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The Rhode Island Consortium for Autism Research and Treatment (RI-CART): A New Statewide Autism Collaborative

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Abstract

Autism is a neurodevelopmental disorder characterized by core deficits in social interaction, language and repetitive behaviors. The need for services is rising sharply as the number of children identified with autism increases. The Rhode Island Consortium for Autism Research and Treatment (RI-CART) was founded in 2009 with the goal of increasing communication among autism researchers throughout the state and improving treatment for children with autism. RI-CART members have several exciting projects in progress, with its larger aim being the creation of a statewide research registry. A statewide registry would benefit research in Rhode Island and allow for larger collaborations nationally.

Keywords

RI-CART; autism; autism spectrum disorder; registry; Rhode Island

WHAT IS AUTISM?

Autism, usually referred to as an autism spectrum disorder (ASD), is a highly heterogeneous, neurodevelopmental disorder with symptoms that typically appear by the second year of life.¹ The main symptoms include core deficits in social interaction, communication and repetitive and inflexible behaviors.² In order to receive a diagnosis of autism, the symptoms must be present by age three, and not be better explained through

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another developmental disorder. While the genetic underpinnings of autism are not completely understood, it is clear from twin studies that autism is a highly heritable disorder.³ Recent advances in genetic research have been able to account for between 10%–20% of autism spectrum diagnoses.⁴

Current estimates indicate that 1 in 88 children have been diagnosed with an autism spectrum disorder, a sharp rise from the prior estimate of 1 in 110.^{5,6} Boys receive a diagnosis of autism spectrum disorder at almost five times the rate of girls.⁶ Unfortunately, epidemiological work beyond the school years is almost nonexistent. In addition to the difficulties of raising a child with autism, the lifetime costs can be substantial for both families and communities as a whole.^{7,8} In order to meet these rising needs, the National Institutes of Health (NIH) has increased federal funding for autism research from \$132 million in 2009 to \$192 million in 2012 and funding is projected to stay at that level for the next two years.⁹

AUTISM IN RHODE ISLAND

Similar to the national numbers, according to the Rhode Island Department of Elementary and Secondary Education there has been a constant rise in the number of school-age children receiving services for an autism spectrum disorder. (See Figure 1.) In the 2011–2012 school year, there were approximately 140,143 children in all Rhode Island schools between preschool and 12th grade. Of those children, approximately 2,099 were receiving support for an autism spectrum disorder, which totaled about 8% of the 24,836 children receiving special education services.¹⁰ If national prevalence estimates can be applied throughout the lifespan, we estimate that there are about 10,000 individuals living with an autism spectrum disorder across the state.

WHY RI-CART?

Rhode Island has a proud and impressive history of supporting children and families with special needs. It was the first state to offer a public special education class and among the first to adopt regulations requiring special education in public schools. Additionally, Rhode Island is the nation's leader in identifying special learning needs among its students.¹¹ Rhode Island is also among the nation's leaders in caring for its children. According to the U.S. Census, 94% of its children are covered by insurance, which is the 7th best in the nation.¹² Despite increasing uncertainty over health care reform, in 2011 Rhode Island became one of 31 states to mandate that insurance covers autism. Benefits to families include coverage for identification, assessment and treatment of autism spectrum disorders.

**VIDEO.**

Eric M. Morrow, MD, PhD, discusses his genetics and autism research

Rhode Island also has an excellent mixture of demographic factors and a unique population density that make it appealing to researchers. In addition to having a small population of a little over 1 million people, the state is the smallest in the United States by a significant margin, making it conceivable to reach a large percentage of its residents. These qualities reduce the burden for participants, as well as researchers, and reduce a bias to collect data from families who are capable of traveling the farthest for a study. Additionally, Rhode Island's population is remarkably stable and diverse. Its population reflects the racial and ethnic diversity found in the United States. Moreover, according to the U.S. Census, about 56% of its residents were born in Rhode Island, with 97% remaining in the state from year to year.¹³

This combination of demographic factors and progressive thinking has led to a rich history of successful longitudinal studies in Rhode Island such as the New England Family Study,¹⁴ the Neonatal Follow-Up Program,¹⁵ and several long-standing, longitudinal studies in psychiatry, including anxiety, depression, OCD and children born after specific neonatal exposures such as amphetamine. What makes Rhode Island unique is that its numerous hospitals are united by one medical school. Despite its size, Rhode Island contains several well-known research institutions and is a national leader in medical research. Furthermore, its academic, research, and clinical programs have strong relationships with governmental representatives and state agencies such as the Department of Health and the Department of Education. This makes Rhode Island strongly positioned to lead innovative research in autism assessment and treatment.

