



Annual Review 2008

Raising funds, raising hope.



The only charity in the UK raising funds for pioneering biomedical research into the causes of autism



AUTISM SPEAKS™
It's time to listen.



From the President of Autism Speaks

**Autism has been at the forefront
of my life for many years.**

When my autistic son Giles died, I decided to concentrate on helping those living with autism. After support services, schools etc I came to realise that the best help, the most strategic thing, was to unravel the causes of autism.

I founded Autism Speaks in 2004 as part of a global campaign directly to raise funds for quality, biomedical research and to encourage others to do likewise.

Much of the work to find out what autism is, as distinct from what autism looks like, is pioneered in British universities and research centres by British scientists.

The experts speak of achieving major breakthroughs within ten years - in time to help today's children. My personal mission is that the causes of autism should be understood by 2012 and its global costs halved by 2020.

Autism costs the UK a staggering £28bn a year. It imposes heavy financial and emotional burdens on those affected, those who care about them and, ultimately, on society. It is one of the most significant but least researched developmental disorders - one in a hundred children are diagnosed as having an autism spectrum disorder, yet autism receives only a fraction of the research funding of much rarer conditions such as childhood leukaemia and cystic fibrosis.

It is Autism Speaks' mission to change this. Autism has been a hidden disorder for too long. Now I ask you to listen and act.

A handwritten signature in black ink that reads "Steve Shirley". The signature is written in a cursive, flowing style.

Dame Stephanie Shirley

From the Chair of Autism Speaks



Why Autism Speaks Must Keep Speaking Up

Taking over the chair from Dame Stephanie Shirley, I quickly learned that Autism Speaks is the only UK charity raising funds for biomedical research into the causes of autism and - surprising though this sounds - there is probably no more serious challenge than autism facing medical science today. How could this be?

Well first, autism is far more widespread than most people realise: there are some 500,000 children and adults with autism in Britain, very nearly 1% of the population.

Second, for many of these people it erodes their quality of life from toddlerhood until they pass away: it is, literally, a life sentence.

Third, in impairing their lives it also impairs the lives of their loved ones, dislocating the day-to-day living and behaviour of countless other people, far more than 500,000 - again from the child's early days onwards.

Fourth, as a consequence of all this, autism costs the country a massive £28 billion every single year, a far greater sum than any other costed medical condition.

But fifth, and this is the shocking clincher, autism attracts less than 0.25% of all state medical research funds - in these terms, a paltry £2 million annually.

Manifestly it is vital to do much more. So Autism Speaks funds fundamental research in four key areas: the causes, biology, diagnosis and treatment of autism spectrum disorders. This scientific research aims to discover and develop new medical ways to help autistic people live better and fuller lives - and in doing so, of course, to improve radically the lives of all those close to them.

With each year that passes scientists working in the realm of autism learn more, and move closer to achieving those aims. But they need more resources, to cover more ground and to do the job more quickly. After all, about another 7,000 children who will develop autism are born in Britain every year. We cannot and must not ignore them.

That is why Autism Speaks must, and will, continue to speak up - indeed to holler at the top of our voices if needs be. Autism is a major and crucial human problem. We cannot stay silent about that.

Winston Fletcher

Winston Fletcher



Image of DTI-sagittal-fibres

From the Chief Executive of Autism Speaks



My son Nathan has Asperger's Syndrome;
his sister is in the photo with him.

She loves him dearly but wishes he
could hug her...

Speaking of research

Autism Speaks has been seeking support for research projects in scientific areas that are 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 autism brain chemistry. Increased understanding in these areas will lead to the development of better targeted and more effective interventions.

We are delighted to report that as a result of our fundraising efforts over the last two years all the major programmes for which we have been seeking support are now in progress. Once again funds were made available to the International Autism Genome Project led by Professor Tony Monaco at the University of Oxford with the aid of financial support from the Lord Faringdon Charitable Trust.

This international search for the genes that confer susceptibility to autism is coming to the end of its second phase during 2009 and there are exciting prospects for future work that will support the diagnosis and treatment of autism.



The British Autism Study of Infant Siblings (BASIS) led by Professor Mark Johnson at Birkbeck College London began work early in 2008 and was formally launched in May.

This network is spread across a number of UK universities and involves studying the baby siblings of children already diagnosed with autism, who are at greater risk of developing autism, to look for early markers of the condition with a view to developing more effective early intervention. Significant funds have been contributed by the Henry Smith Charity, Baily Thomas Charitable Fund, the Mercers Foundation, Autism Speaks and others during 2008 and new funds obtained early in 2009 mean that the project is fully funded for the next two years.

