

Making A Difference In: Massachusetts

May 2009

MISSION

www.AutismSpeaks.org

Autism Speaks is dedicated to increasing awareness, research, advocacy and family services for all who struggle with autism spectrum disorders.

ADVOCACY

www.AutismVotes.org

In January 2009, an autism insurance reform bill was introduced in the Massachusetts legislature. House Bill 0067_001, sponsored by State Representative Barbara A. L'Italien (D-42) and State Senator Frederick E. Berry (D-7), will require private healthcare policies to provide coverage of the diagnosis and treatment of autism spectrum disorders. HB 0067_001 will cover applied behavior analysis (ABA) and other medically necessary, evidence-based treatments prescribed by an insured's treating physician or psychologist. There are currently eight states that have passed similar bills. Sign up to receive advocacy alerts at www.autismvotes.org.

FAMILY SERVICES

www.AutismSpeaks.org/community/family_services

Autism Speaks' grants to community organizations expand existing programs to serve more individuals with autism, and create new programs that demonstrate true innovation in providing services in one of the following areas of need: Education, Recreation/Community Activities, Equipment/Supportive Technology or Young Adult/Adult Services.

In the state of Massachusetts, a total of six grants totaling over \$150,882 have been awarded in two years:

- **Asperger's Association of New England**
 - Destination Independence
- **Autism Services Association**
 - Employment & Community Accessibility for Young Adults with ASD Transitioning from School to Work
- **Child Talk**
 - Using Play to Foster Communication in Children with ASD
- **Massachusetts Advocates for Children**
 - Parents and Professional Training Project: Targeting Outreach to Underserved Families
- **Melmark New England**
 - Family Focused Intervention, Training and Support
- **Nashoba Learning Group (NLG)**
 - New staff training for NLG expansion of student body

ADDITIONAL FAMILY RESOURCES

- **100-Day Kit for Newly Diagnosed Families** – this free kit provides helpful, personalized information which includes local resources, support groups, where and how to find services, local conferences and recreational activities (also available in Spanish).
- **School Community Toolkit** – available online to assist members of the school community in understanding and supporting students with autism.
- **Family Services Resource Guide** – lists numerous MA resources and more nationwide. This extensive, searchable online database brings resources to families, like early intervention to adult services, and is searchable by zip code.
- **Autism Response Team (ART)** – the ART team is comprised of full-time, paid employees who are also parents of children with autism. The ART specialists are experienced and trained to respond to a variety of questions and concerns from families affected by autism. Call 1-800-AUTISM2 to speak with an ART representative.

AWARENESS

www.AutismSpeaks.org

- As a result of the award-winning Autism Speaks "Odds" campaign in partnership with the Ad Council, there has been a 43 percentage point increase in public awareness of ASDs.
- In December 2007, the United Nations declared April 2nd World Autism Awareness Day.
- In Massachusetts, Autism Speaks volunteers and staff organize a number of Autism Awareness Days.

SCIENCE: Local Grants

www.AutismSpeaks.org/science

Autism Speaks has committed over \$98 million in grants to support 773 promising research projects and fellowships into the causes and treatments of autism. The investment in these research grants alone has been leveraged into nearly \$153 million in NIH and other funding. Locally, 70 projects representing over \$10 million in investments have been funded. Some of these projects are:

- **Beth Israel Deaconess Medical Center**
 - Identification of genes involved in autism
 - The language neural network in autism
- **Boston University Lab of Cognitive Neuroscience**
 - Functional connectivity of language areas in autism and specific language impairment
 - Identifying neurobehavioral markers of ASD in high risk infants
- **Boston University, School of Medicine**
 - Cerebellar circuitry in autism
 - Neurobiological markers of language acquisition and functioning in autism
- **Children's Hospital Boston**
 - Early predictors and clinical correlates of autism in the tuberous sclerosis
 - Gene Expression Profiling of Autism Spectrum Disorders
- **Harvard University Medical School**
 - White matter/brain development initiative
 - Identifying gastrointestinal conditions in children with ASD
- **Massachusetts General Hospital**
 - Evaluation of intestinal inflammation and carbohydrate digestion in children with ASD
 - Quality of life for children with ASD and their parents
- **Northeastern University**
 - Environment: The impact of our surroundings upon developing autism methylcobalamin: A target for neurodevelopmental toxins.
- **University of Massachusetts Boston**
 - Social-cognitive processing in infant siblings of children with autism
- **University of Massachusetts Amherst**
 - The identification of non-verbal oral, motor speech and phonological impairment in individuals with ASD

LOCAL VOLUNTEERS

www.walknowforautism.org

A volunteer network of nearly 1,000 supporters work to raise awareness about autism, raise funds, and advocate for statewide autism legislature. Leadership Committees based in the Greater Boston and Western MA areas organize annual **Walk Now for Autism** events.

