



*autistica*

Science in the Service of Autism

## Annual review 2009

Autistica raises and invests funds for medical research that will bring **real benefits** for people with autism and their families



# A Year of Change



## Winston Fletcher, CBE – Chair of the Trustees

Last year I wrote my review within weeks of taking over as chair from Dame Stephanie Shirley, our founder. At that time I knew little about autism, still less about the charity itself. Nonetheless my initial impressions of the charity were exceptionally positive. In that review I wrote:

‘On arrival I found a top-notch and highly motivated professional team, extremely well organised and focussed on its objectives. They are keen as mustard, and will be a joy to work with’.

During 2009 I have learned a fair amount about autism and of course, a lot about this charity. Happily, my initial impressions have been convincingly confirmed. Despite the fact that 2009 was a terrible recessionary year for the economy, we stayed pretty well on course and even managed to double our contributions to autism research. This highly creditable performance is entirely due to the abilities and efforts of our ‘top-notch and highly motivated professional team’. They have indeed proved themselves keen as mustard, and have indeed been a joy to work with.

At the same time as we have grappled, like everyone else, with the tough economic situation, we have taken four major initiatives which we believe will put us in a strong position to move forward again when things begin to recover.

First and foremost, in the first half of 2009 we agreed with our American partners Autism Speaks to sever our formal agreement as of December 31 2009, though we will continue to collaborate with them whenever possible. Hilary Gilfooy provides the background to this decision in her Chief Executive’s review. For us this was a major strategic change. It meant setting up our own high-quality scientific peer review panel and a great deal of time re-branding ourselves. In this we were greatly aided by some of the UK’s leading branding consultants, who generously gave their services without charge. However to achieve a complete re-branding in a few months - from a standing start - for everything from our envelopes to our website, was no mean achievement. All those involved in all aspects of the transition are to be

hugely congratulated, and thanked. We are immodestly pleased with our new name and logo design, and especially pleased with our new strap-line 'Science in the Service of Autism' – which very clearly defines the charity's mission, and brings me to our second key initiative last year.

Coming to autism from the outside I was literally bewildered by all the strands of biomedical research in progress, in the UK and throughout the world: I was utterly unable to see the wood for the trees. So the development of our Science Strategy, published in September 2009, has been a huge help to me personally in defining exactly how science can serve autism. But much more importantly the Science Strategy has helped the charity, and will continue to help the charity, explain to funders and to the public precisely what our aims and objectives are.

This brings me to our third major initiative last year. In July 2009 we issued our first open call for proposals for pilot projects in autism research (the first ever such call by an autism charity). The aim was both to encourage young researchers to put forward their own innovative ideas, and to tempt experienced researchers from other fields to turn their attention to autism. Both aims were handsomely achieved, and we received a total of 19 full proposals and after peer review we selected 4 of these to fund.

Our fourth important initiative was to set up a body of 'Vice Presidents', who will act as ambassadors for Autistica and, naturally, help us in our fundraising activities and we are delighted to have old friends and new on board.

Thus 2009 has been an extremely busy – and I believe successful – year of change. But inevitably not everything ran smoothly. Regrettably, in a matter of a few months, the Trustee Board lost three of its members: two as a result of resignations for personal reasons, but it was the sudden death of Professor Walter Muir of Edinburgh University that has left the Board with an aching gap which will be immensely difficult to fill. Professor Muir, who was an inspirational supporter of the charity, was one of the world's outstanding autism scientists. Such remarkable people are all but impossible to replace. We plan to set up a memorial project in his honour.

We have been exceptionally fortunate in being able to welcome to the Board two new Trustees who know the charity and have proved their ability to help us make progress. Peter Johns and Gordon Smillie joined us on December 1 2010, and are already making a real contribution to our work.

It only remains for me to thank wholeheartedly all the Trustees, Hilary Gilfooy and our top-notch team, together with our many supporters and volunteers, who have put in such an immense amount of work during the year. I am confident they will ensure Autistica continues to go from strength to strength in the support of autism research. I shall be proud to continue to help them.



