

Who funds autism research?

(<http://www.timeshighereducation.co.uk/story.asp?sectioncode=26&storycode=416108&c=2>)

To understand this survey and its implications, it is first necessary to briefly describe how medical research is funded.

Research is generally funded by 'grants' or 'research awards' made to scientists either as individuals or as collaborative research groups or consortia. Research grants are of utmost importance to researchers – the diligence in writing and submitting a research proposal, anxiety around evaluation by peer review, joy on the news of receiving an award, commitment and stamina in conducting the work and publishing the research findings in scientific and medical research journals - are an integral and aspirational part of any scientists life and research career.

So where do researchers get research grants from? Whom do they apply to? In general research grants are available from 'public' or government funding agencies such as the Medical Research Council in the UK and the National Institutes of Health in the US, from 'private' funders such as from charities like Autistica or Cancer Research UK, Trusts such as the Wellcome Trust, philanthropists either through Foundations such as the Waterloo Foundation and Shirley Foundation or individual philanthropic giving or endowments. The pharmaceutical industry also conducts a lot of research to support the rational development of new medicines and these companies like any commercial organisation have their own R&D budgets and increasingly involve collaboration with university based scientists.

The Times survey of autism research funding is based on an analysis of which funders were acknowledged as supporting work published in autism research articles between 2008-2011. All of the funders named in this list have made significant contributions. It is probably no surprise that at the top of the list are the National Institute of Health and the National Institute of Mental Health located in the US (although these funders do support some overseas research). At the most recent International Meeting For Autism Research held in San Diego (May 2011) Dr Tom Insel the Director at NIMH, revealed that NIH had invested two thirds of the \$314m spent on autism research in the US in 2009 (the last year for which figures are available) and \$122m was committed under the American Recovery and Reinvestment Act in response to the economic downturn.

Is the UK falling behind? Should we be concerned? Whilst the US is understandably able to contribute financially on much larger scale than the UK, UK autism research has a significant role to play and continues to play a significant role on the international stage. There are some really strong and unique aspects to UK autism research, of unrivalled quality, and on equal footing to the US. But there is not the same strength in depth. In the modern era, the nature of research is collaborative, research concepts and discoveries cross international boundaries, and the challenges that autism brings to families and individuals are essentially the same - the need for a reliable and timely diagnosis, effective interventions and government policies and service provision informed by a research driven evidence base. So the UK can reap benefits of global autism research.

However, a notable difference between the US and UK is the research funding provided by

charitable organisations such as the US charity Autism Speaks Inc and the impact of this funding, i.e. Autism Speaks Inc is ranked as third in the Times survey list. Autism Speaks raises funds for research by a relatively small number yet large donations from philanthropists but overwhelming by a large number of small donations from individuals like you and me, donated either through small personal donations or by via participation in sponsored events such as walks, runs, bike rides and other challenges. In the UK this kind of individual participation has been very successful for charities like Cancer UK for example with 'Run for Life'.

So who does fund autism research in the UK? The answer is between 2008-2011 is the Medical Research Council and the Wellcome Trust. There has also been substantial philanthropic giving such as the long term and huge commitment of Dame Stephanie Shirley through the Shirley Foundation (and indeed the founder and major support of Autistica). That needs to continue and indeed Autistica will advocate for more investment, particularly from other government funding agencies and we are pleased to see the recent announcement to invite research proposals from the National Institute of Health Research. However, change is needed towards more personal 'ownership' of driving the autism research agenda forward and for autism research charities in the UK to aspire to the model of the widespread individual support as enjoyed by Cancer Research UK.

What difference can you make? Over the last five years, a good number of people have regularly donated their time, their physical and creative energies to raise monies for Autistica, for which we are highly appreciative. But many, many more are needed. We need your support, sign up for our newsletter, be informed but most of all, in any way you can, help Autistica raise money to fund more research, to put Science into the Service of Autism, so that more can be done to bring forward benefits for families and individuals affected by Autism Spectrum Disorders.

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