

# Leadership in Health Care, Research, and Quality Improvement for Children and Adolescents With Autism Spectrum Disorders: Autism Treatment Network and Autism Intervention Research Network on Physical Health

Autism spectrum disorders (ASDs) are a group of highly prevalent, lifelong neurodevelopmental disorders affecting social, communicative, and behavioral functioning. Recent studies estimate the prevalence of ASDs as 1 in 88,<sup>1,2</sup> indicating the public health importance of the disorders and making the development of effective care and treatment of ASD an urgent priority. Among the health care concerns for children and youth with ASD is a major need to strengthen awareness and treatment of associated medical conditions with standardized, comprehensive approaches to evaluation, treatment, and monitoring. Many individuals with ASD have symptoms associated with underlying medical conditions, including seizures, sleep problems, gastrointestinal (GI) disorders, psychiatric conditions, nutritional deficiencies, and metabolic conditions; when left untreated, these conditions may not only compromise general health but also have clear effects on behavior, development, and educational outcomes for individuals with ASD. The problems that many children with ASD have with communication make the diagnosis and monitoring of medical conditions more challenging. Furthermore, the underlying biology of ASD may change the manifestations of various medical conditions and their response to treatment. Thus, special attention to these conditions is crucial for improving the quality of life for individuals with ASD.

## ADDRESSING THE MEDICAL NEEDS OF CHILDREN AND ADOLESCENTS WITH ASD

Children and adolescents with ASD encounter difficulties obtaining appropriate and necessary health care services. They have decreased access to medical specialists,<sup>3–5</sup> coupled with increased medical expenditures and unmet needs, compared with other children with special health care needs and typically developing children.<sup>6,7</sup> Autism Speaks and its predecessor, Cure Autism Now, have recognized the significant unmet medical needs among children and adolescents with ASD as well as the many gaps in knowledge among providers regarding the general health care challenges of individuals with ASD. Parents shared their frustrations and all too familiar tales of having to travel far distances to seek medical attention from the few providers who were able to address to their needs. Recognition from health care professionals that comorbid medical conditions such as GI disturbances, sleep disorders, and epilepsy were real issues that affect children with ASD was sorely needed.

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### KEY WORD

autism spectrum disorder

### ABBREVIATIONS

AIR-P—Autism Intervention Research Network on Physical Health

ASD—autism spectrum disorder

ATN—Autism Treatment Network

FAC—Family Advisory Committee

GI—gastrointestinal

HRSA—Health Resources and Services Administration

NICHQ—National Initiative for Children's Healthcare Quality

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The establishment of the Autism Speaks Autism Treatment Network (ATN) arose in 2005 from a partnership between the Northwest Autism Foundation and clinicians from the MassGeneral Hospital for Children Learning and Developmental Disabilities Evaluation and Rehabilitation Service program (LADDERS). Dr. Margaret Bauman, director of the LADDERS program (currently the Lurie Center), brought together a cadre of experts from 4 other clinical sites in the United States that were interested in developing consensus around a multidisciplinary model of care that included a comprehensive evaluation of associated medical conditions. The founding network sites agreed to develop common strategies for the initial evaluation of children and adolescents with ASD, implement a common patient data registry, and develop the evidence to advance the improvement of care for these children and their families. With initial funding from private philanthropy, the network became part of Autism Speaks in 2007, and this new relationship led to a broader vision with greater leadership and opportunities for growth.<sup>8</sup> With support from Autism Speaks, the ATN has expanded to include 17 treatment and research centers in North America that serve as leaders in developing the evidence to advance the care for children and families with ASD. Figure 1 shows the location of the 17 ATN sites.

