Autism Treatment Network Annual Report for 2009

ATN Autism Treatment Network
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Foreword: Autism Treatment Network 2009 Annual Report

The Autism Treatment Network (ATN) has a mission to provide families of children and adolescents with autism spectrum disorders (ASD) access to a high quality, comprehensive, and multidisciplinary continuum of care in hospitals and major medical centers within their communities. We are excited about the accomplishments of the past year and are eager to tackle the work ahead of us. We have made great strides in multiple areas that are essential to achieving our mission, and pleased to share our progress with you.

The Network has been active on a number of fronts:

- **We have enrolled over 1900 patients into our Registry**, and active data collection on the first round of annual return visits is underway. Data reported here cover more 1400 children enrolled through September 8, 2009.
- **Our efforts establishing Clinical Guidelines** have led to three algorithms in the implementation phase, with additional tools and algorithms in development.
- **Research projects are underway** through a collaborative agreement to establish the Autism Intervention Research Network on Physical Health (AIR-P), with two large studies initiated and four additional studies approved and beginning work.
- **Our sites have been involved in educational and dissemination activities**, providing information to the public and to professional groups through a variety of formats
- **Our clinicians have been making presentations at academic meetings and publishing their findings in professional journals** to further educate and inform professionals in practice.

As we head into 2010, we focus both on continuing our current good work and on promising new activities that will help us reach our goal of improved medical care for all children, adolescents and adults with ASD and support for their families.

Sincerely,

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ATN Medical Director

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Table of Contents

Foreword: Autism Treatment Network 2009 Annual Report 2

About the Autism Treatment Network 4

ATN Registry Activity 2009 5

Clinical Guideline Activity 9

ATN Research Activity 10

Education and Dissemination 12

Scientific Presentations and Publications 14

Goals For 2010 16

References 17

Appendix: Other Site Training and Community Outreach Activities 18

About the Autism Treatment Network

The Autism Treatment Network (ATN) is a collaboration among treatment and research centers, dedicated to providing and expanding access to state-of-the-art comprehensive and coordinated medical care for children and adolescents with autism spectrum disorders (ASD), and advancing the establishment and improvement of standards of care for these children and their families. Many people with ASD have symptoms associated with underlying medical conditions, including seizures, sleep problems, gastrointestinal (GI) disorders, and metabolic conditions, that when left untreated, may compromise not only their general health, but also their behavioral, developmental, and educational outcomes. Because autism was long seen solely as a psychiatric disorder, individuals with ASD and their families have faced barriers in accessing appropriate healthcare, and above all, specialty medical care. The ATN was established in 2005 to address the need for uniform standards for care and treatment for medical issues of children with ASD and better access to the physicians delivering that care. One of the ATN's first goals was to establish a multi-disciplinary national registry to characterize the medical and health issues of children and adolescents with ASD and track their health outcomes.

To learn more about participating sites and other activities go to www.autismspeaks.org/atn.

IF YOU ARE NEW TO AUTISM

WHAT IS AUTISM?

Autism is a general term that is used to describe a group of complex neurodevelopmental brain disorders known as autism spectrum disorders (ASD). These include autistic disorder (also called "classic autism" or "autism"), Asperger's, and Pervasive Developmental Disorder, not otherwise specified (PDD-NOS). Individuals with ASDs have impaired social interaction, language problems and delays, and exhibit repetitive or stereotypic behavior and/or have a restricted range of interests.

Today, it is estimated that one in every 110 children is diagnosed with an ASD, with more cases diagnosed each year than childhood cancer, juvenile diabetes and pediatric AIDS combined. An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by ASD.

HOW ARE ASDs DIAGNOSED?

ASDs are diagnosed by observing an individual's behavior and by doing an interview with a caretaker to get a history of current and past behavior. Currently no genetic or other biological test can determine if someone has autism. There are three main tools used to provide a diagnosis and to classify the severity of an individual's symptoms:

DSM-IV: The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) [1] provides a list of clinical criteria that are used to make a clinical diagnosis of an Autism Spectrum Disorder.

ADOS: Autism Diagnostic Observation Schedule (ADOS) [2] is a standardized assessment designed to measure social and communicative functioning in individuals suspected of have an ASD. It uses observation, play tasks and interviews.

ADI: The Autism Diagnostic Interview (ADI) [3] is a comprehensive diagnostic interview with the parent or caregiver. It is most often used in research settings.

WHAT IS AUTISM SPEAKS AND HOW IS IT RELATED TO THE ATN?

Autism Speaks is the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Autism Speaks funds more than $30 million each year in new autism research. In addition, Autism Speaks provides core funding to support the Autism Treatment Network in addition other clinical programs and initiatives (more at *www.AutismSpeaks.org*).

ATN Registry Activity 2009

The ATN Registry, the first national registry for children with ASD, collects a wealth of data on every child enrolled at ATN sites across the US and Canada. Each participating child must meet well-defined diagnostic criteria for autism spectrum disorders based on the Autism Diagnostic Observation Schedule (ADOS) [2] and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) [1]. Proprietary clinical forms are used to gather information on past medical history, including the pregnancy, labor and delivery; hospitalizations and surgeries; medications and past medical diagnoses. Current medical information is collected regarding height, weight and body mass index (BMI), with specialized examinations conducted on each child including a thorough neurological examination and detailed medical history. Parents complete a battery of questionnaires regarding behavior, gastrointestinal symptoms, sleep problems, and other concerns. Cognitive assessments determine each child's level of functioning and help inform the treatment plan. The purpose of the ATN Registry is to collect information about common medical problems seen in children and adolescents with ASD and better document the presence of these conditions and the efficacy of treatment strategies. Because GI and Sleep problems are common parental complaints that have not received adequate attention, an early aim of the ATN Registry was the characterization of these problems in children with ASD and their effect on global behavioral symptoms and quality of life.

Some of the pertinent findings (as of September 2009) are summarized below.

Demographics

A total of 1,420 children and adolescents 2-18 years old were enrolled into the ATN registry by September 8, 2009. Of these, 931 (66%) were diagnosed with Autism, 115 (8%) were diagnosed with Asperger's and 374 (26%) were diagnosed with PDD/NOS. Males represented 84.5% of the cohort, White/Caucasian children represented 80.1% of the cohort and 128 (9%) children were of Hispanic ethnicity. Thirty-eight percent (38%) of the children were seven years of age or older at the time of consent (i.e. when the family consented to participate in the Registry). The mean age at consent was 6.3 ± 3.6 years.

The ATN Registry cohort represents a cross-sectional population with demographic characteristics similar to the general public in North America. For example, ASD is 4 to 5 times more common in males than in females, and that ratio is also reflected in the patient registry. The racial composition of the ATN group has slightly fewer African American/Black families than would be reflected in national rates, while all other races are comparably represented. This slight difference may be due to several factors such as regional differences, rates of Medicaid coverage, and access to health services in general. It will be important to monitor such differences, as they may indicate a need to improve the availability of specialized ASD services to a broader array of children and families.

Most ATN families have PPO (33%), Public (20%) or HMO (21%) coverage. Twelve percent (12%) have a combination of PPO, Public, HMO, Other or Private/Indemnity. Four percent (4%) have private/indemnity coverage while nine percent (9%) have some "other" type of insurance coverage.