**Winston Fletcher, CBE** – Chair of the Trustees

## From the Chief Executive



To continue the theme set out in our Chair's review 2009 was indeed a year of great change for Autistica, culminating most visibly in our change of name and mission at the end of the year – almost exactly on the fifth anniversary of our creation.

For these first five years the charity was entirely focused on raising funds for and funding high quality, peer reviewed research into the causes and biological basis of autism. Originally linked to the National Alliance for Autism Research (NAAR) in the United States, we then shared our name with American charity Autism Speaks after it merged with NAAR in 2006. These links were of particular value to us in our early years as it allowed us to draw upon the well-established peer review system of our US colleagues and to build upon an existing commitment to sponsor autism research in the UK.

However in line with our status as an independent organisation, it was always anticipated that as we grew we would need to develop these important capabilities ourselves, and this point was reached during 2009 when we issued our first open call for proposals and published our first five-year science strategy. It is also the case that an increasingly important role for Autism Speaks in the United States has been autism advocacy at both local and national level: a role already long-held by other autism charities in the UK. It was therefore agreed during 2009 that the time had come to end our formal Memorandum of Understanding and replace it with informal collaboration. We remain deeply grateful to our former partners for giving us this strong underpinning during our formative years.

The other factor driving change has been the accelerating pace of discovery in autism research. Five years ago it was indeed the case that we knew little about the causes of autism, how it emerged in the young child,

# 500,000

more than half a million individuals  
in the UK are affected by Autism



and what impact it had on the developing brain. Today we know much more about all of these, opening up the exciting prospect that this knowledge can be translated into improved therapies and a better quality of life for all those affected. It has become possible, as our new mission states, to put 'Science in the Service of Autism'.

But there is still much to do. Autism is a lifelong disorder affecting how around 1 in 100 people – more than half a million individuals in the UK - understand, communicate and interact with those around them. Its disabling effects cost the UK £28bn a year, but as a nation we spend less than 0.02% of this sum on

research. This under funding must be addressed if we are to understand and treat autism responsibly and effectively. Autistica has done and will continue to do all in its power to drive forward UK autism research. We are helped enormously in this task by The Shirley Foundation's ongoing support - until 2012 - for our core costs, allowing us to direct our fundraising proceeds directly to this vital task.

Hilary Gilfoy – Chief Executive

# Autistica's science strategy

Our first 5-year science strategy was published in September 2009 and was the result of a considerable process of analysis, review and consultation.

Our aim in developing the strategy was to establish the particular strengths of UK autism research and to consider how Autistica, working in partnership with other key funders, could build upon these strengths to ensure that the UK continues to make a world-class contribution to autism research.



Brain connections revealed by imaging techniques

**As the strategy sets out, the key scientific questions which Autistica believes must be addressed over the next five years are as follows:**

What causes autism and how can we use that knowledge to ease the burden for families?

What are the specific characteristics of autism that are amenable and relevant to treatment?

How can we improve early screening and diagnosis, and our understanding of how autism changes over time, in order to achieve timely and appropriate intervention?

**And the key ways in which we believe we can help to answer these questions are by:**

- Developing a sustainable research infrastructure
- Utilising existing and developing new research capacity
- Adding to existing successful research collaborations
- Building on the UK's strengths in neuro and cognitive science; and
- Consulting with the autism community on the direction of research.

These are all important tasks and our day-to-day activities are now focused on advancing them.

# Autistica's first call for proposals

In July 2009 we issued our first call for research proposals – for pilot projects - and received a tremendous response.

Forty eight outline proposals were received from researchers in twenty four different universities right across the UK and we invited twenty researchers to submit full proposals. Nineteen proposals were received. After a full peer review process led by our Director of Research, Dr Jenny Longmore, which necessitated establishing our own extensive international network of reviewers and own Scientific Advisory Panel, four projects have been selected for funding.

The purpose of pilot projects is to explore promising ideas that either address new research questions or accelerate the research process on a small, test scale, before larger resources are committed. For us a key selection criterion is how well these drive towards answers that will directly benefit people with autism, and we have chosen projects that we believe have the potential to do this.

