

# Autism Treatment Network and Autism Intervention Research Network on Physical Health

## Annual Report 2019



# About the Autism Treatment Network and AIR-P

## VISION:

*Optimal health and quality of life for people with autism spectrum disorders.*

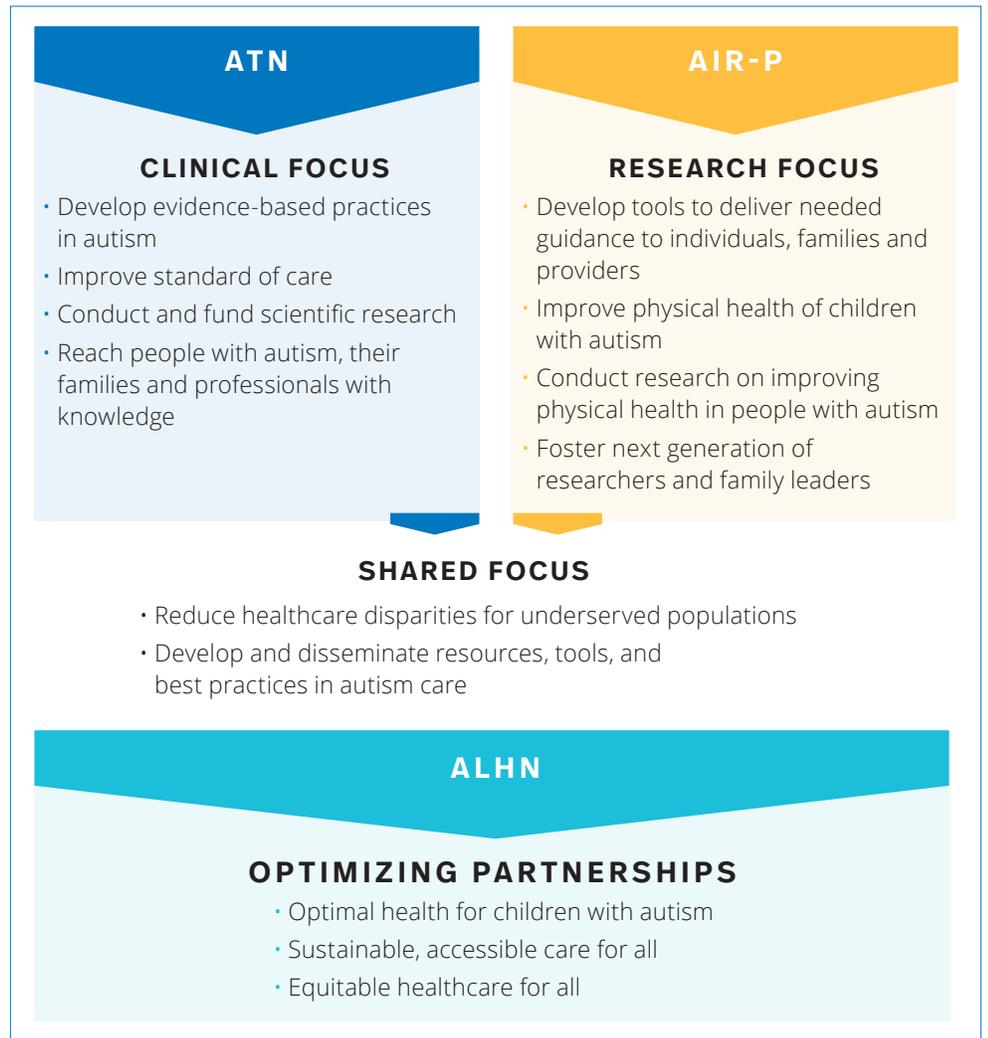
## MISSION:

*Create a sustainable system for care delivery, research and evidence development.*

The Autism Treatment Network (ATN) funded by Autism Speaks (AS), and the Autism Intervention Research Network on Physical Health (AIR-P), funded by Health Resources and Services Administration (HRSA) collaborative agreement UA3 MC 11054 to the Massachusetts General Hospital, form an integrated network. The Network currently consists of 12 leading children's hospitals and academic institutions across North America. Working together, the ATN and AIR-P combine the highest standards and best practices in clinical care with the latest findings in research to advance medical care for children and adolescents with autism.