Medical Conditions

Children with ASD often have associated medical conditions, including gastrointestinal disorders, seizure disorders, and disturbed sleep patterns. Although there have been some studies of these conditions in

children with autism, variations in study designs and samples have left many questions unanswered. The Registry data have the potential to provide important new information regarding these questions.

GI Symptoms

Rates of GI symptoms in children and adolescents with ASD are uncertain; some studies suggest an increased rate over typically developing children while other studies find no difference [4, 5]. The ATN Registry monitors parent report of GI symptoms and examines relationships between these symptoms and other characteristics of ASD.

GI symptom data are available for 1185 children. Of this group, 45% were reported to have GI symptoms. The incidence of these symptoms increased with the child's age, ranging from 39% in those less than 5 years to 51% in those 7 years and older. Of those children with GI symptoms, 59% reported abdominal pain, 51% constipation, 43% diarrhea, 40% an "other" symptom, 31% nausea and 26% bloating. Parental reports of GI problems did not differ by gender, ASD subtype, race or IQ.

Because pain and discomfort are hallmarks of GI problems, GI dysfunctions are often associated with sleep problems, reductions in overall quality of life and exacerbated behavioral problems. Consistent with these observations, the Registry data showed that the percentage of reported sleep problems was higher in children who also had a reported GI problem (50% vs. 37%, $p<0.0001$*). These children were also found to have overall impaired health-related quality of life. Children with parent-reported GI problems had significantly lower scores ($p<0.01$) on the Pediatric Quality of Life Inventory (PedsQL) [6] than children without reported GI problems. This difference was true not only for the overall score but also for all the individual subscales — Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning — demonstrating the impact of GI problems on several aspects of a child's life. Children ages 1 to 5 years with reported GI symptoms had significantly higher Child Behavior Checklist (CBCL) [7] t-scores for total problems, emotionally reactive, anxious/depressed, somatic complaints, sleep problems, internalizing problems, affective problems, and anxiety problems. Children ages 6 to 18 years with GI problems had significantly higher CBCL t-scores for total problems and all subscales than children without GI problems.

*This figure, $p<0.0001$, is known as a "p-value" and is a shorthand way of representing the likelihood that a result is not a product of chance, that is, did not occur at random. The smaller the p-value, the more confidence one may have in the finding.

Significance: *ATN Registry data indicate that parents of children with ASD report high rates of GI symptoms in their children. No association was observed between GI symptoms and ASD category, gender or IQ. Notably, children with GI symptoms have much higher rates of sleep disruption, as well as behavioral abnormalities as measured by the CBCL. This association exists in all areas of problem behavior concerns in the 6-18 year age group. Further, children with GI symptoms have poorer health-related quality of life.*

Psychotropic Medications

Children with autism spectrum disorders increasingly are being treated with psychotropic medications. Pharmacologic treatment of target behaviors in ASD has rapidly gained

acceptance, even though few medications have clear evidence of effectiveness or approval for use for these symptoms specifically in children with ASD.

Medication data were available on 415 children. Of these, 112 (27%) were taking at least one psychotropic medication; 52 (46%) were on two or more medications. Most commonly prescribed medications were risperidone (e.g. Risperdal), alpha agonists (e.g. Catapres), methylphenidate (e.g. Ritalin), SSRIs (e.g. Prozac), amphetamine (e.g. Adderall) and atomoxetine (Strattera). Table 1 shows a breakdown by age group of the number and percent of children being treated with psychotropic medications of the 415 with medication data.

Table 1: Number and Percent of Children on Psychotropic Medication by Age

	Children by Age Group (n=415)			
Number of Medications	<3yo (n=48)	3-5 (n=184)	6-10 (n=131)	>10 (n=52)
None	46 (96%)	163 (89%)	73 (56%)	21 (40%)
1	2 (4%)	17 (9%)	29 (22%)	8 (15%)
2 or more	0	4 (2%)	29 (22%)	23 (44%)

Of the 48 children under the age of 3 only two (4%) were taking a psychotropic medication and none were on 2 or more. Among the children between the ages of 3 and 5, 21 (11%) were taking at least one psychotropic medication and 4 (2%) were taking two or more. Of the 131 children between the ages of 6 and 10, 58 (44%) were taking at least one psychotropic medication with 29 (22%) taking two or more medications and 4 (3%) taking four or more medications. In the group of children older than 10 years, 31 (60%) were taking at least one psychotropic medication with 23 of these (74% of children on medication, 44% overall) on two or more medications.

***Significance**: Prescription of psychotropic medications is common in ASD, with rates steadily increasing with the child's age. Prescription of multiple medications is also common, especially among older children. These findings are consistent with trends reported nationally [8].*

Sleep Problems

The ATN Registry includes the Child Sleep Habits Questionnaire (CSHQ), a widely used measure of children's sleep difficulties [9]. CSHQ data available for 1,068 children in the Registry indicated that 689 (65%) had sleep problems (defined as a CSHQ composite score of greater than 41). Table 2 shows a breakdown of reported sleep problems. The percentage of children with or without sleep problems did not differ by gender, age category, type of ASD, race or IQ (all $p > 0.05$). Children with sleep problems had much higher rates of GI disturbance as well (70% versus 30%, $p<0.0001$), particularly for the following items: "Sleeps too little," "Alarmed by scary dream," "Restless and moves a lot," "Others wake child," "Takes long time to be alert," and "Seems tired."

Table 2: Sleep Problems Reported for Children in the ATN Registry

	Sleep Problems (CSHQ))			
	No		Yes	
	N	%	N	%
GI Problems (Parent Report)				
No	160	42	221	58
Yes	164	30	379	70

CSHQ data on this cohort were compared to published data on a community sample of 469 children [6]. The mean subscale scores were compared using a two-sample t-test. The mean scores for all subscales (bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, sleep disordered breathing, daytime sleepiness and parasomnias) were significantly higher (indicating more problems) for the ATN registry cohort compared to the community sample ($p < .0001$).

Significance: *Children in the ATN Registry have a high rate of reported sleep problems compared to published community samples of typically developing children. Children with GI problems also have higher rates of parent-reported sleep problems than have children without GI problems.*

Other Registry Topics

Analysis of the ATN Registry in 2010 will address several other important topics. Analyses are on-going and emerging findings are targeted for release in 2010.

Use of Complementary and Alternative Medicine (CAM)

CAM use has been an important approach in the treatment plan for many patients, and ASD is no exception. Greater understanding about the frequency and types of CAM and the factors related to its use can help health care providers support families who choose these treatments.

Dysmorphic findings in ASD

Are there relationships between certain physical findings and other characteristics of ASD? Confirming such relationships could better inform treatment, aid in prognosis, and assist in identifying innovative treatment regimens.

Psychiatric co-morbidities

While ASD may be the primary diagnosis for ATN Registry patients, many also have behavioral symptoms consistent with other DSM-IV diagnoses such as ADHD and bipolar disorder. The incidence of these problems, their nature and scope, and reports of treatment regimens used for these complex patients are of interest to autism specialists seeking better treatments.

