2013 Autism Treatment Network Research and Autism Studies Guide







Principle Investigator: Robin Post/Kelly Hunter/Marc Tasse

OSU Department of Theater/Nisonger Center Collaboration

Study Name: Shakespeare and Autism Pilot Study

About the study:

Theatre Students and Teaching Artists bring the Hunter Heartbeat Method (Shakespeare-based theatre activities) to children with ASD in Columbus City Schools. Researchers from the Nisonger Center are conducting research which will determine the ability of the method to effect change to the core features of autism.

Study Participant age range: 8-14 years

Study Coordinator: Robin Post

(614) 292-0834 Root.132@osu.edu

Principle Investigator: Eric Butter, PhD

Nationwide Children's Hospital The Nisonger Center, OSU

Study Name: Autism Treatment Network Biorepository

About the Study:

The ATN (Autism Treatment Network) was established to improve the lives of children and families affected by autism by creating a network of high quality medical care centers engaged in a systematic approach to improving the care of children with ASD and the dissemination of practice guidelines into wider clinical practice. The goal of the ATN Registry is to provide data to identify medical conditions and track medical, behavioral and quality of life outcomes in children with ASD to help identify best practices and improve care. The primary aim of this study, the ATN Biorepository, is to expand the data collection efforts of the Autism Treatment Network to include the collection of biomaterials. The addition of this data to the ATN Registry will increase the depth and breadth of both the ATN data thereby facilitating genetic studies in autism, accelerating the understanding of the causes and varied courses of ASD, and facilitating discovery of new therapeutics.

Study Participant Age Range: 2-17 years

Study Coordinator: Thomas Whitlow

(614) 355-8389

Thomas.Whitlow@nationwidechildrens.org





Principle Investigator: Eric Butter, PhD

Nationwide Children's Hospital The Nisonger Center, OSU

Study Name: SynapDx Autism Spectrum Disorder Gene Expression Analysis

About the Study:

This study is testing a unique way to analyze the potential genes that could be involved in causing autism. The new approach tries to maximize agreement between the classification and a clinical assessment of presence or absence of autism spectrum disorders (ASD). This research is being done at a large number of centers around the country and is enrolling both children with ASD as well as children with other developmental disabilities other than an ASD. This study does involve a blood draw.

Study Participant Age Range: 18-60 months

Study Coordinator: Thomas Whitlow

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Thomas.Whitlow@nationwidechildrens.org

Principle Investigator: Dan Coury, PhD

Nationwide Children's Hospital

Study Name: A Multi-Site Double-Blind Placebo-Controlled Trial of Memantine vs.

Placebo in Children with Autism Targeting Memory and Motor Planning

About the Study:

The Department of Behavior Health at Nationwide Children's Hospital is doing a research study for children with an experimental medicine for the improvement of Thinking, Memory and Learning in children ages 6 to 12 who have been diagnosed with autism. The study will last for 6 months with 11 visits and 2 phone calls. Qualified participants may receive the following at no cost:

Study related medical care

Study medication

Compensation for time and travel

Study Participant Age Range: 6-12 years

Study Coordinator: Melinda Helton, RN

(614) 722-2607

Melinda. Helton@nationwidechildrens.org





Principle Investigator: Mike Aman, PhD

The Nisonger Center, OSU

Study Name: Strattera, Placebo, and Parent Training in Autism

About the study:

Although stimulant medicines, like Ritalin, are the usual treatment for typically developing children with ADHD, they often do not work as well for children with autism spectrum conditions. This cooperative study is being done at O.S.U., University of Rochester, and University of Pittsburgh to enroll a total of 144 children with autism spectrum and attention problems. Many of these youngsters also have problems with impulsiveness and/or over activity. We are enrolling children ages 5 through 14 years of age. Children receive either Strattera (also called atomoxetine) or placebo ("sugar pill") for 10 weeks. Half of the parents are also given training (9 sessions) in behavior intervention principles, one-on-one with a Ph.D. psychologist. We are assessing the children to see if these treatments affect their ability to attend to school-related activities (e.g., homework) and to comply with everyday rules and expectations. After the first 10 weeks, the medication blind is broken if the child seems not to be having a good response. Study doctors then work with parents to find the best medicine that they can for each child. We try to follow each child for 6 months after the first 10 weeks.

Study Participant age range: 5-14 years

Study Coordinator: Adrienne Austin

(614) 685-3219

Adrienne.Austin@osumc.edu

Principle Investigator: Jill Hollway, PhD

The Nisonger Center, OSU

Study Name: Treatment of Overweight Induced by Antipsychotic Medication in

Young People with ASD

About the Study:

Antipsychotics are useful for decreasing problem behavior. However, weight-gain is a frequent side effect. In cooperation with the University of Pittsburgh, University of Toronto, and Vanderbilt University, the O.S.U. Nisonger Center and Nationwide Children's Hospital are evaluating the effects of metformin as a deterrent to weight-gain from antipsychotic use. Children and adolescents will be randomized to either metformin or placebo during the first 16 weeks of the study. All children will have a chance to try the real metformin in the second 16 weeks of the study.

Participant Age Range: 6-17 years

Study Coordinator: Adrienne Austin

(614) 685-3219

Adrienne.Austin@osumc.edu





Co-Principle Investigators: Jill Hollway, PhD / Michael Aman, PhD

The Nisonger Center, OSU

Study Name: An Open-Label Study of the Safety and Tolerability of Memantine in

Pediatric Patients with Autism, Asperger's Disorder, or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

About the study:

Memantine (Namenda) is an FDA approved medication for the treatment of Alzheimer's Disease. In this 48 week study, memantine will be evaluated as a treatment for the core symptoms of autism. All children will receive the real memantine at the beginning of the study. Based on each child's response to the medicine, (she may be randomly assigned to take either the real medicine or a placebo later in the study.