By linking the research focus of the AIR-P with the clinical focus of the ATN, the Network has made fundamental improvements in the care of children with ASD and their families. This report highlights the work conducted in support of the Network's mission to create a sustainable system for care delivery, research and evidence development in autism spectrum disorder (ASD).

In recent years, the important partnership between the ATN and AIR-P has evolved into a new kind of network. This Autism Learning Health Network (ALHN) incorporates innovative research methods that are data-led and informed by patient experiences. ALHN optimizes the successful partnership of the ATN and AIR-P using a systemic approach to measure effectiveness, prompt needed research, rapidly translate research findings into better care and reach underserved individuals.



# Development of the Autism Learning Health Network

## ALHN VISION:

All people with autism spectrum disorder (ASD) will have optimal health, safety and quality of life.

Transitioning the ATN/AIR-P into an **Autism Learning Health Network (ALHN)** represents a systemic shift to close the autism care gap. Learning Health Networks (LHNs) are multisite, practice-based clinical networks that engage patients and families as well as scientists. LHNs continuously collect data embedded in clinical practice, and then use that data to improve care and to guide research into better solutions. The American Board of Pediatrics considers LHNs the best way to achieve population outcomes at scale. This transition is a systemic solution to better reach underserved individuals, measure effectiveness, prompt needed research and rapidly translate research findings into better care. ALHN is the first learning network focused on any pediatric behavioral health condition. This new network model allows for broad expansion leading to a more representative research registry.

## INITIAL FOCUS: Improving health and quality of life by reducing challenging behaviors

Family survey data collected by providers in the network revealed that **challenging behavior affects 93 percent of families, with 85 percent reporting moderate to extreme severity**. Sixty-one percent report these challenging behaviors occur at least once a day or many times per day. Sixty-nine percent of families rated their quality of life as very good and above.

Digging deeper into the underlying types of challenging behavior, the Network has prioritized early identification and treatment of anxiety, irritability and ADHD, which were most commonly reported by parents as causes. In 2019, individual learning labs comprising subject experts and family advocates were established to develop screening protocols and practice pathways for anxiety, irritability and ADHD.

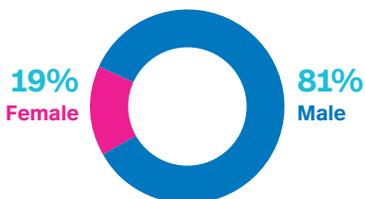
## ABOUT THE FAMILIES IN THE ALHN MEDICAL REGISTRY

### AVERAGE AGE OF DIAGNOSIS

4 years 9 months

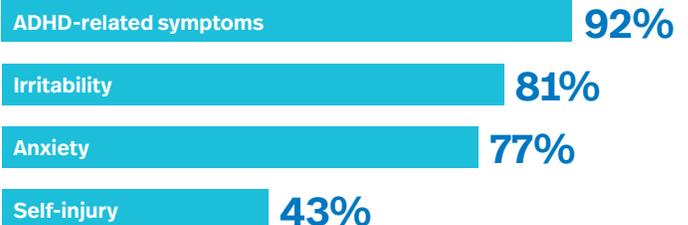


### GENDER RATIO



93%  
of families  
reported  
challenging  
behaviors

### OF THOSE THAT REPORTED BEHAVIOR CHALLENGES:



### OTHER RELATED HEALTH ISSUES REPORTED:

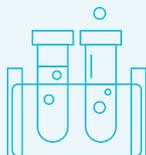


\*Data collected from the first 500 families registered.

Network centers provided autism services to

46,000+  
people in 2019.