WHAT IS RI-CART?

In 2009, a small group of interested parties began to meet at Bradley Hospital to discuss autism research and treatment in Rhode Island. As this group of collaborators grew, it became known as the Rhode Island Consortium for Autism Research and Treatment (RI-CART). From the beginning, RI-CART researchers broke barriers by including treatment providers, community agencies, and parent advocacy groups in the discussion. RI-CART has since expanded to include a diverse array of disciplines such as psychologists, psychiatrists, pediatricians, neurologists, geneticists, neuroscientists, epidemiologists, and educators. Members represent many of the institutions throughout the state, including Brown University and its affiliated hospitals, Rhode Island College, the University of Rhode Island, parent advocacy groups (The Autism Project), community programs (The Groden Center, The Neurodevelopment Center, Gateway Healthcare), and the RI Departments of Education and Health. A list of our members can be found on our website.¹⁶ The group continues to search for further collaborators throughout the state.

This issue of the *Rhode Island Medical Journal* discusses the exciting contributions of the Norman Prince Neurosciences Institute to neuroscience and brain research. This model of cooperation across disciplines for a common goal directly mirrors the aims of RI-CART members. The Norman Prince Neurosciences Institute (NPNI) at Rhode Island Hospital and the Brown University Institute for Brain Science (IBS) are spearheading an effort to bridge basic and clinical neuroscience research and bring laboratory discoveries to the bedside. RI-CART is thrilled to be a partner in their focus on neurodevelopmental disorders and brain development.

What are RI-CART's Goals?

RI-CART members believe that the best way to improve the lives of children with autism spectrum disorder and their families is to improve and expand knowledge of these disorders. We believe that this needs to be accomplished through collaboration between all invested parties. Thus, RI-CART members are united by three overarching goals:

1. To foster research directed at improving treatments and a better understanding of the basic mechanisms of autism spectrum disorders.
2. To enhance communication among parents, educators, and researchers throughout Rhode Island.
3. To use data-driven advocacy and education to inform state health and education programs about the special needs of this population.

RI-CART Research Projects

RI-CART members have several noteworthy projects under-way that will help to shed light on the complexities of autism. One of the first funded RI-CART research projects is a study of barriers to health care and potential improvements to care in an adult population with autism. This project is directed by Dr. Henry Sachs of Bradley Hospital and currently funded by the Rhode Island Foundation. Typically, when a person with an intellectual or developmental disability turns 21, their access to state and federal benefits becomes highly

restricted, making this a transition marked by difficulty. Research has demonstrated that adults with intellectual and developmental disabilities have greater medical needs and decreased access to health care than the general population.^{17,18} The autism literature has generally focused on school-age children, ignoring the large number of adults, making this a vital project. One previous study that focused on the experiences of adults with autism in accessing health care reported that adults with autism experienced significantly less satisfaction with patient-provider communication, as well as significantly higher odds of unmet physical and mental health care needs. This study utilized online survey methods adapted to facilitate the inclusion of adults with autism; however, researchers were unable to reach populations that were not able to use a computer.¹⁹ In the current study, researchers are working together with community institutions and families to conduct interviews and examine medical records of adults with autism to further investigate barriers to health care and possible solutions for this population.