## Each is different:



Dr Jeremy Parr at the University of Newcastle is piloting an Autism Research Register to underpin UK-wide autism research



Dr Janine Lamb at the University of Manchester is exploring whether variations in microRNAs – small molecules that regulate gene function including in brain development – might have a role to play in increasing risk for autism



Dr Joseph McCleery at the University of Birmingham will explore whether toddlers at risk for autism (those with a diagnosed older sibling) respond differently from other children to speech and non-speech sounds



And Professor Peter Kind at the University of Edinburgh will extend his work on the single gene disorder Fragile X syndrome, which produces autism-like symptoms, to explore the point in brain development when loss of this key gene has greatest impact.

We hope that when these pilot studies are completed in two years time they will each lead on to larger projects that will contribute to the better understanding of autism that we believe must go hand in hand with improved services if our vision of improved outcomes for people with autism is to be achieved.



## Autistica's research portfolio

Autistica supports research in scientific areas considered vital to understanding what autism is and how it develops; these include autism genetics, tracking the development of babies at risk for autism, understanding through neuroimaging how the brain differs structurally and functionally in people with autism, and analysing brain chemistry.

Increased understanding in these areas is already opening up avenues towards better targeted and more effective interventions.

Once again funds were made available to the International Autism Genome Project led by Professor Tony Monaco at the University of Oxford. The second phase of this international search for the genes that confer susceptibility to autism was completed during 2009 and there are exciting prospects for future work that will support the diagnosis and treatment of autism. We intend, subject to the availability of funds, to continue to support this important work.

The British Autism Study of Infant Siblings (BASIS) led by Professor Mark Johnson at Birkbeck College London has gone from strength to strength during 2009, and is now supporting a number of new studies as well as the core project. The BASIS network is spread across a number of UK universities and involves studying the 'at risk' baby siblings of children already diagnosed with autism, to look for early

markers of the condition with a view to developing more effective early diagnosis and intervention. BASIS is affiliated to the North American Baby Siblings Research Consortium to ensure that knowledge gleaned by both groups is shared as rapidly and effectively as possible. We are pleased to report that the Charles Wolfson Charitable Trust joined the BASIS funding consortium established by Autistica during 2009.

Professor Sue Leekam took up her post as the first chair of autism research at Cardiff University in April 2009 and has made considerable progress over the last few months in recruiting the students and fellows she needs to establish the Wales Autism Research Centre, which came into being on 2 April 2010 - World Autism Awareness Day. The studentships are funded from a range of sources other than Autistica, proving that our funding of core positions does then attract funds from a much wider base than was the case in autism research before.

The Brain Bank for Autism and Related Developmental Research, funded by Autistica, is now formally established at the University of Oxford under the leadership of Professor Margaret Esiri, and has already exceeded the number of new donations expected in its first year. Post mortem brain tissue is a most precious resource and allows scientists to study autism at the molecular and cellular level in a way that is not possible in living individuals. We are therefore deeply grateful to those who have made donations after the death of a loved one, and those who have signed up as potential donors themselves. During the

year we were also pleased to provide additional funds to the Brain Bank to carry out in depth imaging studies that are revealing astonishing new details about the structure of the brain.

A new project being supported with funds raised during the year from the Garfield Weston Foundation, the Swire Charitable Trust and others is a detailed analysis of DNA samples taken from participants in the Autism Imaging Multicentre Study funded by the Medical Research Council. It is hoped that this may help us to link particular features of autism to underlying genetic differences.

We also continued our support for the ongoing study of twins with autism at the Institute of Psychiatry in London and a study of hypersensitivity in children with autism at the Autism Research Centre in Cambridge.

At the end of the year a new international partnership was formed with the signing of a Memorandum of Understanding with the Prince Salman Center for Disability Research in Saudi Arabia to establish mentored fellowships in the UK, funded by the Center and managed by Autistica, for young Saudi autism researchers.