Clinical Guideline Activity

A primary activity of the ATN is the establishment of best practices for treatment of ASD and associated co-morbid conditions, and the development of the ATN Model of Care. While much of clinical best practice is based on consensus opinion, a growing body of evidence guides and supports the components of this care. The ATN first began work on clinical algorithms to guide care when the network expanded in January 2008.

With the Autism Intervention Research in Physical Health Network (AIR-P) cooperative agreement in late 2008, the ATN adopted a more systematic approach to the development of clinical guidelines. The ATN has entered into collaboration with the National Initiative for Children's Health Care Quality (NICHQ) to develop, implement and disseminate evidence-based clinical guidelines. Several ATN Committees have begun work on clinical guidelines, and two have received particular attention due to their potential impact on patients and families.

What are guidelines?

A **clinical guideline** or **clinical practice guideline** is a document with the aim of guiding doctors in decisions and providing criteria for diagnosis, management, and treatment in a specific area of medicine or for a specific condition. Modern medical guidelines are based on thorough reviews of current evidence that supports performing a certain procedure or ordering a certain lab test. They usually include input from consensus statements, which are based on input from experts in the field, but unlike the latter, they also address practical issues.

The existing recommendations for the evaluation of children with suspected autism mainly reflect expert opinion with only a little supporting evidence. One goal of the AIR-P project is to develop evidence-based guidelines. This process has begun by developing consensus-based guidelines using expert opinion and then studying these recommendations to find evidence for their effectiveness.

For more information on the AIR-P cooperative agreement, please visit our AIR-P webpage: http://www.autismspeaks.org/airp

Management of Insomnia in ASD

Sleep problems are the most common comorbid symptom in ASD, reported in over half of families. A variety of sleep problems are reported, including night waking, early morning awakening, restless sleep, and sleep walking. The most common sleep problem reported is initial insomnia. Under the direction of Beth Malow, M.D., the ATN Sleep Committee has examined the literature, reviewed recommendations from other experts and societies, and evaluated the evidence in drafting their algorithm for evaluation and management of insomnia in ASD. With the guidance of program staff at NICHQ, process measures, output measures and counter measures were identified and steps taken to collect these measures. The algorithm has been piloted in two sites, and its use is currently expanding across other ATN sites.

Management of Constipation

Next to insomnia and other sleep problems, the most frequently identified medical concern of parents of children with ASD is constipation. As noted earlier, GI symptoms are common in ASD and are associated with lower ratings on health-related quality of life measures. Families often report that their primary care provider, or even a pediatric gastroenterologist, has been unable to identify the underlying problem or has been unsuccessful in treating their child's GI symptoms. The ATN GI Committee, under the leadership of George Fuchs, M.D., has reviewed the literature and evaluated current evidence in developing their algorithm. Like the Sleep Committee, they have fashioned a clinical algorithm with accompanying text that elaborates on and supports the recommendations of the guideline.

Additional Guideline Development

All ATN subspecialty committees are engaged in producing clinical guidelines and algorithms to help steer primary care providers through the evaluation and treatment of ASD and common comorbidities. Other guidelines in progress include:

Use of EEG

Current guidelines (from 2000) recommend EEG studies only if clinically indicated, and do not recommend any specific format (extended monitoring, overnight, video, etc.). Research findings gathered over the past decade may provide a better set of criteria for ordering EEG evaluations as well as guidance regarding the type of study to request. The Neurology committee, under the guidance of Gregory Barnes, M.D. and Reet Sidhu, M.D., has developed an EEG algorithm ready for pilot testing in 2010.

Use of MRI

Similar to the recommendations governing EEG studies, the use of MRI is discouraged in most cases due to low yields, high costs, and questionable impact on treatment. New studies may recommend changes to the list of clinical indications and result in improved care.

Psychotropic medication monitoring

Pharmacologic treatment of ASD symptoms is increasing, with the growth in the number of prescriptions for new atypical antipsychotic agents. These medications carry significant risks, including increased risk of developing Type II diabetes, hyperprolactinemia, and excessive weight gain. Risks associated with this class of medication typically include dystonic reactions (movement disorders) and tardive dyskinesia (involuntary, repetitive movements). Despite these concerns, these medications are often not monitored appropriately, and current monitoring recommendations are directed at adults, with little guidance for the pediatric population. The ATN Psychopharmacology Committee is working on recommendations for monitoring these medications, and has plans to develop monitoring guidelines for other psychotropic medications used in ASD.

ATN Research Activity

One of the major challenges in achieving the ATN's mission of improving medical care for children with ASD is the fact that much of medical care currently builds on best clinical practice, without good evidence that shows that this care improves the outcomes for these patients. Targeted, hypothesis-driven research is therefore an important strategy for meeting ATN goals. ATN research began with support from the research grants program of Autism Speaks. The establishment of the AIR-P cooperative agreement with the Maternal and Child Health Bureau (MCHB), with its objective to promote intervention research, has substantially expanded this effort. A basic goal of the ATN research effort is to find answers to the questions that parents ask regarding the care of their children.

The two initial AIR-P research studies have focused on nutrition and on sleep problems.

AIR-P Sleep study

"Development of a Parent-Based Sleep Education Program for Children with Autism Spectrum Disorder"
This three-year study brings together the leadership and expertise of investigators across four ATN centers (Vanderbilt University, Cincinnati Children's Hospital, Bloorview Kids Rehab and Children's Hospital, Denver) under the leadership of Beth Malow, M.D., M.S. (Lead Principal Investigator, Vanderbilt University Medical Center-VUMC). This three-phase study initially compares the impact of a pair of nurse-led interventions, with the aim of identifying which sleep intervention is more effective against a pamphlet that provides general information without any additional intervention. Clinical efficacy is the primary outcome measure that will be determined by a reduction in the time it takes children to fall asleep (sleep latency) measured by actigraphy. The study also aims to determine whether the preferred sleep intervention demonstrates efficacy as indicated by improved sleep latency in a larger study.

In March 2009, the AIR-P sleep study was approved by the ATN Scientific Review Committee and the lead sites are operating with IRB-approved protocols. Enrollment began in May 2009 for the baseline arm of the study (pamphlet). The remaining sites are scheduled to begin active study enrollment in January 2011 (nurse-led interventions).

AIR-P Nutrition study

"Diet and Nutrition in Children with Autism Spectrum Disorders: An Autism Treatment Network Collaborative Study"
This study, led by Susan Hyman, M.D. (Lead Principal Investigator, University of Rochester Medical Center-URMC), will investigate the nutritional intake and dietary patterns of children and adolescents with ASD. Investigators from the five participating ATN centers (URMC, University of Arkansas for Medical Sciences, Cincinnati Children's Hospital, Children's Hospital, Denver, and University of Pittsburgh) plan to examine the correlation between nutritional status and medical and behavioral symptoms, and explore the potential relationships of dietary intake with feeding behavior and food preferences.

The AIR-P nutrition proposal was approved by the ATN Scientific Review Committee in June 2009 and the project successfully launched in September 2009. The participating centers are working actively on enrollment, data management and ongoing IRB modifications to the protocol.