LOCAL OFFICE - Greater Boston

Phone: (617) 924-1225

E-mail: greaterboston@AutismSpeaks.org



Facts About Autism

Did you know...

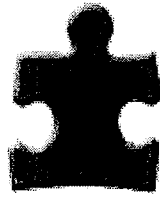
- 1 in 150 children is diagnosed with autism
- 1 in 94 boys is on the autism spectrum
- 67 children are diagnosed per day
- A new case is diagnosed almost every 20 minutes
- More children will be diagnosed with autism this year than with AIDS, diabetes & cancer combined
- Autism is the fastest-growing serious developmental disability in the United States
- Autism costs the nation over \$90 billion per year, a figure expected to double in the next decade
- Autism receives less than 5% of the research funding of many less prevalent childhood diseases
- Boys are four times more likely than girls to have autism
- There is no medical detection or cure for autism

Incidence vs. Private Funding

Leukemia	Affects 1 in 25,000	Funding: \$310 million
Muscular Dystrophy	Affects 1 in 20,000	Funding: \$175 million
Pediatric AIDS	Affects 1 in 8,000	Funding: \$394 million
Juvenile Diabetes	Affects 1 in 500	Funding: \$130 million
Autism	Affects 1 in 150	Funding: \$15 million

National Institutes of Health Funds Allocation

- Total 2005 NIH budget: \$29 billion
- Of this, only \$100 million goes towards autism research. This represents 0.3% of total NIH funding.



AUTISM SPEAKS
it's time to listen.

Learn the signs of Autism

Do you know what to look for? In clinical terms there are a few “absolute indicators,” often referred to as “red flags,” that indicate that a child should be evaluated to ensure that he/she is on the right developmental path.

- A six-month-old should smile or have other expressions of happiness.
- By nine months, a child should have back-and-forth sharing of sounds and facial expressions.
- By one year, a child should be babbling, pointing and showing, reaching, and waving.
- Every child should have some words by 16 months.
- By two years, a child should have meaningful two-word phrases, without simply imitating or repeating.
- A loss of speech or babbling or social skills at any age is cause for concern.
- The child doesn't turn when the parent says their name.
- The child doesn't turn to look when the parent points and says, “Look at...”
- The child fails to make eye contact with people.

If your baby or that of someone you know shows any of these signs that may indicate a child is at risk. A pediatrician or family practitioner should be contacted for an immediate evaluation.

AUTISM

TREATMENT NETWORK

AUTISM TREATMENT NETWORK

For years autism has been considered by some, including many insurance companies, a mental health issue, not a medical one. As a result, in many cases treatment has not been covered. In fact, despite increasing understanding in recent times, many doctors have difficulty providing effective treatment for autistic patients. The Autism Treatment Network (ATN) was established to address these issues.

The ATN is the nation's first network of hospitals and physicians dedicated to furthering the understanding of autism and improving treatments for children and adolescents with autism. The ATN offers families medical care from highly experienced in helping patients with autism and providing treatments for conditions such as gastrointestinal and sleep disorders, which are often associated with autism. In keeping with the collaborative nature of the ATN, doctors share current best practices with other treatment providers. They are dedicated to finding better ways to manage the health of children with autism and sharing new knowledge with other physicians in their personal networks and across the wider medical community.



Where is the ATN?

Currently the network consists of fifteen locations across the country. If you are interested in learning more, email atn@autismspeaks.org or call (888) 8-AUTISM ext. 754.