Nate, our 3 year old son who inspires us every day with each of his tiny achievements

# Financial performance

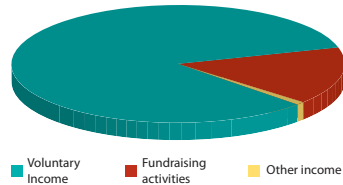
At the end of 2008 the trustees reported that the charity had accumulated substantial volumes of both restricted and unrestricted funds during the year.

They stated that the former were destined for research projects and programmes that either began or grew beyond previous levels of expenditure during 2009, and that the latter would be used to fund research at the trustees' discretion. Both statements proved accurate, with expenditure on autism research more than doubling in 2009 over 2008. Overall the charity committed nearly £1m to its charitable activities during 2009.

## Income 2009

Voluntary Income	£710,506
Fundraising activities	£134,242
Other income	£5,058

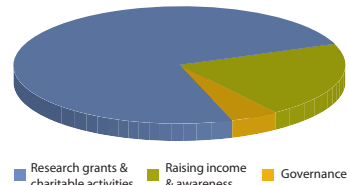
**Total income** **£849,806**



## Expenditure 2009

Research grants & charitable activities	£937,845
Raising income & awareness	£262,859
Governance	£57,297

**Total expenditure** **£1258,001**



Expenditure on autism research **more than doubled** in 2009



## Fundraising

Our task is to raise funds for autism research as quickly and efficiently as we can.



With a strong and stable fundraising team in place we maintained our fundraising performance across a range of activities during some of the most difficult economic circumstances for many years.

Under Head of Events Lynn Hart we ran a full programme of fundraising events in 2009, concentrating our efforts on those we know to be popular with our existing supporters. The single exception was our family-oriented Walk for Autism Research which we concluded was best postponed until 2010.

To compensate for this we further built up our now extensive programme of runs and marathons, including a team of 100 runners in the very popular Royal Parks Half-Marathon and participation in other key running events such as the Reading Half-Marathon, Adidas Women's' Challenge and Great North Run. In addition to these team-based events, a number of individuals continued to support us through individual and ingenious challenges and endeavours.

We once again repeated our popular clay pigeon shoot at the Royal Berkshire Shooting School and lunch at Cliveden Hotel in Buckinghamshire, securing on this occasion Sir John Major as our after-lunch speaker. We were sorry to say goodbye to our most loyal corporate sponsor Nikken at the end of their three-year programme of support, but are pleased that NBC Universal have agreed to sponsor our clay pigeon shoot during 2010.

Trust and Foundation Fundraiser Jane Westley had another successful year, adding further new names to the list of grant-giving trusts providing financial support to Autistica during 2009 and securing repeated grants from a number of others. Trusts and foundations have been a vital source of support during this year of recession, many recognising that fundraising from the public and private individuals is much more challenging in difficult economic times.

## Raising awareness

It is vital, if we are to succeed in our task of accelerating the funding of autism research and bringing forward the development of effective interventions, that we raise awareness of autism itself and why research is so important as well as of our own work.

Under the leadership of Philippa Stannard, our Head of Fundraising Development, we have continued to extend and consolidate our links to those affected by or interested in autism and to raise general awareness of autism and Autistica. As our Chair says in his own review, creating a new name and identity whilst continuing business as usual is no mean challenge and Philippa also led the work on creating the new website and

new materials which underpin our change of name. Once again Design Directions of Twyford came up trumps, creating our new brochures and leaflets featuring the varied faces of autism, kindly contributed by our supporters, entirely free of charge.

Our volunteer Director of Communications Paul Burden has continued to create opportunities for us to talk directly to the media about our work, including contributing to an encouraging panel event at the Science Media Centre in January 2009 on the importance of post-mortem brain studies which was then widely reported.

We hope also that our new cohort of Vice Presidents will have a key role to play in spreading awareness of our work to a wider audience.



This is Luke, he has ADHD and Aspergers Syndrome and is a National Award winning public speaker here in the UK for his conditions.

## Lobbying

Making the case for autism research to government and demonstrating the importance of basing policy for people with autism on a clear understanding of the condition is a key task.

