N I C H D

National Institute of Child Health and Human Development

National Institutes of Health

Autism Research at the NICHD

U.S. Department of Health and Human Services
National Institutes of Health
National Institute of Child Health and Human Development

The NICHD/NIDCD Network on the Neurobiology and Genetics of Autism: The Collaborative Programs of Excellence in Autism (CPEAs)

What is autism?

Autism is a complex neurobiological disorder of development that lasts throughout a person's life. People with autism have problems with social contact and communication, so they might have problems talking with you, or they might not want to look you in the eye. They sometimes have behaviors that they *have* to do before they can pay attention, such as lining up their pencils, or that they do repeatedly, such as saying the same sentence again and again. They may flap their arms to tell you they are happy, or they might hurt themselves to tell you they are not.

One person with autism may have different symptoms or show different behaviors than other people with autism. Because of these differences, health care providers now think of autism as a "spectrum" disorder, or a group of disorders with a range of similar features. Based on their specific strengths and weaknesses, people with Autism Spectrum Disorders (ASDs) may have mild symptoms or more serious symptoms. But they all have an ASD. In this information, the terms "ASD" and "autism" are used to mean the same thing.

The National Institute of Child Health and Human Development (NICHD), part of the National Institutes of Health (NIH), within the U.S. Department of Health and Human Services, is one of the federal agencies doing research on autism, including its causes, how many people have it, and its treatments.

What is the CPEA Network?

In 1997, the NICHD, in collaboration with the **National Institute on Deafness and Other Communication Disorders (NIDCD)**, started a five-year, $45 million, international Network on the Neurobiology and Genetics of Autism. The Network included 10 Collaborative Programs of Excellence in Autism (CPEAs) to conduct research on the possible causes of autism, including genetic, immunological, and environmental factors. In 2002, the NICHD and NIDCD renewed funding for the CPEA Network, agreeing to provide $60 million over a period of five years.

The CPEAs link 129 scientists from 23 universities in the United States, Canada, Britain, and five other countries, and more than 2,000 families of people with autism. Even though each site is studying a unique part of autism, core information collected by CPEA sites in individual studies can be combined and used to study broader research questions that no project could address alone. This shared data set may allow scientists to find similarities and differences among people with autism and their families that would not be possible through a single study.

In fact, as a result of the CPEAs, researchers now have data on the genetics and outward characteristics of the largest group of well-diagnosed persons with autism in the world.

* These sites are not currently CPEAs but are affiliated with the Network.

What sites are in the CPEA Network?

University of Washington

Led by: Geraldine Dawson, Ph.D.
This site conducts studies of:
- The relationships between the brain and behavior in autism;
- Language problems characteristic of autism;
- Early diagnosis of autism and resulting outcomes;
- Neuroimaging studies of autism; and
- The genetics of autism.

Contact:
Autism Research Program Project
Autism Center at the Center for Human Development and Disability
Box 357920, University of Washington, Seattle, WA 98195
1-800-994-9701 or cbrock@u.washington.edu or
http://depts.washington.edu/uwautism/research/participation.html

University of California, Davis

Led by: Sally Rogers, Ph.D.
This site conducts studies of:
- Imitation and motor function in autism;
- Measurement, predictors, course, causes, and external validity of regression in autism; and
- A longitudinal study of the developmental course of autism.

Contact:
U.C. Davis M.I.N.D. Institute
2825 50th Street, Sacramento, CA 95817
1-888-883-0961 or 916-703-0268 or
sjrogers@ucdavis.edu

University of California, Los Angeles

Led by: Marian Sigman, Ph.D.
This site conducts studies of:
- How social, communication, and language deficits in autism start and develop;
- Follow-up and extension of certain treatments for autism;
- Phenotype and genotype in inversion and duplication of chromosome 15; and
- Neuroimaging and deficits in social communication in autism.