Over the course of the past 30 years, patient advocacy groups have been instrumental in raising awareness, advancing the science, and ensuring that patients have access to the appropriate health care and treatments they need.<sup>9</sup> The most successful groups have approached this through collaboration among key stakeholders in government, academia, and health care. Autism Speaks has been successful in advancing science and clinical care by influencing policy makers to recognize the complex challenges

faced by their constituents and sharing their sense of urgency and purpose to ensure that policies do not stand in the way of research and treatment.<sup>10</sup>

Although the development of clinical trials and research networks for pediatric disorders is not novel, the ATN stands alone as North America's first collaborative network of hospitals and physicians dedicated to developing a model of comprehensive care for children and adolescents with ASD in real-world delivery settings. The unique strengths of the ATN include a consortium of academic health centers that provide clinical services to children and adolescents with ASD, a well-established clinical and research infrastructure across these institutions, a large patient registry with ongoing active recruitment and longitudinal data collection, and considerable collective experience in the diagnostic, behavioral, and medical evaluation and treatment of individuals with ASD. The ATN has demonstrated capacity in the systematic collection of behavioral and medical information and central data coordination of network clinical and research activities.

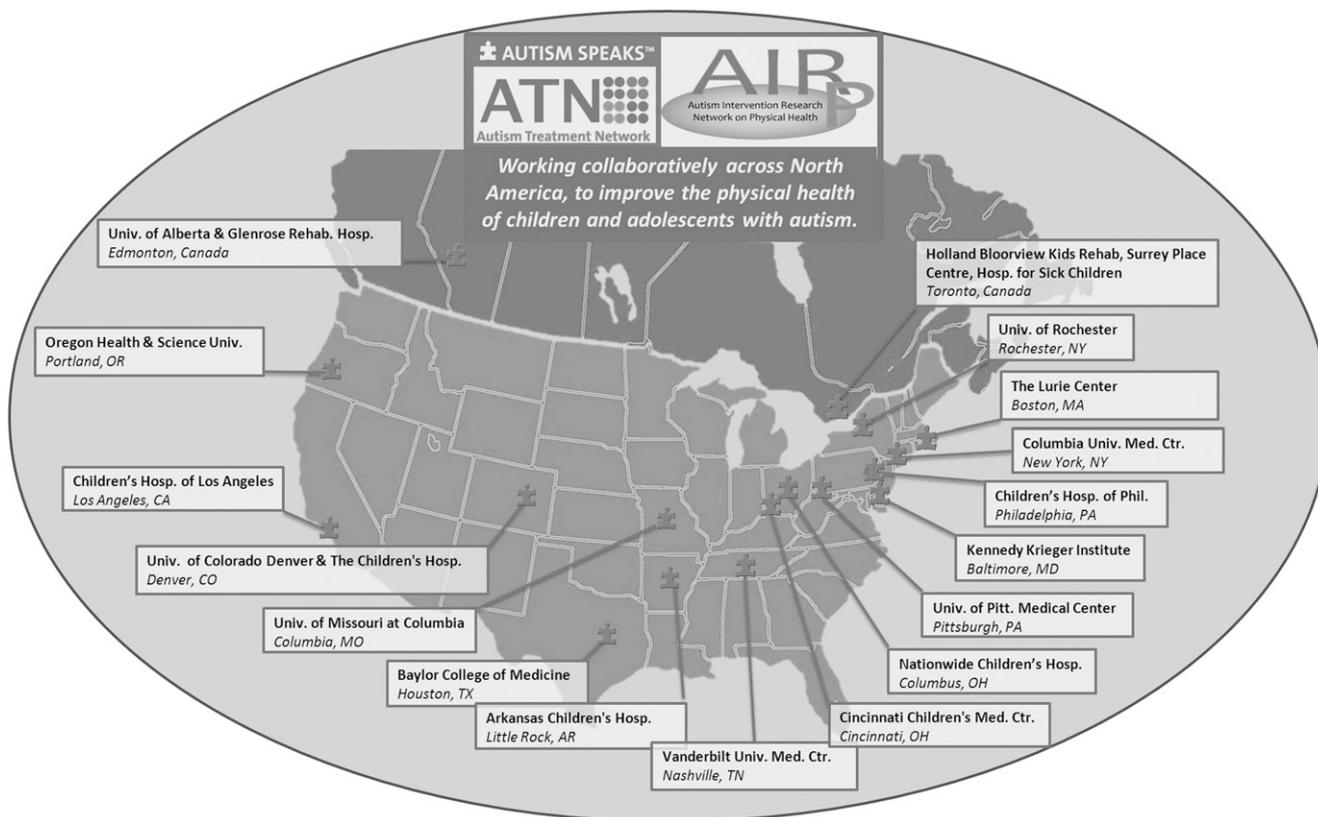
The ATN has a goal of changing the standard of health care for children in the service areas for each site and to share the knowledge gained through the ATN broadly among the practitioner community. Participating centers must commit to a standard comprehensive model of health care, including evaluation and follow-up, entering a minimum of 100 children per year into a common patient registry, participating in network efforts to develop clinical guidelines and tool kits, and collaborating in network research activities. An underlying philosophy of the network has been that improvements in symptoms arising from these medical disorders will allow children with ASD to participate more actively in their educational and behavioral programs and