AIR-P Network RFA

In an effort to accelerate the pace of ATN research, the ATN announced in May 2009 the first AIR-P Network Request for Research Subcontracts (RFA). This announcement invited research proposals in several specific ASD health-related areas including gastroenterology, neurology, metabolics, psychopharmacology, speech pathology and pain. The initiative has two aims: 1) facilitate collaborations to develop innovative research ideas; and 2) carry out pilot studies that will generate preliminary data across key areas of interest to parents, which can be leveraged to seek additional funding opportunities for research. Two particular levels of research were targeted: Level 1, supporting research by junior-level investigators for short-term (1 year) pilot studies; and Level 2, supporting both junior- and senior-level investigators for pilot studies of up to 2 years.

Applicants submitted 16 proposals, and in late August funding was approved for two Level 1 and two Level 2 proposals, which are expected to get underway over the next few months:

Level 1

"Defining the Relation of Sleep Disturbance in Autism Spectrum Disorder to Psychiatric and Behavioral Co-morbidities"

In this study, Suzanne Goldman, Ph.D., of Vanderbilt University Medical Center aims to define the psychiatric and behavioral co-morbidities associated with disordered sleep in children with ASD.

"Bone Mineral Density in Children with Autism Spectrum Disorders"

Ann Neumeyer, M.D., from the MGH/LADDERS Clinic aims in this study to investigate the degree to which bone mineral density is impaired in children with autism and to explore specific additional risk factors.

Level 2

"Prevalence of Creatine Deficiency Syndromes and Genetic Variability in Creatine Metabolism in Children with ASD: A Pilot Study"

Andreas Schulze, M.D., from the University of Toronto is leading the first comprehensive population-based study looking at the prevalence of Creatine Deficiency Syndromes in autism in a diverse ethnic group, which could have implications for the diagnosis, treatment and possible improvement in core symptoms of ASD.

"Markers of Iron Status and Metabolism in Children with ASD"

In this study, Ann Reynolds, M.D., of the University of Colorado aims to evaluate iron intake, iron status and associated sleep disorders in a large, well characterized sample of children with ASD.

Based on the success of the first RFA, the ATN plans a second for further studies in 2010. These studies should add substantially to the understanding and improvement of medical treatment for children and youth with ASD.

Education and Dissemination

The next logical step for ATN activities is to bring our new knowledge and recommendations for treatment to the primary care providers who will use them, and to the families who will benefit from them. ATN sites have hosted numerous educational conferences for professionals and the public during the past year. These include:

Community Dissemination Events:

3/26/2009	Autism Intervention Conference Thompson Center, University of Missouri, Columbia, MO *Margaret Bauman, M.D., Rebecca Landa, Ph.D., Dan Coury, M.D.*
3/26/2009	ATN Autism Symposium: Medical Aspects of Autism Care Bloorview Kids Rehab Centre, Toronto, Ontario, CANADA *Alvin Loh, M.D.*
4/14/2009	Annual Open House, 2009

Center for Autism Related Disorders at Kennedy Krieger Institute
Baltimore, Md.
Rebecca Landa, Ph.D.
The Autism Treatment Network (ATN) and the Autism Intervention Research Physical Health Network (AIR-P)
Dan Coury, M.D.

5/16/2009 Autism: From Science to Treatment
Vanderbilt Kennedy Center, Nashville, TN
Beth Malow, M.D., Jeremy Veenstra-VanderWeele, Ph.D. , Kent Williams, M.D., Greg Barnes, M.D., Tyler Reimschisel, M.D.

8/6/2009 2009 Summer Institute Regional Autism Advisory Council
Xavier University, Cincinnati, Ohio
Dan Coury, M.D.

9/24/09 Morgan Autism Center and Santa Clara University Autism Conference, Autism: Education, Social, and Medical Intervention
Kaiser Permanente, San Jose, CA
Pilar Bernal, M.D., Lisa Croen, Ph.D.
Ann Reynolds, M.D., The Children's Hospital, Denver

11/6/2009 Current Trends in Autism (CTIA) Conference
LADDERS, Boston, MA
Margaret Bauman, M.D., Tim Buie, M.D., Sheldon Wagner, Ph.D., Marvin Natowicz, M.D., Ph.D., Kenneth Sassower, M.D.
David Beversdorf, M.D., University of Missouri

Conferences ranged from half day meetings to four day conferences that in some cases had parallel tracks for parents and professionals. In 2009 these conferences reached out to more than 800 community members.

You can find updated information on new and upcoming events on our webpage at:
http://www.autismspeaks.org/community/outreach/air_p_dissemination.php

Professional Education

Training sessions for professionals were conducted through web-based venues. A series of webinars was developed and delivered to staff at ATN sites, Autism Speaks Science Ambassadors, and MCHB Leadership Education in Neurodevelopmental Disabilities (LEND) programs. Some offerings were:

LEND Webinars

8/20/09	The Autism Treatment Network and the Autism Intervention Research – Physical Health Network Webinar *Dan Coury, M.D.* *Corry Robinson, M.D. (JFK Partners, Colorado)*

Volunteer and Family Advocate Training series

7/16/09	The Autism Treatment Network and the Autism Intervention Research – Physical Health Network *Dan Coury, M.D.*
08/20/09	Talking to Your Doctor about Medical Concerns *Sherry Sellers-Vinson, M.D.*

ATN activity was also promoted via an electronic newsletter and the establishment of the AIR-P web site. These mechanisms are directed to families as well as professional audiences.

Scientific Presentations and Publications

The ATN Care Model was also discussed in meetings with state agencies and organizations, and professional society meetings. In June, Dan Coury, M.D., ATN Medical Director, met with representatives of the state of Washington Department of Health and Department of Education, the Northwest Autism Center, the A-STAR center in Seattle, Seattle Children's Hospital, the University of Washington Autism Center, Madigan Army Medical Center and others to develop a statewide response to the need for diagnostic and treatment services for children and adolescents with ASD. The meeting resulted in an action plan with buy-in from state and county agencies to address this issue.

Dr. Coury also presented at the National Conference and Exposition of the American Academy of Pediatrics in October on the ATN and its activities. While there, he met with AAP leadership to discuss potential collaborative activities in the areas of clinical guideline development and their dissemination, and development of a chronic care model for families with children with autism that primary care providers could effectively utilize. Jim Perrin, M.D., Director of the ATN Clinical Coordinating Center, presented talks on autism at the University of Colorado John F. Kennedy Center, 40th Anniversary Symposium, the University of Minnesota, Minnesota Futures Autism Research Symposium, Minneapolis, and the Medical University of South Carolina Frontiers in Pediatrics Conference (Charleston).

George Fuchs, M.D., Chair of the ATN GI Committee, Dr. Coury and Nancy Jones, Ph.D., ATN Program Director organized a *Symposium on GI Conditions in Autism Spectrum Disorders*, jointly sponsored by Autism Speaks, the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN), and the American Academy of Pediatrics. This all-day symposium featured international experts in the field of pediatric gastroenterology, immunology, and nutrition reviewing the current knowledge base for children with ASD. The symposium was followed by a day-long workshop focused on establishing a research agenda for GI conditions in ASD. Representatives from NIH and other funding agencies were in attendance, and there are plans to present the proceedings of this symposium and workshop to appropriate NIH institutes and other funding agencies in the Spring of 2010. The ATN annual clinical meeting was held in Washington D.C. on November 21-22, and featured sessions on

epilepsy, neuroimaging and psychopharmacology, which should also enhance the research agenda that the ATN will address.

