A First of its Kind Collaborative Network Advancing the Medical Care for Children with Autism Spectrum Disorders

AUTISM SPEAKS
ATN Autism Treatment Network

Autism Treatment Network (ATN)

The ATN is a collaboration of Autism Speaks and 14 of the finest children's hospitals and academic institutions in North America, specializing in multidisciplinary care for children with autism. Together these centers of excellence work to improve medical care in autism by developing best practices and providing a platform for research. ATN best practices are shared with physicians and medical facilities nationwide to improve outcomes for all children with autism. www.autismspeaks.org/ATN

AIR-P
Autism Intervention Research Network on Physical Health

Autism Intervention Research Network for Physical Health (AIR-P)

The AIR-P builds on the strengths of the ATN by conducting research on evidence-based interventions to improve the physical health and well-being of children and adolescents with autism spectrum disorders and other developmental disabilities, development of evidence-based guidelines, and dissemination of guidelines and critical information on network research findings. www.airpnetwork.org

HRSA Collaborative Agreement UA3 MC 11054 to the Massachusetts General Hospital

By linking the research focus of the AIR-P with the clinical focus of the ATN, this combined network has made a fundamental difference in the care of children with ASD and their families.

The Network's priority is Optimal Health and Quality of Life for Individuals with ASD.
- ❖ *Increasing access to care*
- ❖ *Improving quality health*
- ❖ *Across the lifespan*

Accomplishments

Clinical Care
- Providing care to **nearly 40,000 patients per year** through ATN Centers of Excellence
- Family Navigators supported **over 17,600 families** across the US and Canada.
- Developing **standardized multidisciplinary model of care f**or ASD
- Implementing and evaluating models of **Family Navigation services**

Clinical Registry
- First and largest medical registry in ASD, **over 7,000 subjects** spanning diverse communities

Capacity-Building, Training, Dissemination, and Outreach
- Completed and published **22 Tool Kits** covering a variety of medical and behavioral challenges in autism
- Over **240,000** downloads
- In 2015, the network provided **over 1,000 training, dissemination, and outreach events** around the US and Canada, reaching **nearly 50,000 professionals, students, and family members**
- Focus on reaching underserved populations
- Authored **over 80 blogs** for the autism community
- Monthly webinar series: Advances in Autism Research & Care
  - Attendance ranges **between 35-200** for a variety of topics, including genetics, psycho-pharmacology, discussion of DSM5, and an overview of network Registry data; open to LEND/DBP/CAAI programs

Research Accomplishments
- Network has **published nearly 100 manuscripts on topics** including:
  - GI, metabolic, sleep, nutrition, communication, and health services
- Conference presentations of **125+** peer reviewed abstracts
- Completed **25 AIR-P funded studies** (2008 – 2015) | Actively supporting **6 new studies** (2015-present)
- More than **2,000 research participants** from the ATN are enrolled in AIR-P studies

Guideline Development
Practice guidelines developed based on existing evidence from the literature and expert consensus where gaps in evidence exist
- Published the first and only guidelines for management of **constipation, sleep, and ADHD symptoms** in ASD (2012 Pediatrics supplement)
- 2 guidelines for management of **irritability and agitation** as well as **anxiety** were published in the 2015-2016 Pediatrics supplement

Active Autism Speaks Funded Projects

ATN Registry
A clinical registry including medical and behavioral data on individuals (2-17 years 6 months of age) from ATN centers that meet criteria for ASD.

Longitudinal Study of ATN registry participants
A study to better understand long-term outcomes associated with ASD and the relationship of medical co-morbidities to these outcomes.

Comparsion of DSM-IV-TR and DSM-5 Diagnostic Criteria for Autism Spectrum Disorder
To compare DSM-IV-TR and DSM-5 criteria for Autism Spectrum Disorder. Using a sample of 250 children and adolescents who meet DSM-IV-TR criteria for ASD and 150 children and adolescents referred for diagnosis who do not meet DSM-IV-TR criteria. The study will examine whether specificity and sensitivity of DSM-5 ASD diagnosis relative to DSM-IV-TR ASD diagnosis is associated with IQ, comorbid behavior problems, age or ASD symptom severity.

Family Navigation Study
Describing models of Family Navigation services and evaluating impact of family navigation services on caregiver activation/engagement and stress.

Healthcare Disparities project
To identify health disparities among families served by ATN sites and to identify patients from catchment area that do not access specialty care at ATN centers to inform ways to reduce barriers to healthcare for all individuals with ASD

Development of a Care Model Manual
Develop a technical manual to assist medical facilities in developing an autism center or re structure existing clinics to help better serve individuals with autism spectrum disorders and their families. Provide "one pagers" from manual chapters that are a practical tool that can be used by primary care physicians to care for children with ASD in their setting.

Active AIR-P Funded Projects

ECHO Autism
Extension for Community Healthcare Outcomes (ECHO) is an innovative telemedicine-based platform that connects local PCPs with specialists at academic medical centers during biweekly ECHO clinics. This study will examine the effectiveness of "ECHO Autism" in increasing 1) rates of ASD screening during 18-month well-child visits in underserved communities, 2) the proportion of underserved children with ASD who receive screening, appropriate care for sleep problems and constipation, and 3) the monitoring of underserved children with psychotropic medications.

Improving Participation in Dental Care and Oral Health Outcomes for Underserved Children with ASD.
This study is a randomized controlled trial (RCT) to compare the efficacy of the established ATN/AIR-P Dental Tool Kit to a combined regimen involving the Dental Tool Kit and a parent-mediated behavioral intervention. Study objectives include improving home dental hygiene, oral health, and compliance with dental procedures in under-served populations with Autism Spectrum Disorder.

First Impressions: Strategies to Enhance Initial Adult Care Visits for Transitioning Youth with Autism Spectrum Disorders
First Impressions will work with community health center pediatric and adult primary care clinics to test an intervention designed to prepare youth and their families for transition, increase the capacity of physicians and office staff in primary care adult clinics to welcome referred youth with ASD, and establish a single point of contact in the adult primary care office.

Learning Network
The AIR-P/ATN is expanding into a Learning Network (LN) in collaboration with the Anderson Center. We will employ strategies that have been successfully used in other pediatric LNs: collect real-time data for performance feedback and research; engage multidisciplinary clinical teams and family partners; focus on the reduction of unintended care process variation by identifying, adopting and testing best practices; involve providers from underserved communities; and use content and improvement experts to guide evidence-informed change.

Network Sites:
1. Children's Hospital of Los Angeles
2. Children's Hospital of Philadelphia
3. Cincinnati Children's Hospital
4. Lurie Family Autism Center/ MassGeneral Hospital
5. Nationwide Children's Hospital / The Ohio State University
6. Saint Louis University School of Medicine
7. University of Arkansas for Medical Sciences
8. Toronto Autism Network (Holland Bloorview Rehab, Surrey Place Centre and the Hospital for Sick Children)
9. University of Alberta/Glenrose Rehab Hospital
10. University of California – Irvine
11. University of Missouri – Columbia
12. University of Pittsburgh
13. University of Rochester
14. Vanderbilt University Medical Center

For more information
www.autismspeaks.org/ATN | ATN@autismspeaks.org |www.airpnetwork.org
To utilize the ATN registry data for secondary data analysis: http://asatn.org/asatn-query