

# Where We've Been and Where We're Going

## The Autism Society's Proud History

As the nation's oldest grassroots autism organization, the Autism Society has been working to improve the lives of all affected by autism for 46 years. When the organization was founded in 1965, the autism community was very different than it is today: the term "autism" was not widely known, and doctors often blamed the condition on "refrigerator mothers," or parents who were cold and unloving to their children – a theory that we now know to be completely false.

Perhaps even more discouraging than the blame and guilt placed upon parents of children with autism at this time was the complete lack of treatment options. Parents were often told that their child would never improve, and that he or she should be institutionalized. "All practitioners we saw had one characteristic in common – none of them was able to undertake treatment," wrote Rosalind Oppenheim, mother to a then-6-year-old son with autism, in an article in the June 17, 1961, *Saturday Evening Post*. "When will you stop running?' one well-meaning guidance counselor asked us along the way. When indeed? After eighteen costly, heartbreaking months we felt that we had exhausted all the local medical resources."

Oppenheim's article garnered many letters from other parents of children with autism who had had similar experiences. She sent them on to Dr. Bernard Rimland, another parent of a child with autism who was also a psychologist. Not long after, Dr. Rimland published the landmark book *Infantile Autism*, the first work to argue for a physical, not psychological, cause of autism. As other articles were published in contemporary popular literature, more and more letters from parents and professionals were sent on to Dr. Rimland. These letters were "filled with anguish and a sense of despair," he wrote. Because the parents and professionals involved with these children were so alone in their struggle for help, Dr. Rimland made plans to form an organization whereby they could at least be put in touch with one another.

Those plans became reality on November 14, 1965 when about 60 people, mostly parents, came from all over the Northeast to Teaneck, N.J. For many, it was the first meeting with other parents. Most had spent years and a small fortune obtaining a diagnosis, only to learn that no further help was available. Most communities had no facilities for the care or education of children with autism. The group realized more than ever before the need to have a national organization that would work to seek education and care for people with autism, one that would work for adequate legislation, research and publicity for their unique challenges. The Autism Society (then called the National Society for Autistic Children) was born. We all owe a debt of gratitude to these courageous mothers and fathers who had the fortitude and vision to take on the medical establishment and challenge commonly held beliefs about they cause and prognosis of autism. They shaped not only the future for them and their children; they quite literally paved the way for all of us.

Following are some highlights and accomplishments that the Autism Society has achieved over the years.

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**1943:** Dr. Leo Kanner publishes an article entitled, "Autistic Disturbances of Affective Contact," in which he coined the term autism and described the syndrome.

**1948:** Congress passes a law that prohibits discrimination against people with disabilities.

**1961:** Rosalind Oppenheim publishes an article "They Said Our Son Was Hopeless" in the *Saturday Evening Post* to enormous response which she forwards on to Dr. Bernard Rimland.

**1972:** Retiring NSAC president S. Clarence Griffith is appointed to the government's Child Development National Advisory Committee. The Autism Society begins to promote National Autistic Children's Week (now National Autism Awareness Month).



Dr. Bernard Rimland

**1963:** The Developmental Disabilities Act is authorized. The University Affiliated Facilities is established to expand the number of professionals to work with persons with developmental disabilities.

**July 1969:** NSAC establishes an autism specific bookstore. 400 people attend the first NSAC National Conference in Washington D.C.

**1964:** The book *Infantile Autism* by Dr. Rimland makes the first argument for a physical cause of autism

**Early 1965:** CBS produces "Conall," the story of a boy with autism told by his family, letters of response are sent to Dr. Rimland. *Life* magazine publishes an article by Dr. Ivar Lovaas, (father of Applied Behavior Analysis) on his work with children with autism; responses are again sent to Dr. Rimland.



Ruth Christ Sullivan, Ph.D.

**February 1969:** NSAC presents a statement to the Joint Commission on Mental Health of Children refuting the finding that psycho-social trauma is the major cause of mental illness in children.

**Late 1965:** Dr. Rimland, together with 60 others form the National Society for Autistic Children (NSAC) in Teaneck, N.J. (renamed the Autism Society of America in 1987).

**1968:** Ruth Christ Sullivan, Ph.D. becomes the president of NSAC in the first election of officers and board members.

**1966:** NSAC joins the Advisory Committee to the Joint Commission on the Mental Health of Children. NSAC prints its first newsletter.

**1973:** Section 504 provides discrimination protection for people with disabilities by programs receiving federal assistance.

**1975:** Autism is included in the definition of developmental disabilities, allowing individuals with autism to be eligible for benefits under the Developmental Disabilities Act.

Congress passes the Education for All Handicapped Act (EHA) or Public Law 94-142 (reauthorized in 1990 as the Individuals with Disabilities Education Act, or IDEA), requiring a free and appropriate public education for all children with disabilities.

**1970:** NSAC establishes an Information & Referral department to distribute information about autism.

**1976:** NSAC begins its first ongoing autopsy project for the study of brain tissue. The first community-based residence for youths with severe autism is established by the North Carolina NSAC chapter.

**1977:** An NSAC representative testifies before Congress calling for increased autism research and a larger role for the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS).

**1980:** The NSAC definition of autism, developed by Edward R. Ritvo, M.D., and B.J. Freeman, Ph.D. (members of the newly formed Professional Advisory Board), is reflected in the *Diagnostic and Statistical Manual of the American Psychiatric Association (DSM III)*.

**1981:** The U.S. Department of Education removes autism from the category of “seriously emotionally disturbed” in the EHA. The National Institutes of Health (NIH) establishes a section for autism research.