The ATN will present a session covering its clinical guideline development and refinement of its clinical model at the NICHQ Forum in March 2010, and was invited to present on its research activities and the field of ASD via a Topic Symposium at the Pediatric Academic Societies meeting in Vancouver, British Columbia in May 2010.

Presentations

The Registry reviews provided the foundation for abstracts that were submitted for future presentation at scientific meetings. These include:

International Meeting for Autism Research (IMFAR)

"*Sleep is associated with behavior in children with Autism Spectrum Disorders"* – Suzanne Goldman, Ph.D., Beth Malow, M.D. and the ATN Sleep Committee

"Psychotropic Medication Use in Autism Spectrum Disorders" – Daniel Coury, Patricia Manning-Courtney, M.D., Ann Reynolds, M.D., Evdokia Anagnostou, M.D. and the ATN Psychopharmacology Committee

"Parent Reports of Complementary and Alternative Medicine in Children with Autism Spectrum Disorders" – Daniel Coury M.D. and the ATN

"GI Symptoms in Autism Spectrum Disorders" – Kent Williams, M.D., George Fuchs, M.D., Glenn Furuta, M.D., Margaret Marcon, M.D., Daniel Coury, M.D. and the ATN GI Committee

Pediatric Academic Societies (PAS) – Joint Meeting of APS, SPR, APA and AAP

"*Sleep is associated with behavior in children with Autism Spectrum Disorders"* – Suzanne Goldman, Ph.D., Beth Malow, M.D. and the ATN Sleep Committee

"Psychotropic Medication Use in Autism Spectrum Disorders" – Daniel Coury, Patricia Manning-Courtney, M.D., Ann Reynolds, M.D., Evdokia Anagnostou, M.D. and the ATN Psychopharmacology Committee

"Parent Reports of Complementary and Alternative Medicine in Children with Autism Spectrum Disorders" – Daniel Coury, M.D. and the ATN

"GI Symptoms in Autism Spectrum Disorders" – Kent Williams, M.D., George Fuchs, M.D., Glenn Furuta, M.D., Margaret Marcon, M.D., Daniel Coury, M.D. and the ATN GI Committee

SLEEP 2010 – Associated Professional Sleep Societies (APSS) – Joint Meeting of the American Academy of Sleep Medicine and the Sleep Research Society

"Factors Associated with Sleep Problems in Children with Autism Spectrum Disorders" – Suzanne Goldman, Ph.D., Beth Malow, M.D. and the ATN Sleep Committee

Digestive Disease Week (DDW) – Joint Meeting of AASLD, AGA, ASGE, and SSAT
"Association of Parent Reported Behavior Problems, Sleep Problems and Gastrointestinal Problems in Children with Autism Spectrum Disorders" – Kent Williams, M.D., George Fuchs, M.D., Glenn Furuta, M.D., Margaret Marcon, M.D., Daniel Coury, M.D. and the ATN GI Committee

Publications

The ATN has also had several publications in 2009 including an article describing medical conditions in ASD and the role of the ATN in *Current Opinion in Pediatrics.*

Kogan MD, Blumberg SJ, Schieve LA, Boyle CA, Perrin JM, Ghandour RM, Singh GK, Strickland BB, Trevathan E, van Dyck PC. Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder Among Children in the US, 2007. *Pediatrics*. 2009 Oct 124:1395–1403

Coury D, Jones N, Klatka K, Winklosky B, Perrin J. Health Care for Children with Autism. *Current Opinion in Pediatrics*, 2009 Dec; 21(6):828-832

Coury D. Medical Treatment of Autism Spectrum Disorders. *Current Opinion in Neurology* (in press)

Kuhlthau KA, Orlich F, Hall TA, Sikora D, Kovacs EA, Delahaye J, Clemons T.. Health Related Quality of Life in Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders* (in press)

Goals For 2010

As we look ahead to 2010, we have a number of short-term and long-term goals we would like to achieve:

- Completion of the clinical guidelines currently in development, and development of the next set of guidelines and toolkits to promote better clinical care
- Expansion of clinical quality improvement activities across the network
- Continuing and expanding our current research programs
- Further examination of the Registry and dissemination of our findings through presentations at scientific meetings and publication in scientific journals
- Increasing the reach of the ATN clinical model through collaborations with major medical organizations such as the AAP, SDBP, AAN, AACAP and others

We will also be developing a Strategic Plan for the ATN that will extend beyond the current 2008-2010 funding cycle. This will be a high priority, as we anticipate significant changes to our Registry, the dissemination of our care model and delivery of evidence-based care, a major emphasis on quality initiatives, and further research utilizing the population and expertise benefits that only a network like the ATN can accomplish.

2009 was an extraordinary year of achievements for the Autism Treatment Network. We have made great strides in improving care for children and youth with autism, through efforts at standardization, clinical guidelines, development of our comprehensive clinical care model, research into questions that matter to parents, and active dissemination of information to parents and professionals. We look forward to further growth in 2010.

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8. Mandell DS, Morales KH, Marcus SC, Stahmer AC, Doshi J, Polsky DE. Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. Pediatrics. 2008 Mar;121(3):e441-8.

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Appendix: Other Site Training and Community Outreach Activities

ARKANSAS

Formal Presentations

- George Fuchs, M.D. Assisted in organizing the symposium: *"Gastrointestinal Conditions in Children with Autism Spectrum Disorders"*; NASPGHAN Annual Meeting; November 2009.
- Jill Fussell, M.D.; LEND presentation: "Autism/Developmental Delay – an overview"
- Jill James, Ph.D.; *"Glutathione Deficiency in ASD"* Satellite Symposium on Gastrointestinal Conditions in Children with ASD; North American Society of Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN); November 15, 2009

Informal Presentations, Training and Educational Involvements

- Jill James, Ph.D.; research training and experience to three LEND trainees under the Arkansas HRSA LEND program. Annual lectures to all LEND trainees.
- Jill Fussell, M.D.; lectures to junior medical students on child development; regularly features a case-based interactive discussion on a child presenting with developmental delay/language delay who ultimately is diagnosed with autism as the case progresses.
- Maya Lopez, M.D.; monthly lectures on autism on various topics including cultural myths of autism to for residents rotating though Developmental Pediatrics.
- Eldon Schulz, M.D.; PI MHCB LEND Program at Arkansas site. Provides training to graduate trainees in 13 disciplines to enhance their understanding of developmental disabilities (DD), including Autism and to increase the capacity of screen, evaluate and treat children with DD and Autism.

BAYLOR

Formal Presentations

- Diane Treadwell-Deering, M.D.; co-presenter; *"Comorbidity in Autism Spectrum Disorders: Assessment and Treatment"*; American Academy of Child & Adolescent Psychiatry; Hawaii; October 27-November 1, 2009.
- Diane Treadwell-Deering, M.D.; co-presenter; *"A Clinical Consultation": Assessment and Treatment of Comorbidity in Autism Spectrum Disorders"*; American Academy of Child & Adolescent Psychiatry; Hawaii; October 27-November 1, 2009.