Current Locations

Arkansas Children's Hospital/UAMS

Little Rock, Arkansas

Kennedy Krieger Institute

Baltimore, Maryland

Baylor College of Medicine/Texas Children's Hospital

Houston, Texas

Massachusetts General Hospital/LADDERS

Boston, Massachusetts

Bloorview Kids Rehab/The Hospital for Sick Children/Surrey Place Centre

Toronto, Ontario, Canada

Oregon Health & Science University

Portland, Oregon

The Children's Hospital, University of Colorado

Denver, Colorado

University of Missouri - Columbia/Thompson Center

Columbia, Missouri

Cincinnati Children's Hospital Medical Center

Cincinnati, Ohio

University of Pittsburgh Medical Center

Pittsburgh, Pennsylvania

Columbia University Medical Center

New York, New York

University of Rochester Medical Center

Rochester, New York

Kaiser Permanente Autism Spectrum Disorders Center

San Jose, California

The University of Washington Medical Center

Seattle, Washington

Vanderbilt University Medical Center

Nashville, Tennessee

Support the ATN!

Our goal is to establish a standard of care for autism and to make medical treatments available for families across the U.S. and Canada. In order to grow the ATN into the nationwide network we envision, we need your help. Your contributions to Autism Speaks support the ATN. Log on to www.autismspeaks.org/donate to make your contribution today, or mail a check to the address below.

www.autismspeaks.org/atn



Autism Speaks is dedicated to increasing awareness of the growing autism epidemic and to raising money to fund scientists who are searching for a cure. Autism Speaks is the result of bringing together Autism Speaks, Cure Autism Now and the National Alliance for Autism Research, the three leading organizations dedicated to accelerating and funding biomedical research into the causes, prevention, treatments and cure for Autism Spectrum Disorders; to increasing awareness of the nation's fastest-growing developmental disorder; and to advocating for the needs of affected families. Autism Speaks and its predecessor organizations have awarded autism research grants valued at more than 50 million dollars. To learn more about Autism Speaks, please visit www.autismspeaks.org.

Autism Speaks
5455 Wilshire Blvd # 2250
Los Angeles, CA 90036
(888) 8-AUTISM

100 Day Kit: Newly Diagnosed Families

A tool kit to assist families in getting the critical information they need in the first 100 days after an autism diagnosis.

Request A Kit

Newly diagnosed families, within six months of receiving an autism spectrum diagnosis, may request a kit.

On line:

www.autismspeaks.org/community/family_services/100_day_kit.php

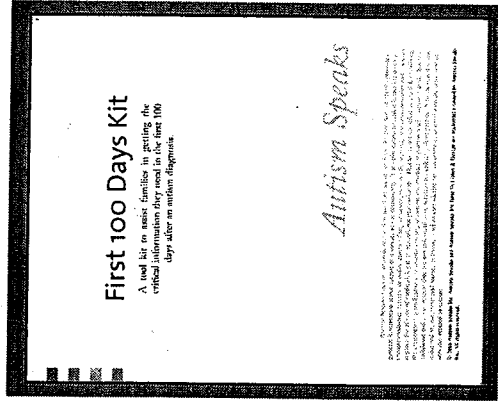
Phone:

888- AUTISM 2 (288-4762)

100 Day Kit Available in PDF

For families whose children have been diagnosed with autism longer than 6 months, agencies, schools, or autism organizations, the 100 Day Kit is available on line in a PDF format to view and download.

www.autismspeaks.org/community/family_services/100_day_kit.php



For more information

contact

Email: 100daykit@autismspeaks.org

Phone: 888-AUTISM 2 (288-4762)

888-288-4962 (Bilingual Spanish Speaking)

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www.AutismSpeaks.org



TARGETED INITIATIVES

As important as individual grants, initiative projects give Autism Speaks a much more proactive role in promoting specific research. Initiatives frequently involve formation of collaborative research consortia, support of targeted research, organization of research meetings, and creation of research resources. Autism is a complex disease and we believe initiatives that bring together researchers in varied fields (genetics, behavioral sciences, and many others) promote a collaborative approach that will help solve the mysteries of this devastating disorder as quickly as possible.

Our **targeted initiatives and collaborative programs** include:

± ENVIRONMENTAL FACTORS IN AUTISM INITIATIVE

- The role of environmental factors in the development of autism is a crucial area of study. The Environmental Factors in Autism Initiative targets research that seeks to understand and identify the potential role environmental factors play in triggering autism.

± BRAIN DEVELOPMENT INITIATIVE

- The Brain Development Initiative takes its impetus from a confluence of findings on abnormal brain development in autism. This initiative focuses on bridging research disciplines - brain structure, function, chemistry, and genetics—to fund innovative work in understanding why brain development goes awry.