**1988:** Temple Grandin is the first member-elected person with autism to serve on the Autism Society Board of Directors. The motion picture *Rain Man* is released, increasing the public’s awareness of autism. Prevalence rates state that 1 in 2,000 children have autism.

**1985:** Congress passes a bill for the official establishment of National Autism Week.

**1987:** The membership of NSAC votes to change the name of the organization to the Autism Society of America.

**1990:** The Autism Society's annual conference facilitates the formation of the Network of Autism Training and Technical Assistance Programs (NATTAP). Congress reauthorizes the EHA and renames it the Individuals with Disabilities Education Act (IDEA). Congress passes the Americans with Disabilities Act (ADA).

**1994:** The NIH convenes a unique workshop to discuss the latest in autism research.

**1996:** The Autism Society forms the Autism Society of America Foundation focused on autism research. The award-winning website [www.autism-society.org](http://www.autism-society.org) is launched. Prevalence rates released state that 1 in 500 children have autism.

**1998:** The Autism Society of America Foundation launches both the Autism Research Registry and Autism Tissue Program. The Workforce Investment Act (Public Law 105-220) ensures that employees with disabilities have access to and use of information and data that is comparable to that of other employees.

**1991:** Autism receives a separate category under IDEA, ensuring that students with autism will receive Individualized Education Programs (IEPs) and appropriate educational programming. The Autism Society adopts an Options Policy, stating that individuals can freely select services and therapies best suited for them.

**1999:** The Autism Society launches the autism puzzle ribbon to promote international autism awareness. Ticket to Work and Work Incentives Improvement Act is enacted, protecting Medicaid coverage for employed people with disabilities.

**2001:** The Autism Society's President is appointed to the first Interagency Autism Coordinating Committee.

**2002:** The Autism Society launches the e-newsletter ASA-Net. National Association of Residential Providers for Adults with Autism (NARPAA) is founded. *Autism 101*, an online learning course, is a popular addition to the Autism Society website. The Autism Society and Adamec Harley-Davidson introduce Ticket to Ride autism awareness motorcycle events.

**2004:** The Autism Society launches Autism Source™, an online referral database of autism-related services and supports.

**2005:** The Autism Society teams up with Dennis Debbaudt to launch its Safe and Sound™ Initiative focused on general safety, emergency preparedness/prevention, and risk management for first responders and the autism community.

In the earliest days of my career as a classroom teacher, little was known about autism. At that time, my support and knowledge came from parents associated with the Autism Society. It is this ongoing support from parents associated with the Autism Society and from local chapters that helped me grow as a professional. Begun as a grassroots effort, the reasons for starting this organization are still relevant today. Families still need access to resources and need support from others who understand. It is this grassroots and local focus that is the lifeblood and strength of the organization. I am a lifetime member of the Autism Society and served on the board of directors in many roles, including as chair of the board. While much has been learned about autism, the challenges related to services remain today. The Autism Society has the potential to help solve some of our most pressing issues.

—Cathy Pratt, Ph.D., BCBA, Director, Indiana Resource Center for Autism/IIDC and Autism Society Panel of Professional Advisors

**2010:** AMC Theatres and the Autism Society pilot FOCUS (Furthering Opportunities Cultivating Untapped Strengths), a competitive employment initiative for people with autism and other disabilities. HBO Films produces "Temple Grandin" a movie which receives wide critical acclaim.

**2011:** The Keeping All Students Safe Act is introduced in Congress to address restraint and seclusion and other behavioral control methods in schools. Together with AMC Theatres and Area 23a, the Autism Society promotes a national run of the feature documentary Wretches & Jabberers. The Combating Autism Act (CAA) is reauthorized by Congress. Chapter leaders representing each state come together for the inaugural meeting of the Society Assembly.

**2000:** President Bill Clinton signs the Children's Health Act of 2000. Representatives Chris Smith and Mike Doyle form the bipartisan Coalition for Autism Research and Education (CARE), also known as the Autism Caucus.

The Autism Society continues to be the nation's leading grassroots autism organization with a network of chapters nationwide, working to improve the lives of all affected by autism. We strive to improve quality of life TODAY, by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy.

**2009:** Prevalence of autism spectrum disorders rises to one percent of U.S. children (or 1 in 110 births). President Barack Obama names autism as a major American health concern, of the same degree as cancer and heart disease. The Autism Society Launches the Vote 4 Autism advocacy campaign so advocates can contact Congressional members and express their opinion on pending legislation.

The 1Power4Autism website fosters and supports local autism awareness events to support the Autism Society's mission.

**2008:** Autism and Environmental Health 101, an online course, is released. Monthly Sensory Friendly Films are launched around the country in partnership with AMC Theatres. The Autism Society teams up with Pump It Up to kick off Bounce for Autism™ events nationwide.

**2007:** The Centers for Disease Control and Prevention find the prevalence of autism to be one in 150 births. The American Academy of Pediatrics issues new guidelines for pediatricians suggesting two screenings for autism before a child turns two. The Autism Society forms the Advisory Panel of People on the Spectrum of Autism (PSA) and launches their Treatment Guided Research Initiative. The Autism Society is a co-founder of the Collaboration to Promote Self-Determination (CPSD) to promote opportunities for those with intellectual disabilities.

**2006:** Autism Society marks the passing of founder Dr. Bernard Rimland. The Autism Society's Environmental Health Project is established with a special issue of the *Autism Advocate*. The Combating Autism Act (CAA) is authorized addressing the need for autism research and allotting \$48 million to diagnostic and intervention services for autism spectrum disorders.