Prof Sue Leekam was appointed as the first chair of autism research at Cardiff University at the end of 2008, commencing work in April 2009. Autism Speaks shared the fundraising for this post and its associated fellowship with Wales' national autism charity Autism Cymru, and alongside the commitment to support the new research centre from Cardiff University itself, we were successful in securing funds from the Welsh Assembly Government, Baily Thomas Charitable Fund, the Waterloo Trust, the Freemasons Grand Charity, Autism Initiatives and others. These funds will be handed over early in 2009. As a result of this success we have been asked by University College London to help them to raise funds for a new autism research centre to be established there in 2010.

BRAIN BANK for AUTISM
 Related Developmental Research

The major news during 2008 was the receipt of a single private gift of £200,000 which our trustees have decided to use to support the UK Brain Bank for Autism and Related Developmental Research for three years. The new brain bank, based at Oxford University, was launched in late

summer 2008 and has already received a number of new brain donations. 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. The bank will co-ordinate its activities with those of the Autism Tissue Programme in the United States which is sponsored by our sister charity Autism Speaks Inc.

Other smaller projects supported during 2008 included the ongoing study of twins with autism at the Institute of Psychiatry in London that involves further neuroimaging work, and a new fellowship - using donated funds - at the Autism Research Centre in Cambridge.

We regard recruiting new researchers to autism as a vital part of our task, both those at the beginning of their research career and experienced scientists from adjacent fields who may already have knowledge that will prove critical to our understanding of autism. To this end we worked throughout the year to secure support for a programme of UK fellowships at both junior and senior levels from a number of funders in both the UK and overseas, and we hope to see this work come to fruition during 2009.



My beautiful boy Jack who has no language but can show all his emotions in his face. I love him so much even when he is very stressed!



My son Harry enjoying this year's Autism Speaks' walk at Swinley Forest. Harry loves bouncing so a Tigger face was a must!

Speaking of fundraising

Our task is to raise funds for autism research as quickly and efficiently as we can. We have made good progress across a range of fundraising activities. Overall our voluntary income including gifts in kind and fundraising receipts rose from £833k in 2007, to £1.3m in 2008.

Under Head of Events Lynn Hart we ran a full programme of fundraising events in 2008, providing a range of opportunities for both new and existing donors to show their support. Once again our first 2008 Walk for Autism Research took place in the rain at Alnwick Garden in May courtesy of The Duchess of Northumberland. Our second walk took place in the Swinley Forest, Berkshire on a calm and bright day in October.

During the year, in response to requests from supporters, we began building up participation in what is now an extensive programme of runs and marathons, culminating in a team of 50 runners taking part in the new Royal Parks Half-Marathon. In addition to these



team-based events, a number of individuals continued to support us through personal and ingenious challenges and endeavours.



We repeated our popular "rugby stars" clay pigeon shoot at the Royal Berkshire Shooting School and lunch at Cliveden Hotel in Berkshire, at which Lady Astor spoke of the Astor family's connections with Cliveden and movingly of her autistic daughter.



Golfer Ernie Els, who has a son with autism, nominated Autism Speaks as the beneficiary of the Calloway Golf Longest Drive Competition, leading to significant sponsorship from the Alfred Dunhill Links Tournament. Our principal corporate sponsor Nikken Europe continued to provide significant support during 2008 and this been vital in both spreading the word about Autism Speaks and securing fundraising income in our early years.

Trust and Foundation fundraiser Jane Westley had a very successful year, adding more than a dozen new names to the list of grant-giving trusts providing financial support to Autism Speaks during 2008. This has been complemented by a large number of donations from private and family trusts throughout the year, many of them given on an unrestricted basis. Every year new trusts join us in our drive to discover the causes of autism by funding essential biomedical research and we work hard to foster lasting relationships with them all. We are always looking for new supporters and would be pleased to hear from any trusts and foundations interested in funding autism research.



The Freemasons' Grand Charity hand-over a cheque for £40,000. Their Chief Executive Laura Chapman, said:

"We are proud to be associated with the work of Autism Speaks and this research which brings hope to all who deal with the hardships of autism."

Speaking of 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.

Under the leadership of Philippa Stannard, our Head of Fundraising Development, much has been done to extend our links to those affected by or interested in autism and to raise general awareness of autism and Autism Speaks. Our redesigned website is now visited by around 1,500 people per day or half a million in a year, and the number of people signing up for our e-newsletter increases by about 50 per week.

Through social networking sites such as FaceBook and MySpace we are in touch with well over 3,000 'friends'.



To mark the United Nation's first World Autism Awareness Day,

we organised an eBay character auction, where seventeen top-selling authors, including Lee Child, Jodi Picoult, Louis de Bernieres and Darren Shan, offered literary lovers everywhere the opportunity to have their name featured in an upcoming novel. As well as raising funds, this event raised much online awareness.