demonstrate less disability in areas of behavior and functioning. A major goal has been to increase children's and families' access to comprehensive multidisciplinary health care and expand the use of this care to far larger numbers of children and youth with ASD.

### Patient Registry

A critical component of the ATN is the patient registry, which currently tracks >5000 children and adolescents with ASD between the ages of 2 and 17 years, with ongoing enrollment of new patients. To participate in the ATN, sites must agree to carry out an evaluation consistent across the sites, allowing comparison and contrast through common measures, and enter the data from that evaluation into the ATN registry. The registry contains deidentified data collected across a wide range of domains, including medical, developmental, morphologic, behavioral, and family history, making it one of the largest systematic repositories of rich, multidisciplinary data for children and youth with ASD. The database also includes measures of quality of life and patient satisfaction. Data are collected for all children at baseline and annually, and data from interim medical visits, if clinically indicated, also captured. The registry is centralized at the EMMES Corporation, which serves as the data coordinating center for the network. The ATN supports data management capabilities at each site to ensure the quality and accuracy of the data collected. Table 1 provides a copy of the ATN Assessment Battery.

One of the early goals of the ATN patient registry was to better understand the prevalence of medical conditions and symptomatology among children with ASD and to determine whether these rates differed from those in the general pediatric population. Additionally, it was important to evaluate whether there were important relationships among



**FIGURE 1**  
Map of the 17 ATN sites.

symptom domains that were unique to the ASD population that could inform treatment and impact quality of life. The large numbers of patients in the registry have allowed us to estimate prevalence for key areas of medical concern such as sleep (44%) and GI disturbance (51%) and provide some data on the relationship among particular medical conditions, again such as sleep and GI disturbance. Moving forward, however, the goal is to refocus the registry and streamline the amount of data collected to maximize the longitudinal aspects of this clinically rich population and capture more information on treatment outcome. This will help reduce the amount of data collected by clinicians and serve as a more useful platform to support both treatment outcome and comparative effectiveness research.

In 2011, the National Institute of Mental Health funded a pilot project to collect

biospecimens (blood, plasma, urine) from patients at a select number of ATN sites with the infrastructure capacity to support these activities. This investment has enhanced the quality and scope of the enriched phenotype data and will provide researchers with a powerful sample for biologic and genetic studies in autism, accelerating the understanding of the etiology and pathophysiology of ASD and allowing patient stratification in clinical trials.

### The Network Today

The mission of the ATN is to promote a sustainable national system of community-accessible programs offering state-of-the-art comprehensive and coordinated medical care for all children and adolescents with ASD and to develop evidence to support the ongoing improvement of health care for these children and their families. The goals of the ATN are to improve the quality of

health care for children and adolescents with ASD; increase the availability of a comprehensive, coordinated, longitudinal care model for all children with ASD; advance the evidence base and research on medical issues to provide better care for these children; and be the leading clinical network on medical issues related to ASD. In 2011 alone, the ATN provided care to >27 000 children and adolescents with ASD across their autism programs. The ATN now has a protocol for follow-up care that is critical for tracking long-term outcomes for individuals with ASD.