Study Participant Age Range: 6-12 years

Study Coordinator: Lauren Wargelin

(614) 688-8214

Lauren.Wargelin@osumc.edu

Principle Investigator: Eric Butter, PhD

Nationwide Children's Hospital The Nisonger Center, OSU

Study Name: Parent Training Study in Young Children with Autism

About the Study:

Many young children on the autism spectrum display behavioral issues such as tantrums, aggression, or self-injury. Researchers at OSU's Nisonger Center are conducting a study to help parents learn how to reduce these problem behaviors. Specifically, we are comparing the effectiveness of two programs: structured parent training (PT) and an intensive psycho educational program (PEP). This six month study involves parents receiving 11-13 individual sessions of either PT or PEP (randomly assigned) with a psychologist, along with monthly assessments.

Study Participant Age Range: 3-6 years

Study Coordinator: Jill Pritchett

(614) 685-3200

jill.pritchett@osumc.edu





Principal Investigators: Mike Aman, PhD

The Nisonger Center, OSU

Study Name: Anxiety Study: Developing a Scale for Anxiety in Children with Autism Spectrum

Disorders

About the study:

This study aims to develop a scale for measuring anxiety in children with Autism Spectrum Disorders. Ways in which anxiety presents itself in children with ASD will be identified through parent focus groups. This information will then be used to generate a scale for parents and clinicians to measure anxiety in children with ASD. Data on this anxiety scale will be collected from hundreds of families who will use it to report symptoms of anxiety in their child with ASD. This is a four-year, multisite research study; The Ohio State University will be working with researchers at Emory University and Children's Hospital of Philadelphia to enroll 900 families across sites.

Study Participant Age Range: 5-17 years

Study Coordinator: Jill Pritchett

(614) 685-3200

jill.pritchett@osumc.edu

Principle Investigators: Jack Stevens, PhD

Nationwide Children's Hospital

Study Name: Telephone Care Management to Address Sleep Problems in Young

Children with Autism

About the Study:

Many children have sleep problems. Some take hours to fall asleep, others fall asleep quickly but then wake up and can't get back to sleep. Some need their parents to sleep with them. Often times this is difficult on the whole family.

The Division of Psychology and The Center for Biobehavioral Health are working together on a research study for children who have problems getting to sleep or staying asleep. This study tests a telephone based intervention. Through a series of phone calls, a health care provider will contact parents to discuss behavioral tactics that might help their children with autism spectrum disorders sleep better.

Study Participant Age Range: 3 -6 years

Study Coordinator: Karen Carter

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Participate in Autism Research Today!

Did you know that <u>only 5% of children with autism</u> in the U.S. participate in clinical research studies each year, while nearly 90% of children with cancer are enrolled in research studies?

There are many opportunities for families to participate in research:

ResearchMatch - Become a research volunteer, visit https://www.researchmatch.org/?
rm=autismsubregistry - it is a secure, easy to use, volunteer registry funded by the National Institutes of Health (NIH).

<u>StudySearch</u> - Find a research study on http://studysearch.osumc.edu/ a listing of research studies at The Ohio State University.

614-293-HERO (4376) - Call with your questions.

Where Can I Find Research Studies?

Ohio

Autism Treatment Network at Nationwide Children's Hospital

http://www.nationwidechildrens.org/autism-treatment-network

Nationwide Children's Hospital

http://www.nationwidechildrens.org/pediatric-clinical-research-studies

Ingram-White Castle

http://faculty.psy.ohio-state.edu/petrill/

The Ohio State University/Nisonger Center

http://treat.osu.edu/

Nationally

Autism Speaks

http://www.autismspeaks.org/science/resources-programs/autism-clinical-trials-network

Autism Treatment Network

http://www.autismspeaks.org/science/resources-programs/autism-treatment





Where Can I Find Out More About Research?

Autism Speaks

"The decision to become a participant in drug research is an important one, all the more so if you are making this decision for your child or other dependent. It is an option that is becoming increasingly available to individuals and families affected by autism spectrum disorder (ASD). This is because research into the causes and biology of autism is advancing in ways that make it feasible to identify drugs that may relieve disabling symptoms.

The goal of this guide is to both answer common questions and pose additional ones that may be important for you to consider. The decision of whether or not to participate in autism drug studies should be guided by your goals and values as well as a clear understanding of potential risks and –benefits and possible demands upon you, your child and your family. We encourage you to jot down questions that may arise as you review this material – questions that you may want to discuss with your family, personal physician and the researchers leading the study you are considering."

Please go the link below for more information.

http://www.autismspeaks.org/science/participate-research/participants-guide-drug-research Or http://www.autismspeaks.org/science

Organization for Autism Research (OAR)

The OAR website aim is to help answer those questions by introducing you to the domain of autism research and providing some tools for understanding, evaluating and applying research findings to your child's autism. http://www.researchautism.org/family/research/index.asp

Please plan to attend the next Families with Autism Medical Lecture Series (FAMLS)

Research and Autism Fall 2013

For details, please visit www.nationwidechildrens.org/autism-treatment-network





Notes:			











The Child Development Center (CDC) Autism Treatment Network (ATN)

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Visit us at:

www.nationwidechildrens.org/autism-treatment-network