- Diane Treadwell-Deering, M.D.; co-presenter; *"Review of Genetic Research in Autism and Clinical Implications"*; American Academy of Child & Adolescent Psychiatry; Hawaii; October 27-November 1, 2009.

- Diane Treadwell-Deering, M.D.; keynote speaker at the East Texas Autism Coalition on September 12, 2009.

- Diane Treadwell-Deering, M.D.; interview featured on Houston's Fox News regarding Autism and breastfeeding; November 25, 2009.

Informal Presentations, Training and Educational Involvements

- Sherry Vinson, M.D.; training of three program year one residents in Neurodevelopmental Disabilities in the medical, behavioral, educational management for individuals with an Autism Spectrum Disorder; Academic Year 2009-10.

- Sherry Vinson, M.D; training of General Pediatric Residents during their required month rotation through the developmental pediatrics; includes in-clinic time with Dr. Vinson seeing return ATN patients.

- Sherry Vinson, M.D.; planning committee for the Baylor College of Medicine 2009 *Chronic Illness: Transition to Adulthood Conference*; aim: to educate parents, healthcare professionals, educators and legislators on how to help individuals with chronic conditions, including an autism spectrum disorder, transition to adulthood; November 5-6, 2009.

BLOORVIEW (TORONTO)

Formal Presentations

- Peggy Marcon, M.D.; *"The Gut and Autism - Where are we in 2009? Evidence, Investigation, Treatment, Health"*; Mukibaum Treatment Centres "Come to your Senses" Conference; Oct 23, 2009

- Wendy Roberts, M.D.; Keynote address: "*The Mystery of Autism - What is it, How do we Assess it and How do we Treat it?"*; Mukibaum Treatment Centres "Come to your Senses" Conference; October 24, 2009

Informal Presentations, Training and Educational Involvements

- Wendy Roberts, M.D. and Evdokia Anagnostou, M.D.; University of Toronto Child Development Update: *Seminar on Psychopharmacology in ASD*; November 14, 2009.

- Wendy Roberts, M.D.; lectures at Family Practice Rounds for clinicians at North York General Hospital and Women's College Hospital; *Medical issues of children with ASD*; attendance: 100 and 50 respectively.

Hosted Conferences and Symposia

- ATN Toronto Medical Symposium 2009; *"Medical Aspects of Care in children with ASD"*; 161 attendees including 73 medical professionals, 55 parents, and 33 other clinicians and educators. Topics: gastrointestinal disorders, feeding, sleep, metabolic evaluation; March 26-28, 2009.

- Hospital for Sick Children, University of Toronto; Annual Paediatric Update (Continuing Medical Education); featured seminar *"Headlines in Autism Spectrum Disorders"*; April 27, 2009 to May 2, 2009.

CINCINNATI

Formal Presentations

- Patricia Manning-Courtney, M.D.; Webcast; "*Warning Signs Your Child May be Autistic"; http://www.healthradio.net;* August 5, 2009

Informal Presentations, Training and Educational Involvements

- Patricia Manning-Courtney, M.D.; Cynthia Molloy, M.D., MS; Nicole Bing, Psy.D; Donna Murray, Ph.D. Leadership Education in Neurodevelopmental and Related Disabilities (LEND) training; 2 trainees; *"Overview to Autism Spectrum Disorders"*; 2010.

- Donna Murray, Ph.D.; graduate level course *"Communication Issues in Autism Spectrum Disorders"*; College of Allied Health Sciences, Department of Communication Sciences and Disorders; 2009

COLORADO

Formal Presentations

- Ann Reynolds, M.D.; *"Gastrointestinal Dysfunction in Children with Autism Spectrum Disorders"*;, JFK Partners and IDDRC 40th Anniversary Research Symposium, February, 2009, Denver, Colo.

- Ann Reynolds, M.D.; *"The Autism Treatment Network and The Autism Intervention Research Network for Physical Health (AIR-P): Mechanisms for Improving Diagnosis and Management of Sleep Disorders, Gastrointestinal Disorders, and Nutrition in Children with Autism Spectrum Disorders"*; The Morgan Autism Center and the University of Santa Clara Autism Conference, September 2009, Santa Clara, Calif.

- Dan Atkins, M.D.; *"Diarrhea and Allergies in Children with ASD";* Satellite Symposium on Gastrointestinal Conditions in Children with ASD; North American Society of Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN); November 15, 2009

Informal Presentations, Training and Educational Involvements

- Cordelia Robinson, Ph.D., RN, Director of the LEND program Mentor for LEND trainees; Lead Faculty - CLSC 6654 and 6655 *"Key Concepts in Neurodevelopmental Disabilities I and II"*; 2009

- Susan Hepburn, Ph.D.; Lead Faculty – CLSC 6668 *"Assessment and Screening of Autism"* Course ; LEND; 2009

- Susan Hepburn, Ph.D.; Lead Faculty – CLSC 6663 *"Evidence Based Interventions for Children and Youth with Autism and Neurodevelopmental Disabilities"*; LEND; 2009

- Susan Hepburn, Ph.D.; Lead faculty – *Child Development Seminar* for psychiatry fellows and doctoral level psychology interns at University of Colorado School of Medicine; 2009

- Glen Furuta, M.D.; Moderator, *"Gastrointestinal Manifestations of Autism"*, North American Society of Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN); November 12, 2009

COLUMBIA

Formal Presentations

- Erica Kovacs, Ph.D.; *"Social Thinking and Autism"* workshop; Sinergia/The Metropolitan Parent Center, New York, NY; March, 2009.

Informal Presentations, Training and Educational Involvements

- Maureen McSwiggan-Hardin, NP-P, RN; presentation on the ATN; Children's Health Involving Parents (CHIP) early childhood treatment agency; New York, NY; March, 2009

- Maureen McSwiggan-Hardin, NP-P, RN, presentation on the ATN at Autism Fair, Westchester, N.Y.; April, 2009

- Agnes Whitaker, M.D. and Maureen McSwiggan-Hardin, NP-P, RN, presentation on the ATN at Mind and Body in Autism; Columbia University, Teacher's College; April, 2009

- Erica Kovacs, Ph.D.; Media Interview Radio interview for *"Science on the radio report on autism."* Internet science news podcast; April, 2009

- Maureen McSwiggan-Hardin, NP-P, RN; *"Autism and the ATN";* lecture to Nurse Practitioner Fellows, Columbia University. August, 2009

- Maureen McSwiggan-Hardin, NP-P, RN; *"Siblings and ATN"*, presentation to parent support group; New York, N.Y.. September, 2009

- Agnes Whitaker, M.D.; Center for Discovery; presentation on the ATN; to an audience that included educators, legislators, and parents. New York, N.Y.. September, 2009

- Erica Kovacs, Ph.D.; on-camera interview as expert on autism spectrum disorders for documentary film, "Rockism." Film directed by graduate journalism student at NYU (M.