The then chair of the All-Party Parliamentary Group on Autism, Janet Dean MP, once again kindly hosted our annual House of Commons reception in May, bringing together a lively mix of families, researchers, funders, and ministers, members of the Houses of Parliament and government officials to exchange views and learn from each other.

We are privileged to be members of the Advisory Group to the APPGA, an active and effective group of parliamentarians, many of them with family links to autism. The group continued to be highly active in 2009 completing its first-ever formal inquiry into the transition from childhood to



Phil Hope, Care Services Minister, speaks at the Autistica 2010 House of Commons reception

adulthood for people with autism and finding many of the shortcomings in service provision it revealed repeated in the highly influential review on autism published by the National Audit Office in June 2009 and

subsequently supported by the Public Accounts Committee.

Autistica was pleased to be a member of the coalition of autism charities led by the National Autistic Society that supported the 2009 Autism Bill, which achieved the very rare distinction for a private member's bill of actually becoming law after it won government support. The Autism Act 2009 places a legal obligation on local authorities and the NHS to identify and plan services for adults with autism, and is the first ever condition-specific legislation. Eileen Hopkins of Autistica led one of the working groups advising the Department of Health on the ensuing strategy for adults with autism, and we were also part of the steering group for a research project sponsored by the Department for Children, Schools and Families which explored why rates of special educational need, and specifically those associated with autism, vary widely across local authorities.

Other ways in which we are seeking to influence public sector attitudes to and support for autism research are through our continuing programme of meetings with key public sector figures including ministers, parliamentarians and civil servants. We have had regular meetings with policy advisers at Number 10 throughout 2009 and were invited to the seminar on autism hosted by Sarah Brown, wife of Prime Minister Gordon Brown, in December 2009. Mrs Brown also showed her support for the autism community by taking part in a broadcast to mark the second World Autism Awareness Day on 2 April 2009.



# Governance

## Patron:

Professor Sir Michael Rutter

## Trustees:

Winston Fletcher, CBE (Chair)

- ★ Peter Johns  
Dame Bridget Ogilvie
- ★ Dr. Ann Olivarius  
Dr. Ian Ragan
- ★ Gordon Smillie  
Clare Thompson (Treasurer)

## Adviser to the Board on Autism spectrum disorders:

Dr Danny Beath

## President:

- ★ Dame Stephanie Shirley

## Vice Presidents:

- Jane Asher
- ★ Lady Elizabeth Astor
- ★ Sir Christopher Ball
- ★ Angie Barrow  
Christine, Lady Bett  
Josephine, Lady Bonfield
- ★ Ken Giles  
Hugh Merrill MVO
- ★ Dr Zenobia Sharma  
The Lady Vallance

★ indicates family link with autism spectrum disorders

# Saying thank you and looking forward

Once again in 2009 we owe an enormous debt to those who support, sponsor, nurture and fund us, from the individuals who have toiled through marathons, to the major trusts and foundations who have found value in our work, to the private givers – large and small – and the dedicated researchers all of whom have trusted us to take forward their own ambitions for a better future for people with autism.

New opportunities to increase our understanding are opening up even as we write, with plans for at least two new UK autism research centres under development, and potential new funding sources being explored. There is a commitment to people with autism on the part of government that we have not seen before and we will do all we can to ensure that a proper evidence base becomes an essential future element of policy planning and service delivery.



Autistica is dedicated to raising and investing funds to support high-quality peer reviewed research which focuses on determining the causes and biological basis of autism spectrum disorders; improving diagnosis; and advancing and evaluating new treatments and interventions.

We are committed to ensuring that increased understanding and new scientific knowledge will improve the quality of life for all those affected.

Autism is one of the most significant but least researched developmental disorders and Autistica has set itself the task of achieving major breakthroughs within ten years.



# *autistica*

Science in the Service of Autism

**Rotherfield House  
7 Fairmile  
Henley-on-Thames  
RG9 2JR  
United Kingdom**

Tel: +44 (0)1491 412311  
info@autistica.org.uk

Company No. 5184164  
Charity No. 1107350  
Registered in England



© Autistica 2010  
[www.autistica.org.uk](http://www.autistica.org.uk)