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3

clinical trials published +

9

current active studies

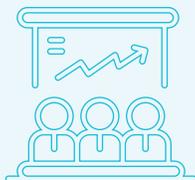


27

family navigators support

8,000+

families with care and resources



1000+

community training and outreach events hosted  
this year with

71

hosted in non-English speaking communities



# Family and Community Engagement

*It's very meaningful to help community providers improve their understanding of the family experience with autism. Family-centered care is critical for quality care, and I feel like my experience and voice make a difference.*

*—FAC member, Cincinnati Children's Hospital*

## Family Advisory Committee

Engaging families is vital to achieving the network's mission. Two parent representatives from each network site serve on the ATN/AIR-P Family Advisory Committee (FAC) to represent the concerns and interests of the families served by our Network. The FAC works to ensure network activities and research are family-centered and reflect their needs. This group was instrumental in advocating for the need to address challenging behaviors, which was also supported by the clinical data.

FAC members are also deeply involved in outreach efforts. Parent partners offer crucial support to the local autism community and provide valuable experience from the family perspective during ECHO Autism webinars as expert hub team members.

FAC members serve on all ATN / AIR-P / ALHN committees, in addition to attending ECHO sessions and joining network workgroups focused on research studies, toolkits and network goals.



AIR-P provided funding for two FAC members and two other network representatives to participate in an 8-month intensive **quality improvement training** through the Intermediate Improvement Science Series (I<sup>2</sup>S<sup>2</sup>). Two additional Network Principal Investigators were funded by AIR-P to participate in the 8 month Advanced Improvement Methods in Healthcare (AIM) course to advance quality improvement science and research within the network.



**Two FAC members co-authored a manuscript** describing the transition of the ATN to the Autism Learning Health Network

A University of Missouri **FAC member and self-advocate co-authored publication in the journal Autism**, "ECHO Autism Transition: Enhancing healthcare for adolescents and young adults with autism spectrum disorder"

# Research

**205 patients enrolled in 2019 (1,318 to date) in newly developed ALHN patient registry**

## Medical Registries

In 2019, ALHN accelerated the development of its patient registry with additional funding from PCORI, a federal agency. Integrating clinical data from patient visits into this registry helps conduct research across the Network. Patient registries are a vital tool for autism research by supporting:

- **better representation** of the full range of children with autism, including from groups typically underrepresented in autism research
- **data-informed clinical care** to much more rapidly provide evidence about what works and what doesn't to treat related health conditions in autism
- continuous **quality improvement** modeling of clinical care
- research questions led by data representing the **needs of a more diverse patient population**



The previous **ATN Medical Registry** with 7,000 participants was converted in 2019 to a controlled-access platform to allow deidentified registry data to be readily available for secondary data analysis research.

For more information, visit <http://asatn.org/request/data>.

**13 ATN/AIR-P research studies published using network support and resources in 2019**

## Publications & Proceedings

**Over 140 manuscripts** have been published from network research and activities to date, in addition to 58 manuscripts using the ATN Registry for secondary data analysis.

To date, **185 ATN/AIR-P abstracts** have been accepted to academic conferences. 13 abstracts were submitted to academic conferences in 2019.

Visit [asatn.org](http://asatn.org) for a full list of all network abstracts and publications.

# Active Autism Treatment Network Studies in 2019

## **AIR-P-funded:**

### *Physical Exercise to Reduce Anxiety in Underserved Children with ASD (PETRA)*

This study tests whether a physical exercise intervention reduces anxiety in children in underserved families.

### *Improving Participation in Dental Care and Oral Health Outcomes for Underserved Children with Autism*

This study is a randomized controlled trial to compare the established ATN/AIR-P Dental Toolkit to an alternative regimen that combines the Dental Toolkit with a parent-mediated behavioral intervention.