The ATN involves a multidisciplinary medical care model that brings together medical specialists across 6 key areas of pediatric medicine, including developmental/behavioral pediatrics, sleep, GI, metabolics/genetics, neurology, and psychiatry. These medical specialty groups are enhanced by the availability of a strong behavioral

**TABLE 1** ATN Assessment Battery

Domain	Assessment	Informant
Diagnostic	Autism Diagnostic Observation Scale <sup>13,14</sup> <i>Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision</i> checklist <sup>15</sup>	Clinician interview
Cognitive <sup>a</sup>	Mullen Scale of Early Learning <sup>16</sup>  Bayley Scales of Infant Development, Third Edition <sup>17</sup> Stanford-Binet, Fifth Edition <sup>18–20</sup> Differential Abilities Scale—II <sup>21</sup> Wechsler Preschool and Primary Scale of Intelligence, Third Edition <sup>22</sup> Wechsler Intelligence Scale for Children—Fourth Edition <sup>23</sup> Wechsler Abbreviated Scale of Intelligence <sup>24</sup> Leiter International Performance Scale—Revised <sup>25</sup>	Child/clinician interview
Adaptive Behavioral/other psychiatric comorbidity	Vineland Adaptive Behavior Scales—II <sup>26–28</sup> Child Behavior Checklist for Children <sup>29,30</sup>	Parent interview Parent questionnaire
Communication <sup>a</sup>	Aberrant Behavioral Checklist <sup>31,32</sup> Clinical Evaluation of Language Fundamentals, Fourth Edition <sup>33</sup> Preschool Clinical Evaluation of Language Fundamentals, Second Edition <sup>33</sup> Preschool Language Scale, Fourth Edition Oral and Written Language Scales: Listening Comprehension and Oral Expression Scales <sup>34</sup>	Child/clinician interview
Medical	Medical/Family History Questionnaire Child Evaluation (Baseline, Interim, Follow-up)	Parent questionnaire Clinician evaluation
Psychosocial	Pediatric Quality of Life Inventory <sup>35</sup>	Parent questionnaire
Patient Satisfaction	Satisfaction Questionnaire	Parent questionnaire

<sup>a</sup> Approved assessments in a particular domain; clinician will select one based on age and ability.

sciences group comprising leading clinical psychologists and speech language pathologists who provide expert advice on diagnostic issues, behavioral interventions and management, and clinical outcomes. The teams are required to work closely with a team of occupational, physical, and behavioral specialists and provide access and/or referrals to these allied health professionals in local communities to support a child's individual needs.

Specialty ATN committees in the areas of GI, sleep disorders, neurology, metabolics/genetics, and behavioral science are developing standards and guidelines for the clinical management of individuals with ASD. Specialty group committees meet regularly and work collaboratively to develop common screening, treatment, and evaluative tools for primary care physicians to

help standardize care across the diverse medical settings where children with ASD receive services. The ATN systematically gathers information that will move the field from consensus-based to evidence-based practice guidelines. Each specialty group committee includes a lead medical autism specialist and a behavioral science specialist to provide a multidisciplinary perspective to care as well as ensure the applicability of guidelines to generalist care.