± INNOVATIVE TECHNOLOGY FOR AUTISM INITIATIVE

- The Innovative Technology for Autism Initiative was established to lead in the development of products that provide real world solutions to issues faced by those with autism, their families, educators, healthcare specialists, and researchers. The program sponsors grants, classes and technical symposia, among others.

± AUTISM GENOME PROJECT

- The Autism Genome Project (AGP) is the largest study ever conducted to find the genes associated with inherited risk for autism. The project is a public/private research partnership involving a consortium of approximately 50 academic and research institutions. The ultimate goal is to enable doctors to biologically diagnose autism and researchers to develop universal medical treatments and a cure.

± AUTISM EPIDEMIOLOGY NETWORK

- Autism Speaks and the Centers for Disease Control and Prevention (CDC) are co-sponsoring the Autism Epidemiology Network in an international effort to understand the causes of autism, particularly across diverse genetic and cultural settings.

± HIGH RISK BABY SIBLINGS CONSORTIUM

- The High Risk Baby Siblings Research Consortium was established in 2003 with the goal of bringing together the major research groups in the field (including the National Institutes of Health and scientists representing 17 research institutions worldwide) to discover the earliest behavioral and biomedical markers of autism spectrum disorder.



GRANTS and FELLOWSHIPS

Autism Speaks offers many types of grants which target critical areas of autism research. Our goal is to facilitate efforts that will produce significant findings and lead to additional research support from government and other funding agencies. Fellowships provide the necessary resources to support and encourage the development of young scientists who benefit from the mentorship of prominent researchers.

Our grants and fellowships include:

- ✦ **PILOT STUDIES** - Grants for Pilot Studies are intended to draw new investigators into the field of autism research and to allow researchers to collect preliminary data to show the plausibility of an innovative area of exploration.
- ✦ **BASIC and CLINICAL GRANTS** - Basic and Clinical Grants fund a broad range of areas, providing researchers the opportunity to pursue leads that have shown promise in pilot studies and offering larger awards over a longer period of time.
- ✦ **TREATMENT GRANTS** - Treatment Grants address the urgent need to develop effective therapies to treat those living with the disorder today by supporting research focused on all aspects of treatment including behavioral, biomedical and technological interventions.
- ✦ **INNOVATIVE TECHNOLOGY FOR AUTISM GRANTS** - The goal of the Innovative Technology for Autism Grants is to spur development of new technology to assist those living with autism. Areas of focus include assistive technologies, educational products, rehabilitation technologies, data communication and telecommunications technologies, and tools such as lab equipment, informatics and assessment instruments.
- ✦ **AUGMENTATION and OPPORTUNITY-BRIDGE AWARDS** - The Augmentation and Opportunity-Bridge Award is designed to supplement or expand the scope of existing funded research projects. These additional funds enhance the scientific value of the overall endeavor and capitalize on projects which are already underway.
- ✦ **PHYSICIAN/INVESTIGATOR BEGINNING AUTISM RESEARCH FELLOWSHIPS** - Our Physician/Investigator Beginning Autism Research (PIBAR) Fellowships support medical doctors who wish to spend a year devoted to doing autism research. Both parents and researchers have come to realize the difficulty in finding experts in autism in clinical and research settings. We believe this investment in autism research training will encourage many of our fellows to assume teaching roles and join departments around the country and the world, increasing the number of sites with expertise in autism.
- ✦ **MENTOR-BASED FELLOWSHIPS** - Mentor-Based Fellowships are pre-doctoral and post-doctoral fellowship awards offered to encourage and support the training of young scientists interested in devoting their careers to autism research.

SCHOOL Community Tool Kit

A tool kit to assist members of the school community in understanding and supporting students with autism.

About this Kit

As the rate of autism diagnosis increases, many more public and private schools will include students with autism. Learners with autism may have some additional challenges in the school environment, but with the support of the school community students with autism can make great strides and become valued members of a student body. Just as students can learn from each member of the school community, the school staff and peers can learn that students with autism have a lot to offer in return.

This tool kit is not intended to be a curriculum for special education for students on the autism spectrum, but rather a support for the general education and administrative school staff who interact with students with autism in various capacities.

School Community Tool Kit Modules

- What is autism?
- How might a child with special needs be a part of our school?
- General Strategies for Intervention
- For specific members of the School Community
- Resources
- Appendix

School Community Tool Kit PDF

The School Community Tool Kit is available on line in PDF format to view and download at www.AutismSpeaks.org/school



For more information

contact
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917-475-5075

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