### *Ameliorate Childhood Obesity Risk from Newer Antipsychotics for individuals with Autism Spectrum Disorder (ACORN)*

This one-year pilot study will adapt and test an empirically validated pediatric weight management program (Healthy Habits for Life; HH4L) for youth with ASD who gain weight on second-generation antipsychotics.

### *ECHO Autism Study*

This 10-site randomized controlled trial study had each of the participating ATN/AIR-P sites function as “hubs” (lead mentoring sites) and provide teleconference-based education interventions with 148 Primary Care Providers (PCPs). Results show significant increases in autism screening, general developmental screening, PCP autism knowledge, PCP self-efficacy and significant decreases in number of perceived barriers to caring for children, however there was no change in management of comorbidities.

### *ECHO Autism Transition Study*

This pilot project continued the success of the ECHO Autism work conducted through the AIR-P network by providing a 12-week training to pediatricians, family medicine practitioners and adult primary care providers on caring for transition aged individuals with ASD.

### *Evaluation of a Multimedia Sleep Education Package in Children with ASD (Sleep Ed)*

This is a one-year pilot study that explored whether a multimedia sleep education package can be successfully provided to families and show efficacy in improving sleep habits and sleep problems, along with parenting sense of competence.

### *The Emotion Awareness and Skills Enhancement Program for Youth with ASD and Intellectual Disability (EASE-ID): A Mind-Body Intervention to Improve Sleep, Health, and Emotion Regulation (EASE)*

This is a one-year research effort to extend the benefits of a previously developed mindfulness-based intervention to youth with ASD and intellectual disability and evaluate its impact on sleep and overall physical health.

### *Resiliency Program for Siblings of Children with Autism Spectrum Disorder (SibResiliency)*

This study is a pilot wait-list controlled trial to improve resiliency in teenage siblings of children with Autism Spectrum Disorder using an eight-session virtual Mind-Body intervention.

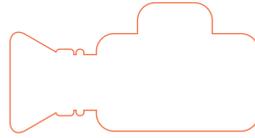
## **Autism Speaks, AIR-P, and Quadrant Biosciences co-funded:**

### *Neurophysiologic and Cognitive Effects of Minocycline in Adolescents with ASD*

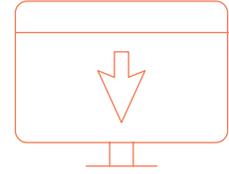
This study will examine effects of short-term treatment with the antibiotic minocycline on EEGs in persons with ASD compared to a placebo and potential effects on memory, social gaze, psychophysical markers, attentional impairments, quality of life and other concerns in adolescents with ASD.

# Training and Outreach

## Family + Provider Outreach



2 video tool kits about communication supports were developed in English and Spanish, and 2 sleep video tool kits were also translated into Spanish



To date: 617,000+ tool kits have been downloaded and over 25,000 tool kit flash drives have been distributed

Find the tool kits at [www.autismspeaks.org](http://www.autismspeaks.org) and <http://airpnetwork.org>.

## Provider Training

**ECHO Autism** is a tele-mentoring learning network offering real-time access to autism and behavioral experts, putting best practices in autism care for medical, behavioral and educational concerns in the hands of community providers. AIR-P provided the initial seed funding for ECHO Autism studies, which in turn led to AS funding for continued expansion of the clinical ECHO Autism model into more communities.

- **ECHO Autism Primary Care mentored an additional 427 community-based medical providers in 2019** in best practices, autism screening, identification, and treatment and care. These providers can reach more remote populations without ready access to experts and proper treatment for ASD, with the goal of providing the best care regardless of where they live. The Network has supported the **training of 1,145 PCPs** in total.
- **Launched ECHO Autism projects on Transition to Adulthood**

## Pre- and Post-Doctoral Training

Training support for early-career researchers develops the **next generation of researchers in the field.**

**1,689 pre- and post-doctoral** students, residents and fellows received training at ATN/AIR-P sites.

The Network supported **3 post-graduate fellows** at the Clinical Coordinating Center at Massachusetts General Hospital.