Contact:
UCLA Center for Autism Research and Treatment (CART)
760 Westwood Plaza, Los Angeles, CA 92868
310-825-0180 or info@autism.ucla.edu or
www.autism.ucla.edu

AFFILIATED PROGRAM* AT THE University of California, Irvine

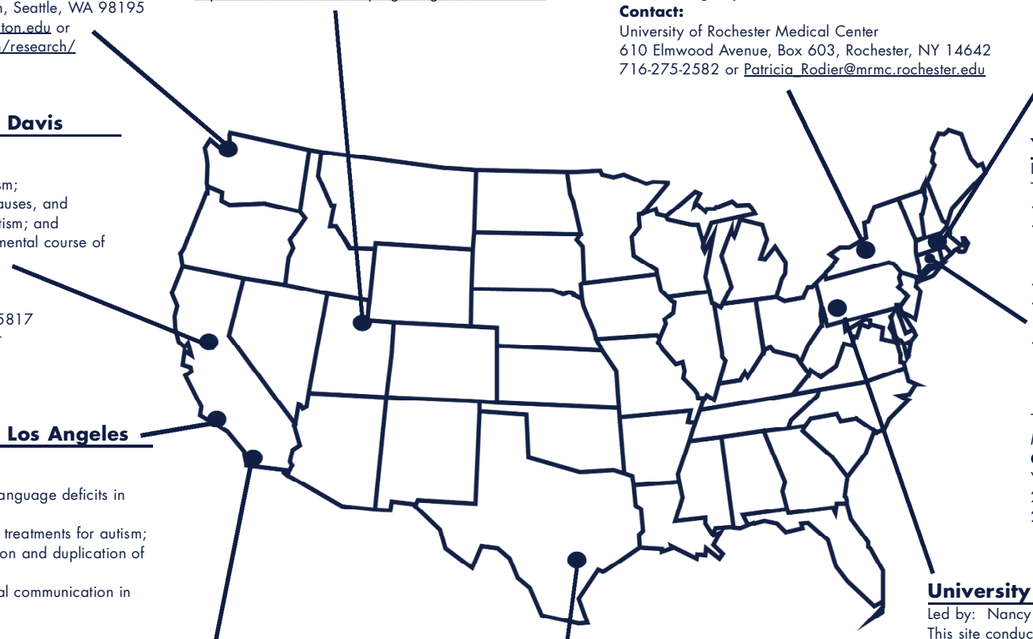
Led by: Anne Spence, Ph.D.
This site conducts studies of:
- Genes involved in autism; and
- Brain structureand regression in autism.

Contact:
Department of Pediatrics, 4482
U.C. Irvine Medical Center
101 City Drive, Orange, CA 92868
714-456-8848 or maspence@uci.edu

University of Utah

Led by: William McMahon, M.D.
This site conducts studies of:
- Genetics and genetic susceptibility of autism;
- Brain development; and
- Serotonin function and immune system functioning in autism.

Contact:
Utah Autism Research Project
421 Wakara Way, Suite 143, Salt Lake City, UT 84108
801-585-9098 or
http://utahautismresearchprogram.genetics.utah.edu/



AFFILIATED PROGRAM* AT THE University of Texas Health Science Center at Houston

Led by: Katherine Loveland, Ph.D.
This site conducts studies of:
- Development of communication and social behavior and its relationship to brain function in autism;
- Abnormalities in brain structure related to autism; and
- Animal studies of brain structure, injury, and behavior.

Contact:
The Autism Research Laboratory, Center for Human Development Research
University of Texas Mental Sciences Institute
1300 Moursund Street, Houston, TX 77030
713-500-2580 or
http://www.uth.tmc.edu/schools/med/psychiatry/msi/chdr2/autism.htm

University of Rochester Medical Center

Led by: Patricia Rodier, Ph.D.
This site conducts studies of:
- Animal models and mechanisms of injury in autism;
- Behaviors that distinguish autism from other disorders; and
- Mutations in genes involved in early development and influences on gene function.

This research is done in conjunction with the University of Rochester Medical Center's Departments of Pediatrics and Neurology, the Hospital for Sick Children (Toronto), Cornell Medical College, and the U.S. Environmental Protection Agency.