Another currently funded project is the Rhode Island Multi-site Genetic Study of Autism and Intellectual Disabilities. This project is directed by Dr. Eric Morrow and currently funded by the Simons Foundation for Autism Research Initiative (SFARI), representing a collaboration with the third largest national funding agency for autism research.²⁰ While research has clearly demonstrated that autism spectrum disorders have a strong genetic component,⁴ the utility of clinical testing requires a great deal more research.²¹ Dr. Morrow's laboratory uses genome-wide strategies to identify genes involved in autism spectrum disorders. This research will contribute to the advancing understanding of the complex genetic underpinnings of autism spectrum disorders with the long term goal of improving diagnosis and treatments. Other complementary projects to examine the role of gene-environment interactions are also planned and follow-up projects that build on this initial SFARI-funded project are likely.

Future projects will be enabled through the creation of a statewide research registry. This model is drawn from other pediatric illness, such as pediatric cancers, where all patients in major centers were enrolled in clinical treatment trials. This approach has subsequently led to a number of curative treatments for cancers that previously carried a very high mortality rate. RI-CART's aim is to enroll all individuals in Rhode Island with an autism spectrum disorder diagnosis into this registry. Participants will be evaluated using the Autism Diagnostic Observation Schedule (ADOS), a clinical interview considered the gold standard of autism assessment. Registrants and their immediate family members will also be invited to provide biological samples for genetic, stem cell, and environmental exposure studies. The registry data will be stored on a secure web-based platform where de-identified data may be shared with qualified investigators in the future. The implementation of further research will be augmented by the existing ADOS assessments and genetic data already collected.

In the near future, RI-CART plans to welcome an education specialist and a parent liaison to its staff and increase the number of clinicians conducting the ADOS assessment. Families will benefit from participation in RI-CART by virtue of receiving state-of-the-art autism assessments as well as long-term access to RI-CART staff and expertise. These efforts will allow us to provide an infrastructure of support for families in a range of domains, working

collaboratively with community service providers and educators. Ultimately, RI-CART members have several larger goals as part of our long-term aims. These include the first complete statewide study of autism, large scale genetic and epidemiological studies, the ability to provide high-quality targeted treatments to people with autism spectrum disorders and their families as well as potential collaborations with the National Database for Autism Research (NDAR) and Interactive Autism Network (IAN).

SUMMARY

Despite the rising rates of autism in Rhode Island and across the United States, there is reason for optimism. Through its unique multi-disciplinary approach that allows for wide collaborations among all interested parties in the state, RI-CART will serve as a national model for biomedical and treatment research. RI-CART members are already making strong progress towards our goal of improved communication throughout the state and are working hard towards improving the lives of children with autism as well as their families.

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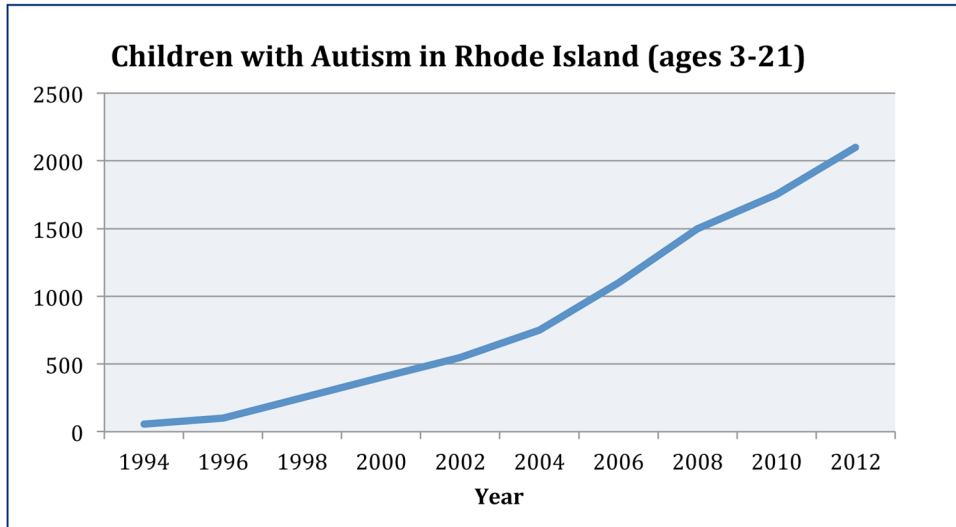


Figure 1.
Children with Autism in Rhode Island 1994–2012