DeLateur) that profiles three rock bands whose members are all teens with autism that is scheduled to be screened at NYU film festival in January 2010. October, 2009

- Maureen McSwiggan-Hardin, NP-P, RN; information session at the League School for children with ASD. December, 2009

KAISER

Formal Presentations

- Pilar Bernal, M.D. and Lisa Croen, Ph.D.; presentations at the Morgan Autism Center ASD annual conference; San Jose, Calif.; September 2009

KENNEDY KRIEGER

Formal Presentations

- Rebecca Landa, Ph.D., CCC-SLP *"Early Identification and Intervention in Autism Spectrum Disorders"*; Thompson Center Annual Autism Intervention Conference; Columbia, Mo.; March 2009

- Anil Darbari, M.D. *"Gastrointestinal Issues in Children with Autism";* Center for Autism and Related Disorders (CARD) Annual Conference; Kennedy Krieger Institute, Baltimore, Md.., October 29, 2009

- Rebecca Landa, Ph.D., CCC-SLP; *"Early Detection of Autism Spectrum Disorders"* Center for Autism and Related Disorders (CARD) Annual Conference; Kennedy Krieger Institute, Baltimore, Md.; October 29, 2009

Informal Presentations, Training and Educational Involvements

- Various clinicians; Center for Autism and Related Disorders (CARD) Annual Conference; topics included: early diagnosis; the utility of neuropsychological evaluation, GI issues, the role of epilepsy and EEG; attendees included: physicians, educators, speech-language pathologists, occupational therapists, psychologists, policy makers, social workers, administrators, and family members; October 29-30, 2009

LADDERS

Formal Presentations

- Margaret Bauman, M.D.; *"Overview of Medical Interventions for Autism Spectrum Disorders";* Thompson Center Annual Autism Intervention Conference; Columbia, Mo.; March 2009

- Margaret Bauman, M.D.; *"Match.com: Can Research and Clinical Care Find Happiness Together?";* Current Trends in Autism – 2009 Conference; Boston, Mass.; November 6, 2009

- Timothy Buie, M.D.; *"Gastrointestinal Issues in Autism – What we Know Now"*; Current Trends in Autism – 2009 Conference; Boston, Mass.; November 6, 2009

- Timothy Buie, M.D.; *"Clinical Aspects and Treatment of Reflux in Children with ASD";* Satellite Symposium on Gastrointestinal Conditions in Children with ASD; North American Society of Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN); November 15, 2009

- Marvin Natowicz, M.D., Ph.D.; *"Genetic and Metabolic Analysis in Autism: A Clinical Study"*; Current Trends in Autism – 2009 Conference; Boston, Mass.; November 6, 2009

MISSOURI

Formal Presentations

- Judith Miles, M.D., Ph.D.; "*Delineating Autism's Clinical and Genetic Heterogeneity: A Clinical Geneticist's Approach";* Harvard and MIT Autism Seminar Series, Mass General Hospital, Boston, Mass.; January 12, 2009

- Judith Miles, M.D., Ph.D.; Autism: An Overview of Genetic, Treatment, and Outcome Determinants, TIPS Lecture, Thompson Center, Columbia, Mo.; January 23, 2009

- Judith Miles, M.D., Ph.D.; Children with Autism: Diagnosis, Causes, & Treatment, American Physical Therapy Association Annual Meeting, Las Vegas, Nev., February 11, 2009

- Judith Miles, M.D., Ph.D.; *"Delineating Autism's Clinical and Genetic Heterogeneity: A Clinical Geneticist's Approach"*, Autism Symposium: Fitting the pieces together with practice and research, Children's Mercy Hospitals; Kansas City, Mo., April 21, 2009

Informal Presentations, Training and Educational Involvements

- Stephen Kanne, Ph.D., ABPP; TIPS (Training in Interdisciplinary Partnerships and Services) for Kids - LEND training program; 2009
- Rachel Brown, M.D. *"Clinical Challenges Using Psychotropic Medications with Children with Autism";* Thompson Center Clinical Forum Series; October 22, 2009
- Stroud, Kanne, Lowry, Boyd; Autism Lecture; TIPS; 15 participants; Thompson Center, Columbia, Mo., January 23, 2009

- Judith Miles, M.D., Ph.D.; Autism Dysmorphology Measure (ADM) Training Seminar and Picture Gallery, Child Health Residents, MU School of Medicine, Columbia, Mo., 17 participants January 26, 2009
- Judith Miles, M.D., Ph.D. Vaccination Review, Missouri Medical Focus radio segment, KBIA Radio interview, (unknown audience) March 5, 2009

- David Beversdorf, M.D.; *"Autism Research – cognitive pharmacology, animal models, and translational directions"*, Neurology Grand Rounds, Columbia, Mo.; August 19, 2009

OHSU

Formal Presentations

- Robert Steiner, M.D.; *"You may have inherited more than your blue eyes: Jewish Genetic Diseases"*; NTSAD Foundation seminar, Neveh Shalom Synagogue, Portland, Ore., April, 2009.

- Robert Steiner, M.D.; *"Poisoned by Cholesterol: Niemann Pick Type C";* Medical Genetics Grand Rounds, OHSU, Portland; January 2009.

- Robert Steiner, M.D.; *"Challenging Clinical Case: Metabolic Acidosis"*; Pediatric Grand Rounds. OHSU, Portland; January 2009.

- Robert Steiner, M.D.; Strategies in Forming Effective Teams or Networks Panel: CTSA Program. Advancing Rare Diseases Research Through Networks and Collaboration Conference, National Institutes of Health, Bethesda, Md., July 16, 2009

- Kyle Johnson, M.D.; *"Assessment of Pediatric Obstructive Sleep Apnea"*, 18th Annual Respiratory Care Conference, Troutdale, Ore., September 11, 2009.

- Kyle Johnson, M.D.; *"Sleep in Special Populations"* (Medical, Psychiatric, and Neurodevelopmental Disorders, Best Practices Course at the Fifth Annual Conference on Pediatric Sleep Medicine, Westminster, Colo., October 2, 2009.

Informal Presentations, Training and Educational Involvements

Robert Steiner, M.D.; *"Smith Lemli-Opitz Syndrome: From Bench to Bedside and Back";* Medical Scientist Training Program Grand Rounds; Oregon Health & Science University; March, 2009.

- Karen Grant, Psy.D; *"An overview and autism spectrum disorder";* teaches this subject on a quarterly basis at Portland State University, Portland, Ore.; throughout 2009

- Karen Grant, Psy.D; *Asperger's Syndrome and College.* Half day in-service presentation at Chemekeda College, Salem, Ore.; September 2009

- Karen Grant, Psy.D; *Asperger's Syndrome in Middle and High School* Half Day training at Concordia University, Portland, Ore.; October, 2009

- Karen Grant, Psy.D; *Asperger's Syndrome and College: Strategies for success and self-advocacy.* Half day in-service presentation at Chemekeda College, Salem, Ore.; November 2009

- Robin McCoy, M.D.; numerous trainings at community hospitals in the area of initial screening for ASD and referral. She also presents at OHSU Pediatric Grand Rounds and noon conferences on topics related to ASD.