### THE ATN AS THE AUTISM INTERVENTION RESEARCH NETWORK ON PHYSICAL HEALTH

#### Development and Implementation

The strong base of clinical care, guideline development, and a patient registry afforded by the Autism Speaks ATN allowed the network to compete

successfully in 2008 for one of the major activities supported by the Combating Autism Act, the Autism Intervention Research Network on Physical Health (AIR-P). AIR-P funding has provided substantial new opportunities for the ATN, in particular supporting a portfolio of clinical research projects to address questions that parents bring to their clinicians, as well as new opportunities to strengthen the methods behind guideline development, testing, and implementation. Total funding from the Resources and Services Administration (HRSA) and Autism Speaks exceeds \$7 million a year; optimizes the investments made by both organizations in infrastructure, research, and treatment; and provides a viable solution to overcoming some of the challenges in improving ASD care and research. The AIR-P also supports expansion of efforts to interact with professional communities and parent groups to share the guidelines and research results in ways that can improve care for children with ASD and their families.

#### AIR-P Research

A fundamental element of the AIR-P has been the development of research activities that can lead to improved care for children with ASD. The Interagency Autism Coordinating Committee Strategic Plan identified research on the treatment of co-occurring medical conditions in children with ASD as a priority for their 5-year period.<sup>11</sup> Until the development of the AIR-P, no focused and dedicated strategy existed to develop a portfolio of clinical research directed toward these conditions. Half of the AIR-P funding is dedicated to protocol-driven clinical research. The network initially proposed 2 main research studies: (1) an in-depth assessment of nutrition among a large number of children with ASD and (2) a randomized trial of 2 strategies for nonpharmacologic interventions to improve sleep in children with ASD. In

addition, the network developed an internal request for applications mechanism, allowing investigators across the network to apply for research support. To ensure scientific integrity of the research, the ATN used its scientific review committee, consisting of researchers across the network as well as additional content experts, to carry out systematic peer review of proposals, aiding in decisions about which proposals to fund and how to improve the projects. This initial request for applications led to the support of 4 projects in addition to the original 2 signature proposals. In the second year, the AIR-P held another similar competition leading to support for 5 additional projects. More than 1500 children have participated in AIR-P funded research projects. Table 2 lists AIR-P research projects and participating sites.

When the AIR-P competed successfully with renewed funding in 2011, the network proposed 2 new studies, both randomized clinical trials. The first is a study of the use of Metformin to address the problem of significant weight gain among children taking atypical antipsychotic medications, the second a trial of iron for children with sleep problems and low serum iron levels. The AIR-P will continue to expand research in the network as well as seek additional external funding from a variety of sources for its research endeavors.

### Quality Improvement and Dissemination of Best Practices

Resources from the AIR-P have supported collaboration between the ATN and the National Initiative for Children's Healthcare Quality (NICHQ). NICHQ has substantial expertise in improving care in many areas of child health, for preventive services as well as care for children with a wide variety of chronic health conditions. NICHQ initially worked with network sites to implement guidelines in the areas of constipation and sleep (both published in this supplement), develop