ECHO Autism moves knowledge to community providers



Graphic courtesy ECHO Autism, University of Missouri Health Care, Department of Child Health

# Reducing Health Care Disparities

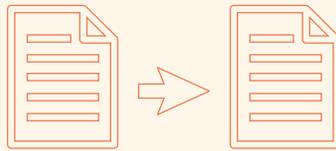
ATN/AIR-P has been making great strides in reducing health care disparities across the Network in the U.S. and Canada.

71

events targeting underserved communities  
hosted in non-English speaking  
communities

50%

of grant-funded projects focused  
on underserved communities  
at all 12 network sites

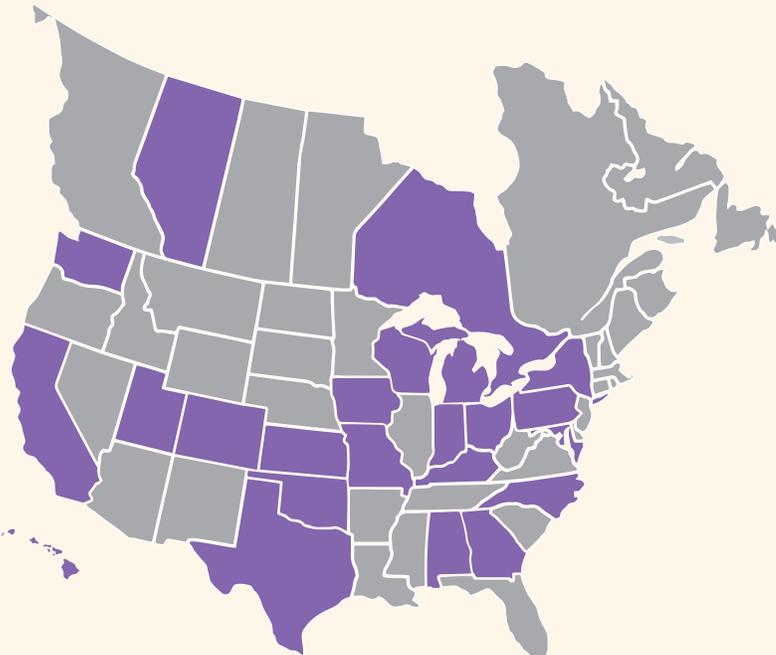


Translated all 23 tool kits

covering medical and behavioral topics in autism, as well as one-page lay summaries, into Spanish in 2019

Tool kits available in up to 6 languages:  
English, Spanish, Arabic, Vietnamese, French, Somali

## Communities Reached Through ECHO Autism Primary Care



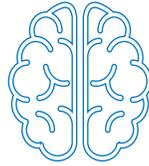
## 4 Countries Participating in ECHO Autism Primary Care

Canada  
Thailand  
Vietnam  
Moldova

# Leveraged Funding

Network sites have leveraged over **\$16 million** in funding from external sources in 2019. Major funding from the National Institutes of Mental Health, the Ontario Brain Institute, the Department of Defense, the Simons Foundation, and the Department of Education supported a wide variety of projects across the network.

## Funding includes:



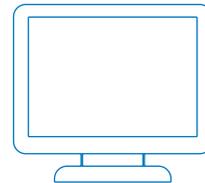
A discovery project that explores **how aging happens in the autistic brain**



A study exploring if **exercise bikes are an acceptable tool** to be used for physical exercise in children with ASD