- All clinicians; LEND (Leadership Education in Neurodevelopmental Disabilities) provide training as follows: Psychology interns, 4-month rotation; Speech Language Pathology, six month rotation; and students from other allied health disciplines (Occupational Therapy, Physical Therapy), from 2-8 weeks within the Autism Clinics throughout 2009.

PITTSBURGH

Formal Presentations

- Nancy Minshew, M.D.; *"New Neurobiology of Autism"*; Robert Wood Johnson Medical School, Neurology; Grand Rounds; Camden, N.J.; January 14, 2009

- Nancy Minshew, M.D.; *"Advances in Science and Wisdom of Those Who Live With It"*; Allegheny General Hospital Grand Rounds; Pittsburgh, Penn.; January 29, 2009

- Nancy Minshew, M.D.; *"Autism: From Men and Mice With Wise Comments from Mars"* ; UCLA Center of Autism Research and Treatment; Los Angeles, Calif.; February 6, 2009

- Nancy Minshew, M.D.; *"Autism: What We Know"*; University of Pittsburgh, Greensburg Campus; Greensburg, Penn.; February 26, 2009

- Nancy Minshew, M.D.; *"Recognizing Autism and the New Concepts around Neurobiology"*; University of Pittsburgh NIMH Fellowship Program in Mental Health Research; Pittsburgh, Penn.; February 27, 2009

- Nancy Minshew, M.D.; *"Autism: Towards an Integrated Model of Diverse Research Findings"*; Wolfson Children's Hospital Autism Symposium; Jacksonville, Fla.; March 11, 2009

- Nancy Minshew, M.D.; *"Autism: What We Know; Important Research Developments"*; Autism Society of America; New York, N.Y.; April 7, 2009

- Nancy Minshew, M.D.; *"Facial Recognition, Configural Processing, and concept Formation in High-Functioning Autism"*; International Society for Autism Research (IMFAR); Chicago, Ill.; April 8, 2009

- Nancy Minshew, M.D.; *"Neuropsychiatry Advances in Autism"*; APA Annual Meeting; San Francisco, Calif.; May 17, 2009

- Nancy Minshew, M.D.; *"How Do the Mind and Brain Think in Autism/"* and *"The Cause of Autism: Its Footprint Tells"*; Edge Hill University; Lancashire, UK; May 22, 2009.

- Nancy Minshew, M.D.; *"Adults with Autism"* ; Cold Spring Harbor Laboratory; Cold Spring Harbor, N.Y.; June 24, 2009

- Nancy Minshew, M.D.; *"The State of Autism Research: What Do We Know"*; Pennsylvania Immunization Conference; Hershey, Penn.; June 25, 2009

- Nancy Minshew, M.D.; *"Autism in the 21st Century*"; Wesley Spectrum Services; Pittsburgh, Penn.; November 2, 2009

- Nancy Minshew, M.D.; *"The Details are in the Connections: Deciphering Heterogeneity in ASD"*; Interdisciplinary Council on Developmental and Learning Disorders; Bethesda, Md.; November 7, 2009

- Nancy Minshew, M.D.; *"How the Brain in Autism Defines Perception, Thinking, & Their World: A Different Sense of Reality";* ARC; Pittsburgh, Penn.; November 13, 2009

- Nancy Minshew, M.D.; *"How the Brain Thinks in Autism: Implications for Language Intervention"* ASHA Division I Language Learning Education – New Orleans, La.; November 19, 2009

Informal Presentations, Training and Educational Involvements

- Nancy Minshew, M.D.; *"Neurobiologic Basis of Autism/Underconnectivity"*; Autism Course for Child and Adolescent Psychiatry Fellows; Pittsburgh, Penn.; March 26, 2009

- Nancy Minshew, M.D.; "Autism as a Developmental Neurobiologic Disorder"; Western Psychiatric Institute and Clinic; Child and Adolescent Psychiatry Fellows; Pittsburgh, Penn.; April 9, 2009

- Nancy Minshew, M.D.; "Understanding How the Mind and Brain Think in Autism", "The Cause of Autism: Its Footprint Tells," and "Medical Consultation on the Medical Aspects of Autism – Meeting with Physicians"; Bowling Green State University; Bowling Green, Ohio; June 6, 2009

- Nancy Minshew, M.D.; "Neurologic Basis of Autism"; Western Psychiatric Institute and Clinic; Adult Psychiatry Residents; Pittsburgh, Penn.; November 12, 2009

ROCHESTER

Formal Presentations

- Susan L. Hyman, M.D; "*Feeding Behaviors in Children with Autism Spectrum Disorders;* Satellite Symposium on Gastrointestinal Conditions in Children with ASD; North American Society of Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN); November 15, 2009

- Susan L. Hyman, M.D; *"Complementary and Alternative Treatments In Autism"*; Pediatric Grand Rounds; Lebonheur Children's Medical Center; Memphis, Tenn.; February 25, 2009

Informal Presentations, Training and Educational Involvements

- Lynn Cole, PNP; PNP and Psychiatric Nurse Practitioner training programs with didactic and clinical training in ASD; throughout 2009

- Chin To Fong, M.D.; Genetics course and Developmental and Behavioral pediatric lectures on autism and child development; University of Rochester Medical Center; Rochester, N.Y. 2009

- Stephen Sulkes, M.D. directs training of LEND Fellows; formal curriculum related to assessment, multidisciplinary care, advocacy, parent support; one of the three groups each year does their mentored research on a topic related to autism

- Community Lectures: Multiple faculty have spoken at community sites regarding the ATN and component topics including sleep/ATN for Early Intervention (Smith), GI and Nutrition and ATN for Early Intervention and at Upstate UCP in Utica (Hyman), Pediatric Grand Rounds (GI/Nutrition – Hyman/Stewart) and many more.

VANDERBILT

Formal Presentations

- Beth Malow, M.D.; *"Melatonin for Children with Autism"*; Sleep Grand Rounds, University of British Columbia Department of Pediatrics; Vancouver, Canada, April 2009.

- Beth Malow, M.D.; "*Meet the Professor, Sleep and Neurodevelopmental Disorders";* invited speaker, American Academy of Sleep Medicine Annual Meeting; Seattle, Wash., June 2009.

- Adkins, K., McGrew, S.G., Stone, W.L., Surdyka, K.L., Goldman, S.E., Wofford, D., & Malow, B.A. Sleep and behavior in children with autism spectrum disorders – Effects of supplemental melatonin. Presented at the International Meeting for Autism Research (IMFAR), Chicago, May,2009.

Informal Presentations, Training and Educational Involvements

- Beth Malow, M.D.; *Helping Your Child with ASD to Sleep"*. Autism parent training; Vancouver, Canada, April 2009

- Evon Lee, Ph.D. and Tyler Reimschisel, M.D.: *"Introduction to Autism Spectrum Disorders: Diagnosis and Medical Issues"* Presentation for the LEND Grant/MIND Seminars; Nashville, Tenn.; 2009

- Kent Williams, M.D.; *"Occurrence and Treatment Of GI Disorders In Children with ASD"*; lecture to pediatric GI fellows; Nashville, Tenn.; 2009

SOURCE OF DATA:
Autism patients enrolled in the ATN Registry at one of the ATN centers in the U.S or Canada, 2009

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