Contact:
University of Rochester Medical Center
610 Elmwood Avenue, Box 603, Rochester, NY 14642
716-275-2582 or Patricia_Rodier@mrmc.rochester.edu

Boston University

Led by: Helen Tager-Flusberg, Ph.D.
This site conducts studies of:
- Social-communicative abilities in autism;
- Language delays and problems in autism; and
- Brain pathology underlying social-communicative and language impairments in autism, using structural and functional magnetic resonance imaging.

Contact:
Laboratory of Developmental Cognitive Neuroscience
Department of Anatomy and Neurobiology
Boston University School of Medicine
715 Albany Street, L-814, Boston, MA 02118-2526
617-414-1312 or htagerf@bu.edu

Yale University

Led by: Fred Volkmar, M.D.
This site conducts studies of:
- Genetics of persons with autism;
- The genetics of persons with autism and Asperger syndrome, their families, and family members with related disorders;
- Changes to the nervous system in autism;
- Behavior problems, epilepsy, and puberty in adolescents with autism; and
- Regression studies that seek to define the phenomena, predict outcomes, and evaluate medical factors that may play a role in autism, such as vaccines, seizures, and prenatal conditions.

This research is done in conjunction with the University of Michigan, the University of Chicago, and Harvard University.

Contact:
Yale Child Study Center
230 South Frontage Road, New Haven, CT 06520-7900
203-785-5930 or http://info.med.yale.edu/chldstdy/

University of Pittsburgh

Led by: Nancy Minshew, M.D.
This site conducts studies of:
- Organizing information into concepts in persons with high-functioning autism and Asperger syndrome;
- Visual perception and visual processing in persons with high-functioning autism and Asperger syndrome;
- Sensory, motor, and executive problems in persons with high-functioning autism and Asperger syndrome; and
- Functional brain imaging of language and cognition in persons with high-functioning autism and Asperger syndrome

This research is done in conjunction with Carnegie Mellon University and the University of Illinois, Chicago.

Contact:
University of Pittsburgh Autism Research Program
Webster Hall, Suite 300, 3811 O'Hara Street, Pittsburgh, PA 15213
1-866-647-3436 or autismrecruiter@msx.upmc.edu or
http://www.pitt.edu/~nminshew

The CPEA Data Coordinating Center

In 2003, the CPEA Network launched a Data Coordinating Center in Medford, Massachusetts, to provide data management and statistical support for Network activities. The Center will also maintain a Web site to facilitate communication and coordinate activities within the CPEAs. Three groups are managing different tasks in the Data Coordinating Center: DMSTAT, Inc.; the Boston University Statistics and Consulting Unit; and the Department of Biostatistics at the Boston University School of Public Health. The Center will provide combined support for the CPEA Network and for the eight sites of the Studies to Advance Autism Research and Treatment (STAART) Centers Program, a five-year, $65 million effort supported by five NIH Institutes, including the NICHD. Such support will allow more data to be processed quickly and compared, which may increase the speed of discoveries from these research efforts.

How can I get involved in the CPEA Network?

If you are interested in taking part in one of the CPEA studies, or want more information about one of the sites, contact the Network site nearest you. You are welcome to participate in many different studies, but you can only take part in one study of genetics. The success of this research depends on family participation. To find out what studies related to autism are currently looking for participants, please visit **http://www.nichd.nih.gov/autism/research.cfm** and select the "Autism Clinical Trials Currently Recruiting Patients" link. You can also visit **http://clinicaltrials.gov** or call **1-800-411-1222** to find out what federal studies related to autism are seeking patients.

Where can I get more information on autism?

For more information on autism and autism research, contact the NICHD, which supports and conducts research on topics related to the health of children, adults, families, and populations, including autism and developmental disabilities. The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from the reproductive process, and that all children have the chance to fulfill their potential for a healthy and productive life, free of disease or disability, and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation. You can contact the NICHD through the NICHD Information Resource Center at:

Mail: P.O. Box 3006, Rockville, MD 20847
Phone: 1-800-370-2943 (TTY: 1-888-320-6942)
Fax: (301) 984-1473
E-mail: NICHDInformationResourceCenter@mail.nih.gov (Please use AUTISM in the subject line)
Internet: http://www.nichd.nih.gov/autism

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