We have continued to work hard to ensure that Autism Speaks is brought appropriately to the attention of leading UK media and through them to the public at large. We have encouraged links between researchers and journalists, and particularly appreciate the work of The Science Media Centre in supporting this. Autism research can be subject to ill-informed speculation and comment, but we do believe that despite occasional lapses the accuracy of reporting has improved. We are particularly grateful to our volunteer Director of Communications Paul Burden; and to the families affected by autism that have represented life with autism both to the media and in our fundraising materials.



This is Sarah having a really good day

Speaking to government



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 chair of the All-Party Parliamentary Group on Autism (APPGA), Janet Dean MP, kindly hosted our now annual House of Commons reception in May, once again bringing together this lively mix of families, researchers, funders, ministers, members of the Houses of Parliament and government officials to exchange views and learn from each other. The APPGA continued to be highly active in 2008, preparing a report entitled "Half Way There?" on progress in the development of autism policy, research and services since its ten-year Autism Manifesto was published in 2003. This update concluded that while the picture for children had clearly improved very little progress had been made for adults with autism. Developing this theme the group then launched its first-ever formal inquiry examining the transition from childhood to adulthood for people with autism.

Also, in the middle of 2008 the Department of Health announced that it was to study the prevalence of autism in the adult population, and to develop a strategy for adults with autism. Autism Speaks is contributing to both of these activities and, furthermore, is one of the charities supporting the Autism Bill, which places a legal obligation on local authorities to identify and plan services for those with autism which was launched later in the year.

We are also part of the steering group for a research project sponsored by the Department for Children, Schools and Families which is exploring why rates of special educational need, and specifically those associated with autism, vary widely across local authorities. We were also delighted to be early contributors to research into services for adults with autism by the National Audit Office which will be published in May 2009.

Other ways in which we are seeking to influence public sector attitudes to and support for autism research are through our membership of the Autism Research Co-ordination Group chaired by the Department for Children, Schools and Families; and through continuing our programme of



meetings with key public sector figures including ministers, parliamentarians and civil servants.

We were delighted that in October Sarah Brown, wife of Prime Minister Gordon Brown, followed up the reception for Autism Speaks held at Number 10 Downing Street in September 2007 by meeting Bob and Suzanne Wright, co-founders of Autism Speaks Inc, during a visit to the UK. Mrs Brown declared her personal support for the UN-designated World Autism Awareness Day which she had also shown by attending a UN meeting on autism in New York the previous month.

*Our beautiful
non-verbal daughter*

Speaking to autism researchers

An important part of what we do is ensuring that researchers are given opportunities not only to share findings but to exchange ideas and build collaborations that allow research to progress at a faster pace than would otherwise be possible.



Autism Speaks was therefore proud to share sponsorship of the big event of 2008 - the first International Meeting for Autism Research to take place outside North America which was held in London in May - with its sister charity and with the Medical Research Council (MRC) and others. By far the largest such meeting so far, over 1200 researchers gathered to discuss latest findings and there was a sense of progress and energy at how fast the field is now moving which was shared by the interested families who attended.

The year began with an important research meeting on Frontiers in the Neurobiology of Autism sponsored and hosted by the Wellcome Trust, and organised by Dr Jenny Longmore of Autism Speaks. The meeting was extremely well-attended by 40 leading

researchers from around the world and new ideas and collaborations have developed as a result.

We continued our meetings with the Office of Strategic Co-ordination for Health Research to press the case for better funding of autism research across the full span of publicly-funded health research including the NHS, and our regular dialogue with the MRC on matters of shared interest. We were delighted that towards the end of the year the MRC and Autism Speaks Inc provided joint funding to take forward the work of Prof Adrian Bird of Edinburgh University on Rett's Syndrome, a single-gene disorder that produces autism-like symptoms.

Speaking with other autism organisations

The ultimate aim of all we do is to improve the quality of life for people with autism, and it is important that what we do is set in the context of the work that others do - in differing ways - to achieve this end.

Our key partnership is with our sister charity in the United States, Autism Speaks Inc, the largest

non-governmental funder of autism research in the world. We were pleased to welcome co-founders Bob and Suzanne Wright to meetings of our Development Committee in April and Trustee Board in October. At the end of the year we welcomed the appointment of Dr Simon Wallace as Autism Speaks' Director of Scientific Development Europe, who is based in the UK.



The first UN-designated World Autism Awareness Day on 2 April 2008 created a real opportunity for autism organisations to work together

to raise awareness of autism and call upon governments to fulfil their obligations to people with autism. Autism Speaks took the lead in sharing information about World Autism Awareness Day with other UK autism charities. Our co-ordinated achievements included a call to government to sign the UN declaration of rights for people with disabilities.

