



This is what Spectrum 10K has said about:

Past work and statements of Spectrum 10K researchers

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1. Do previous writings/ comments contradict stated Spectrum 10K aims and values?

No members of the research team have published opinions or are conducting research that contradicts the aims: “Spectrum 10K aims to investigate genetic and environmental factors that contribute to the wellbeing of autistic individuals and their families.”

We are aware that some members of the public believe our researchers are seeking a prenatal test for autism as a way to prevent autistic babies from being born in the future. We have categorically stated that this is not the case. Aspects of some published articles appear to have been misinterpreted or taken out of context.

One example relates to an article published by Professor Simon Baron-Cohen in 2009, which includes the line “Caution is needed before scientists embrace prenatal testing so that we do not inadvertently repeat the history of eugenics or inadvertently ‘cure’ not just autism but the associated talents that are not in need of treatment.” This article has been interpreted by some as meaning that Professor Baron-Cohen was, at that time, in support of a prenatal test and cure for autism and concerned only about the preservation of ‘associated talents’. In fact, the opposite is true.

Professor Baron-Cohen clarifies that he has never been in support of a cure for autism and has never been in favour of a prenatal screening test for autism. Indeed, his article in 2001 was one of the first to question why autism was seen as a disorder, disease or even a disability, and argued strongly for recognizing



autism as a difference. He was the first person to introduce the term Autism Spectrum Conditions (ASC) instead of Autism Spectrum Disorder (ASD), to shift perception away from disease or disorder and towards difference and disability. His intention in the 2009 article mentioned above was to encourage scientists to question the then widespread assumption that autism needed a cure. He was at the forefront of encouraging scientists and clinicians to question this.

Professor Baron-Cohen has explained that in highlighting how ‘cures for autism’ could also lead to a loss of talents, he was making the point that autism entails both strengths as well as challenges. In another 2009 article, in *Community Care* magazine, he clearly stated his own position that all autistic people’s lives have value, whether or not they have talents. In response to a *Guardian* article misrepresenting ARC research as developing a prenatal test for autism (the ARC has never conducted research with the aim of developing a prenatal test for autism) Professor Baron-Cohen wrote a series of commentaries in *New Scientist* to correct the record. More recently, he has reiterated both his and the ARC’s opposition to eugenics and to viewing autism as a disease or disorder in need of a cure. His keynote speech at the UN in New York on Autism Awareness Day 2017 was one of the first to address the topic of autism and human rights, and his record over many decades shows his commitment to respecting autistic people. He is outspoken in his support of neurodiversity.

It is also important to note that the Spectrum 10K Principal Investigators make a distinction between autism and severe neurodevelopmental conditions, the latter being conditions in which the individual may have developmental delays, intellectual disability, epilepsy, and/or motor coordination difficulties, as well as potentially impaired development of other organs, e.g. congenital heart defects. Examples are DDX3X syndrome, Wiedemann-Steiner Syndrome (KMT2A), and Kabuki syndrome (KMT2D). Cures, treatments and improved clinical management for some conditions in this category may be needed for some symptoms in some individuals. The PIs are aware that some parents who already have one child with such conditions may request prenatal testing because they wish to avoid having a second child with the same condition. The PIs see this as outside of their roles as scientists and are aware that this use of prenatal testing is provided as part of clinical care within the NHS

(<https://www.genomicseducation.hee.nhs.uk/blog/what-is-nipd/>,
<https://bwc.nhs.uk/prenatal-reproductive-genomic-testing/>).

It would be wrong for the PIs to comment on parental choice to terminate a pregnancy, but the PIs encourage more discussion and debate in the public on these bioethical issues. To reiterate, it is important to distinguish seeking a cure or treatment for such co-occurring conditions, which may be wanted as part of medical care, and which the PIs do support, vs. seeking a cure or treatment for autism itself, which the PIs do not support. Finally, and again to be clear, none of the PIs support prevention of autism.

There is also a lack of clarity in terminology, perhaps more in the US than in the UK. At times, those with severe developmental conditions and autism are referred to only as ‘autistic’, rather than as having severe developmental disorders *and*



autism. This can lead to misunderstandings, and research seeking a cure or treatment for severe neurodevelopmental conditions can be misconstrued as seeking to cure autism. We hope we have been clear that none of the PIs are seeking to prevent or cure autism.

2. Is Autism Speaks involved in Spectrum 10K?

Autism Speaks is not involved in Spectrum 10K. Autism Speaks is not providing any of the funding for the project. We have not discussed the project with Autism Speaks at any point.

During Spectrum 10K, we plan to analyse previously collected genetic data from several other databases. One of the databases that we plan to use is the Autism Genetic Resource Exchange (AGRE), which is owned by Autism Speaks. We will have to apply to Autism Speaks for approval to access AGRE and pay a small fee to Autism Speaks for each piece of data that we access. This will not enable Autism Speaks to influence Spectrum 10K in any way other than approving or denying our application. For more information about the process for accessing AGRE, visit <https://www.autismspeaks.org/applying-access-agre-data-and-biomaterials>.

Some members of the research team have an indirect relationship with Autism Speaks. The ARC and the Spectrum 10K PI, Simon Baron-Cohen, are involved in AIMS-2-TRIALS, which is a research project being carried out by 48 European organisations. Whilst AIMS-2-TRIALS is primarily funded by the European Union, it receives some of its funding from Autism Speaks. Spectrum 10K is not directly involved with AIMS-2-TRIALS in any way. For more information about Autism Speaks' role in AIMS-2-TRIALS, visit <https://www.aims-2-trials.eu/about-aims-2-trials/team/autism-speaks/>.

In addition, in 2010 one graduate student at the ARC was funded by a predoctoral fellowship investigating 'Hypersensitivity in autism: a psychophysiological and neuroscientific approach', which was funded by Autism Speaks. The fellowship ended in 2012 and the ARC has received no direct funding from Autism Speaks since then.

3. What was Daniel Geschwind's role in Cure Autism Now (which later became Autism Speaks)?

In the 1990s Professor Daniel Geschwind chaired Cure Autism Now's (CAN) scientific advisory board as a neurologist.

Cure Autism Now was created by parents in the autism community in the 1990s to fund autism research, primarily for syndromic forms of autism (autism with a known genetic cause, such as Fragile X syndrome and Tuberous Sclerosis Complex), at a time when there was almost no funding.



Daniel Geschwind's research was never funded by CAN. He did not receive money from CAN for his involvement.

Daniel Geschwind shares the values of the rest of the Spectrum 10K team. He acknowledges that language, concepts and priorities of the autism community have changed over the past 30 years.