

Autism Speaks



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Mission

Autism Speaks is the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments, and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

Strategy/Approach

Autism Speaks provides funding and facilitates research into all aspects of autism, and advocates for further commitment of resources toward autism by engaging with federal, state, and local officials with its **Autism Votes** initiative. Autism Speaks has also created a number of tools for patients and their families through its **Family Services** initiative.

The organization is dedicated to facilitating global research into the causes, treatments, and prevention of autism by promoting cross-disciplinary cooperation, funding research, organizing research summit meetings, and establishing standards for data collection and management to benefit the scientific community.

Key programs include:

- **Autism Genetic Resource Exchange (AGRE)** – a repository of genetic and clinical information that is made available to autism researchers worldwide.
- **Autism Treatment Network (ATN)** – Established in 2005 as the nation's first network of hospitals and physicians aiming to bridge gaps in knowledge and understanding and to improve treatment for individuals with autism.
- **Autism Tissue Program (ATP)** – A parent-led post-mortem brain tissue donation program dedicated to autism research.
- **Autism Clinical Trials Network (ACTN)** – Focused on translational research, the critical step necessary to transfer findings from the laboratory to clinical application.
- **Interactive Autism Network** – Online project bringing together tens of thousands of people nationwide affected by autism spectrum disorders (ASD) and hundreds of researchers in a search for answers.
- **YOU Can Participate!** – Provides information to families affected by autism about national and local research studies through its Family Participation in Research Studies Web Listing.
- **Global Autism Public Health Initiative (GAPHI)** – Works to foster collaborations among governments, communities, and scientists in order to support a self-sustaining public health infrastructure to enhance

awareness and capacity for autism services and research.

- **Preclinical Autism Consortium for Therapeutics (PACT)**—addressing the lack of movement of promising autism medications moving into clinical trials and that there are no FDA approved medications for treating the disorder's core symptoms.
- **Delivering Scientific Innovation for Autism LLC (DELSIA)**—established in 2012 as a non-for-profit affiliate of Autism Speaks. An innovative funding vehicle with the goal of improving outcomes for individuals with autism spectrum disorder. DELSIA facilitates this by ensuring scientific breakthroughs and technological advances are developed into products that improve health and quality of life for individuals with autism and their families.
- **Autism Investment Conference**—annual conference, began in 2013, for investors, life science executives, biotech/pharmaceutical development professionals, research analysts, health care providers, and entrepreneurs. The goal of the conference is to educate attendees about many of the unique opportunities, challenges, and risks facing autism product development today.

Research Portfolio

Autism Speaks aims to identify and support promising research in the hope that results from these efforts will produce significant findings that will be reported in peer-reviewed journals and lead to additional research support from government or other funding agencies. The organization's science portfolio targets five specific areas: etiology, biology, diagnosis, treatment, and dissemination (translating science into practice). Funding mechanisms include:

- **Grants** – Each year, Autism Speaks holds a variety of investigator-initiated grant calls – from basic to clinical to treatment. These include pilot grants, basic and clinical grants, and treatment and technology grants.
- **Fellowships** – Autism Speaks fellowships provide resources to support and encourage the development of young scientists who benefit from the mentorship of prominent researchers. These include the Dennis Weatherstone Predoctoral Fellowship, offered to encourage and support the training of young scientists interested in devoting their careers to autism research, and the Postdoctoral Fellowship in Translational Autism Research, designed to support promising, well-qualified postdoctoral scientists in their pursuit of translational research training.

- **Initiatives** – Autism Speaks supports a variety of collaborations and consortiums in autism research, including the Autism Genome Project, Environmental Factors in Autism Initiative, GAPHI, Innovative Technology for Autism Initiative, Move the Needle, High Risk Baby Siblings Research Consortium, and the Toddler Treatment Network.
- **Resources** – Autism Speaks created several open resources available for the scientific community, including AGRE and ATP. In addition, the ACTN and ATN provide infrastructure for collaborative medical research and clinical trials.

Partnership Practices

Autism Speaks has formed robust partnerships with patient groups, corporations, and government entities both in the United States and worldwide. For example, it teamed with **Hewlett-Packard** and the **Doug Flutie Jr. Foundation for Autism** to launch “Hacking Autism,” an initiative that took ideas from the autism community and engaged volunteer developers to create “apps” and other technologies that give those with autism a voice. It also works with retailers such as **Toys“R”Us**, **T.J. Maxx**, **Dollar General**, and **Home Depot** on various fundraising campaigns.

Autism Speaks partners with pharmaceutical and biotech companies. For example, an international consortium of scientists, led by Roche, King’s College London, and Autism Speaks, is collaborating on one of the largest-ever academic-industry research projects to find new methods for the development of drugs for ASD. European Autism Interventions – A Multicentre Study for Developing New Medications is the largest single grant for autism research in the world and the largest for the study of any mental health disorder in Europe. The project brings together top scientists from universities around the world, experts from Autism Speaks, and major global drug companies including **Roche**, **Eli Lilly**, **Servier**, **Janssen Pharmaceutica**, **Pfizer**, and **Vifor Pharma**.

Autism Speaks affiliate **DELSIA** also partners with pharmaceutical and biotech companies. Their first partnership with Seaside Therapeutics was announced in December 2012.

Financials

Autism Speaks is a 501(c)(3) tax-exempt nonprofit organization. The most recent financial information available is from 2012.¹

Year ending 12/31/12:

- Revenue: \$58,817,403
- Assets: \$17,979,095
- Grants paid: \$5,000,000
- Gifts received: \$50,086,016
- Expenditures: \$64,127,886

Key Accomplishments

- In 2012, Autism Speaks awarded more than \$5 million to new autism research.
- Committed more than \$199 million to autism research since its inception.
- 17 clinical centers across North America are part of the Autism Speaks’ Autism Treatment Network.
- 4,000 children are enrolled in the ATN patient registry, and more than 22,000 families are served annually.
- 29 states have enacted autism insurance reform laws thanks to Autism Speaks’ advocacy efforts.
- Funded more than 737 research projects and fellowships, which has been leveraged into nearly \$153 million in NIH and other funding for the continuation of these scientific studies.
- The “Learn the Signs” public service announcement has become the number one Ad Council campaign in donated media, garnering more than \$258 million in donated media since its inception.
- Funded the first study to screen a general population for autism to better estimate the prevalence. (Found that 1 in 38 South Korean children are affected by ASD.)
- Launched the Translational Medicine Research Initiative with the goal of turning biological findings into practical diagnostic and treatment methods.

Leadership

Autism Speaks is governed by a **Board of Directors** and supported by **Advisory Committees and Boards**, a **Family Services Committee**, and a New York-based leadership staff.

- **President:** Liz Feld
- **Executive Vice President, Strategic Communications:** Michael Rosen
- **Chief Science Officer:** Rob Ring, Robert.Ring@autismspeaks.org

Other Information

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- **Executive Director:** Ann Gibbons
- **Director, Field Development:** Susan Pereles

¹ Information obtained from Autism Speaks, <http://www.autismspeaks.org/about-us/annual-reports>, July 2013.