Speaking of the future

We do not know what impact the current economic situation will have upon our fundraising endeavours but, with a strong case for support, we are optimistic that we have built a foundation that will see us through these more difficult times.

During 2008 Autism Speaks has been able to move progressively from being primarily a fundraiser for autism research to being a funder too. For the first time we have not only raised the funds we need for the key projects to which we are already committed, but ended the year with the means to issue our first call for new proposals in 2009. We are excited about this and about being able to contribute to the worldwide effort to co-ordinate and streamline autism research. We are cheered by the knowledge that the government has recently announced that there will be no reduction in its commitment to medical research, and look forward to the now approaching days when we see the translation of research findings into real and practical benefits for those we seek to help.

Saying Thank You

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 - who have trusted us to take forward their own ambitions for a better future for people with autism. We would also like to say thank you to those companies and individuals who have generously provided gifts in kind, with special thanks to Design Directions of Twyford, who continue to provide all our design work free of charge.

Hilary Gilfoy

Key supporters include:

Alfred Dunhill Links Championship Committee
Autism Speaks Berkshire Local Volunteer Group
Callaway Golf Company
H & R Sykes Charitable Trust
Lord Faringdon Charitable Trust
Mercers' Charitable Foundation
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The John Lewis Partnership
The Kirby Laing Foundation
The Marlow Trust
The McGrath Charitable Trust
The Sandra Charitable Trust
The Shirley Foundation
The Sir Michael Bett Charitable Trust
The Sydney and Elizabeth Corob Charitable Trust
The Welsh Assembly Government



*My twin boys both have Autism.
They may both have it and they
even look alike, but they are as
different as night and day!*

Autism Speaks income and expenditure account for the year to 31 December 2008

Income	£000
Voluntary income	1,136
Fundraising activities	151
Other income	16
Total income	1,303

Expenditure	£000
Research & charitable activities	458
Raising income & awareness	333
Governance	60
Total expenditure	851

Funds generated in year for future research	452
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The statement of financial activities includes all gains and losses recognised in the year.

All incoming resources and resources expended derive from continuing operations.

The figures and financial information for the year to 31 December 2008 do not constitute the statutory financial statements for that year. Those financial statements have been delivered to the Registrar and included the auditors' report which was unqualified and did not contain a statement either under section 237(2) of the 1985 Act (section 498(2) of the 2006 Act) (accounting records or returns inadequate or accounts not agreeing with records and returns), or section 237(3) (section 498(3) of the 2006 Act) (failure to obtain necessary information and explanations).

Autism Speaks' Patrons:

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Geraldine Peacock CBE

President:

Dame Stephanie Shirley

Trustees:

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Adviser on Autism Spectrum Disorders:

Dr Danny Beath

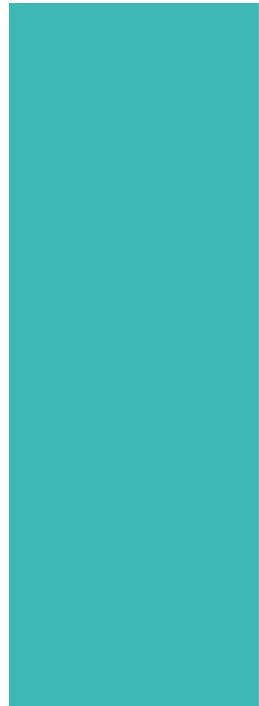
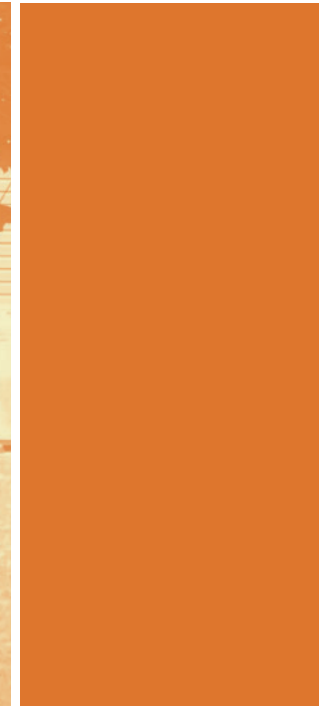
Chief Executive:

Hilary Gilfoxy

Development Committee:

Christine, Lady Bett
Josephine, Lady Bonfield
Elizabeth Corob
Helene Kydd
Hugh Merrill MVO
Gordon Smillie
The Lady Vallance

Thanks also to the families who kindly provided the individual photographs and quotations included in this review.



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