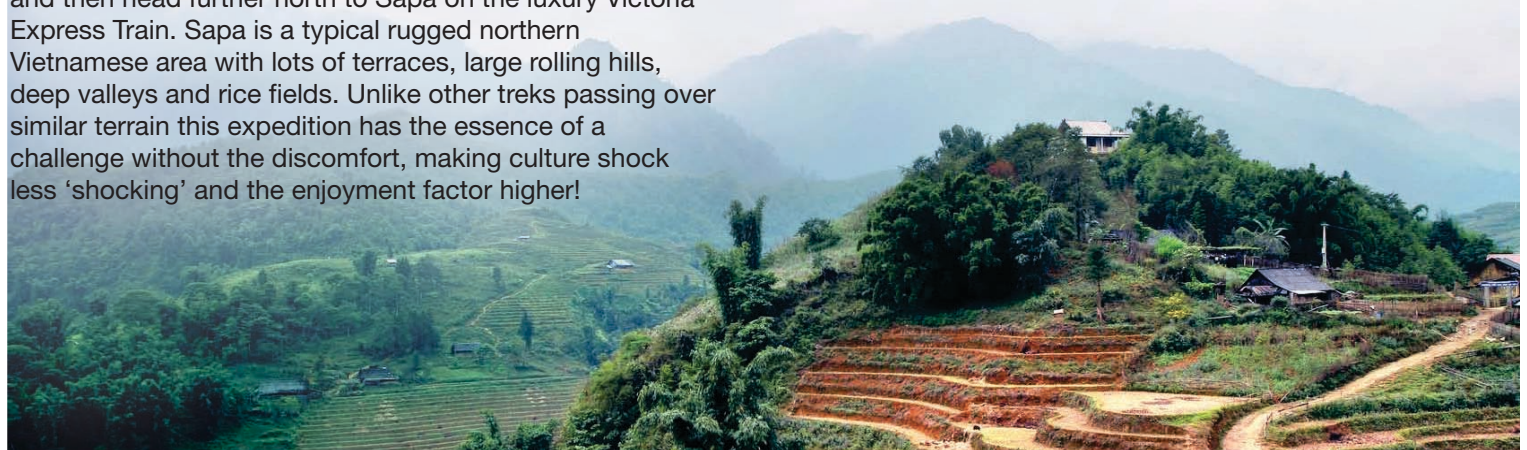
### London to Paris Bike Ride 24 - 28 June

We are sure this unique event will inspire and enthuse experienced cyclists out there, as well as those who are new to the sport, but want an unforgettable challenge... This grand 280 mile route from London (Greenwich) to Central Paris is a classic - ride from one exciting European capital to another—in just four days!

### London Nightrider 19 June

A fantastic challenge taking in all the key sights of London by night. Starting at Crystal Palace in south east London the challenge follows a 100km circular route. Make the most of quiet roads and explore the country's capital city by moonlight on your bike.

**These events would make excellent company team events, so perhaps your organisation might get involved?**





World Autism  
Awareness Day

## Stand up for Autism

2nd April 2010

**UK autism charities have come together to 'Stand up for Autism' on World Autism Awareness Day and ask you to do the same!**

Find out how you can make a difference by visiting the UK World Autism Awareness Site - [www.waad.org.uk](http://www.waad.org.uk).

You can upload a photo and leave a message, join the World Autism Awareness Day Facebook site and post a Stand up for Autism YouTube video. There are also listings of events being organised around the country.



Autistica has produced t-shirts with both the World Autism Awareness Day and Autistica logo, which you can order by calling Nicole on 01491 412311 or completing the order form on the back of this newsletter.

World Autism Awareness Day posters for your school, college, work place, community hall or library can be downloaded from [www.waad.org.uk](http://www.waad.org.uk). Alternatively we can either email or post a hard copy to you – just contact Nicole Haworth on [nicole.haworth@autistica.org.uk](mailto:nicole.haworth@autistica.org.uk)



Thank you to Melanie C and her fan club for choosing our charity to benefit from the sales of Mel's 2010 calendar and raising £1000!

## Professor Stephen Hawking at dinner to endorse Autistica's contribution to autism research



Autistica's advancement of autism research is acknowledged by much of the UK's science community. In January, Professor Stephen Hawking was the guest of honour at a dinner hosted by Lord Rees, master of Trinity College Cambridge to mark the progress achieved in advancing autism research by Autistica

and Cambridge University's own Autism Research Centre. Guests with connections to the university and from a number of organisations funding or undertaking medical research listened to speeches by Professor Hawking's daughter Lucy (whose son has autism), head of the Autism Research Centre Professor Simon Baron-Cohen, and our own Chair of Trustees Winston Fletcher. There was then a lively discussion chaired by our President Dame Stephanie Shirley on how we can continue to accelerate research to the benefit of people with autism and their families.

The dinner took place in the Master's Lodging, dating to Tudor times, and furnished with historical items including Sir Isaac Newton's clock and an imposing

## The Funny Side of Autism - a book about the funny things children with autism do and say.

The editor of the book, Lisa Masters says: 'My goal in writing this book is two-fold. Firstly, I think it is important to show a side of autism that is hardly ever portrayed, and secondly, I want to help public awareness by showing people how children with autism think. This book shows there are bright moments when raising a child with autism. Moments that make you laugh, learn from and fuel you to go on.'



For all sales made outside the USA, Lisa will make a donation to Autistica.

Please visit [www.TheFunnySideofAutism.com](http://www.TheFunnySideofAutism.com) to buy your copy.