**TABLE 2** AIR-P Research Studies and Participating Sites

Diet and Nutrition in Children With ASD	University of Rochester Medical Center <sup>a</sup> Arkansas Children's Hospital, UAMS Cincinnati Children's Hospital Medical Center University of Pittsburgh Medical Center The Children's Hospital, University of Colorado, Denver
Markers of Iron Status and Metabolism in Children With ASD	The Children's Hospital, University of Colorado, Denver <sup>a</sup> University of Rochester Medical Center Arkansas Children's Hospital, UAMS Cincinnati Children's Hospital Medical Center University of Pittsburgh Medical Center
Parent-Based Sleep Education Program for Children With ASD	Vanderbilt University Medical Center <sup>a</sup> The Children's Hospital, University of Colorado, Denver Holland Bloorview Kids Rehabilitation Hospital/The Hospital for Sick Children/Surrey Place Centre
Defining the Relation of Sleep Disturbance in ASD to Psychiatric and Behavioral Comorbidities	Vanderbilt University Medical Center <sup>a</sup>
Constipation and Toilet Training in Autism	Holland Bloorview Kids Rehabilitation Hospital/The Hospital for Sick Children/Surrey Place Centre <sup>a</sup>
Epileptiform Discharges and Its Relation to Cognition and Behavior in Children With ASD	Vanderbilt University Medical Center <sup>a</sup> Columbia University Medical Center The Lurie Center, MassGeneral Hospital for Children
The Study of Toddlers With Autism and Regression (STAR) Protocol—Screening for Treatable Disorders and Biomarkers of Inflammation and Immune Activation in the Plasma and Central Nervous System	Holland Bloorview Kids Rehabilitation Hospital/The Hospital for Sick Children/Surrey Place Centre <sup>a</sup> Arkansas Children's Hospital, University of Arkansas for Medical Sciences Kennedy Krieger Institute Maternal Cholesterol and Autism Oregon Health and Science University Kennedy Krieger Institute The Children's Hospital, University of Colorado, Denver
Prevalence of Creatine Deficiency Syndrome in Children With ASD and the Impact of Genotypic Variability of Creatine Deficiency Syndrome Genes	Holland Bloorview Kids Rehabilitation Hospital/The Hospital for Sick Children/Surrey Place Centre <sup>a</sup> The Lurie Center, MassGeneral Hospital for Children The Children's Hospital, University of Colorado, Denver
Bone Mineral Density in Children With ASD	The Lurie Center, Mass General Hospital for Children <sup>a</sup>
Autism Impact Measures (AIM): A New Tool to Measure Treatment Outcome in ASD	Baylor College of Medicine/Texas Children's Hospital <sup>a</sup> Oregon Health and Science University

<sup>a</sup> The first center listed is lead site for multisite projects.

ways of measuring feasibility and impact, and carry out field testing of guidelines in several ATN sites. This initial work has led now to a much more ambitious program focused on a continuous quality improvement collaborative, which includes learning methods to examine elements of clinical care and to improve this care through a series of plan-do-study-act cycles. These efforts integrate with other quality improvement programs in each participating institution and also serve as guides for the dissemination of best practices across

North America. With the support of AIR-P funding, ATN clinicians and practitioners have also conducted 23 trainings nationwide reaching >1600 medical providers and families in their local communities in the first 3 years.

### Tool Kits for Parents and Professionals

Because of the ATN mission to improve the health and medical care of individuals with autism and their families, the network has pioneered in developing tool kits that focus on

health-related issues to help families and individuals with ASD with daily living and health care. All the tool kits are free resources that families and medical professionals can download from the Autism Speaks web site ([www.autismspeaks.org](http://www.autismspeaks.org)).<sup>12</sup> Each tool kit provides information designed to empower families and individuals with ASD. AIR-P funds have directly supported the development of many of these tool kits in collaboration with the ATN health care providers. Clinicians work with the ATN family advisory committee to develop new ideas for tool kit development. Examples include the medication decision aid “Should My Child Take Medicine for Challenging Behavior?” This interactive tool kit provides questions and worksheets that help families work with their

doctor to make decisions that reflect the family’s goals and values for their child. The ATN has also released 2 versions of the “Taking the Work out of Blood Work” tool kit, 1 for parents and 1 for health care providers. Both provide information and techniques for managing blood work, including printable materials that can help prepare a child for a less stressful visit. Other tool kits have focused on topics such as sleep, visiting the dentist, and the use of visual supports to facilitate medical care. AIR-P funding has helped the ATN share best practices with families and health care practitioners outside their local service areas.

### Family Advisory Committee

In 2011, with HRSA funds, the ATN established the Family Advisory

Committee (FAC) to ensure that there was parent involvement across all levels of the network. The FAC comprises 2 parent representatives from each of the clinical sites who share their perspectives on clinical and research priorities, provide input on the ongoing activities of the network, and offer feedback to the subspecialty committees on their planned activities. All members are parents of a child or adolescent with an ASD, many of whom receive or have received services at an ATN center. Locally, FAC members are encouraged to engage in quality improvement efforts, which may include participation in the HRSA-funded NICHQ Autism Collaborative, and also provide feedback and perspective on the quality and impact of care at their sites.

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