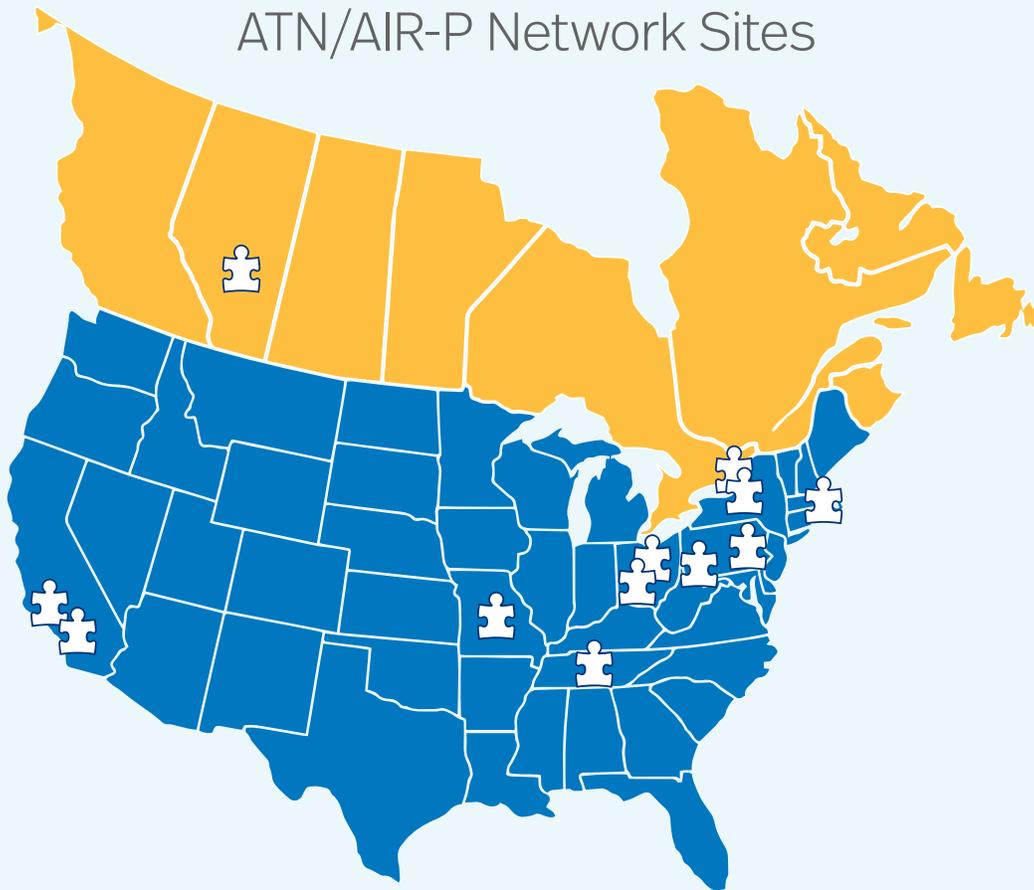
Designing a clinical ECHO program and conducting a qualitative/mixed methods study of the **impact of clinical ECHO on Primary Care Providers** in the Cincinnati community



Development of an **electronic health application** that fuses advanced computational strategies with expert knowledge and tools for ASD screening and diagnosis. This tool provides support for enhanced screening across diverse communities and gives users a clear decision pathway to triage early, accurate diagnostic needs and meaningful engagement in early treatment.

# Thank You!

ATN/ AIR-P leadership would like to thank the participating sites for their hard work and dedication. A special thanks to the Network Family Advisory Committee and the children and families impacted by ASD.



Children’s Hospital Los Angeles

Children’s Hospital of Philadelphia

The Kelly O’Leary Center for Autism Spectrum Disorders at Cincinnati Children’s Hospital Medical Center

The Lurie Center for Autism at the Massachusetts General Hospital for Children

Nationwide Children’s Hospital

Toronto Autism Network (Holland Bloorview Rehabilitation, Surrey Place Centre, and the Hospital for Sick Children)

University of Alberta and Glenrose Rehabilitation Hospital

The Center for Autism & Neurodevelopmental Disorders at the University of California — Irvine

University of Missouri — Thompson Center for Autism and Neurodevelopmental Disorders

The Center for Autism and Developmental Disorders at the University of Pittsburgh Medical Center

The Division of Developmental and Behavioral Pediatrics at the University of Rochester Medical Center

The Autism Clinic at Vanderbilt University Medical Center

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