## Autistica Events

We hope we can tempt you with one of our popular events this year. Please contact Lynn Hart on 01491 411569 or at [lynn.hart@autistica.org.uk](mailto:lynn.hart@autistica.org.uk) for more information.

### Charity Clay Shoot

The Royal Berkshire Shooting School,  
Friday, 11th June



Our fourth Charity Clay Shoot this year is kindly sponsored by NBC Universal. With many of our 100 tickets already taken from the world of TV and media, we urge you to book as soon as possible for what we believe is going to be our best Charity Clay Shoot yet.

If you are team building, entertaining or simply feel you deserve a day out of the office, we can promise you a great day. All you have to do is turn up – it is highly organised and completely safe and beginners and non-shooters are welcome to join us. Guns are supplied, although do bring your own if you wish. Also included is a full morning's shooting with refreshments, 3 course lunch, wine, entertainment, competitions and a prize-giving ceremony.

Teams cost £1500 for 4 people. Single guns £375 and Non-Shooting guests, £95.

**For more details visit:**

[www.autistica.org.uk/events/clayshoot.php](http://www.autistica.org.uk/events/clayshoot.php)

### Walk for Autism Research

The Alnwick Garden, Northumberland  
Sunday 13th June



Taffy Thomas MBE, the first ever Laureate Storyteller is coming along to support our third fundraising walk at The Alnwick Garden and delight us all with his stories and riddles.

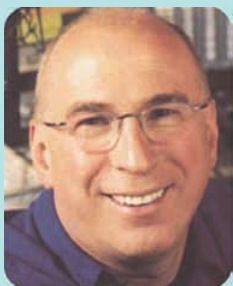
**Register online today at**

[www.autistica.org.uk/events/alnwick.php](http://www.autistica.org.uk/events/alnwick.php)



### 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 summers 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 arranged for those who would like a walk, otherwise guests are welcome to relax and simply enjoy the ambience.

**For more details visit:**

[www.autistica.org.uk/events/lunch\\_10.php](http://www.autistica.org.uk/events/lunch_10.php)

### Volunteers

Can you help us?

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

Please email [lynn.hart@autistica.org.uk](mailto:lynn.hart@autistica.org.uk) if you feel you can support us this way. Thank you.

## Donation Form

As a fundraising charity that receives no statutory funding, we are reliant on donations and gifts that enable us to continue to fund ground-breaking autism research currently taking place in the UK. Your support is appreciated at this time.

- I enclose my cheque/CAF Voucher payable to Autistica, or  
 Please debit my Credit Card/CAF Charity Card Account  
 I enclose cash amounting to: \_\_\_\_\_

Mastercard / Visa / Maestro / CAF / Other

Card No: ----

Exp Date: / Issue Number (Maestro): \_\_\_\_\_

Mr / Mrs / Miss / Other: \_\_\_\_\_ First Name: \_\_\_\_\_

Surname: \_\_\_\_\_

Address: \_\_\_\_\_

Town: \_\_\_\_\_ County: \_\_\_\_\_

Postcode: \_\_\_\_\_ Telephone: \_\_\_\_\_

Have you signed a Gift Aid Declaration for us yet?  
Signing the declaration below allows us to claim back the tax you've already paid on your donation. That means we get an extra 28p for every pound you give - at no extra cost to you.

*giftaid it*

### DECLARATION

I am a taxpayer. I want Autistica to reclaim tax on this donation and on all donations made in the last 6 years and any subsequent donations I make.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**PLEASE NOTE: you must pay an amount of UK Income Tax or Capital Gains Tax equal or more than the amount reclaimed on your donations. Contact us for further information or if your tax situation changes, or you wish to cancel this declaration.**

- I do not wish to receive any more mailings from Autistica.

## Supporting Autistica

We hope you will agree that Autistica is a charity worthy of support.

As well as making a donation you can help us in many other ways and we hope you will consider one of these:

### Street Collections

Help us raise funds and spread awareness about Autistica by organising a street collection in your town. We can organise the permits, send you the collection tins, t-shirts and ID badges – if you can gather the volunteers!

### Putting on a fundraising event

Our supporters have raised thousands of pounds by organising an event to benefit Autistica. We can provide fundraising ideas support, advice and literature. If this is of interest, please contact Philippa Stannard on 01189 016876 or at [philippa.stannard@autistica.org.uk](mailto:philippa.stannard@autistica.org.uk)

### Keeping our costs down

We can send future copies of this newsletter by email if you prefer. Please email [info@autistica.org.uk](mailto:info@autistica.org.uk) with your email address.

### A donation to Autistica

Every donation to Autistica is greatly appreciated and brings us a little but closer to finding better diagnosis and treatments for autistic people.

## Autistica / WAAD T-shirt order form

Mr / Mrs / Miss / Other: \_\_\_\_\_ First Name: \_\_\_\_\_

Surname: \_\_\_\_\_

Address: \_\_\_\_\_

Town: \_\_\_\_\_ County: \_\_\_\_\_

Postcode: \_\_\_\_\_ Telephone: \_\_\_\_\_

### Post & Packing

**1 shirt - £1.50 2 shirts - £2.00 3 shirts - £2.50 4 shirts - £3.00**  
5+ Please contact us

Size	No Required	Cost	TOTAL
		£5.00	
		£5.00	
		£5.00	
		£5.00	
		£4.50	
		£4.50	
		<b>Total of above</b>	
		<b>P &amp; P</b>	
		<b>TOTAL TO PAY</b>	

Please send your form and cheque, made payable to 'AUTISTICA', to the address below