

research & resources

• WAISMAN CENTER NEWS FOR FAMILIES • UNIVERSITY OF WISCONSIN-MADISON

Greetings! You have received this newsletter because you are on a mailing list maintained by the Waisman Center's Research Participation Core (formerly known as the Human Subjects Core). "Research and Resources" has been published for the past nine years and sent to families who want to be informed about research projects at the Waisman Center. The newsletter has also been distributed to numerous organizations and professionals in the state of Wisconsin and surrounding areas to share news about Waisman Center research developments.

Unfortunately, I have not been able to prepare a newsletter for a while. The good news is that the delay in the newsletter publication was due to our making improvements in how the Research Participation Core serves as a liaison between families and Waisman Center investigators. I hope that the benefits gained from our improvements make the delay in publication tolerable. Still, I will try to make amends and offer an explanation by sharing my "Top Ten List" like David Letterman does in his late night TV show.

Best wishes—Susan Vial, Research Participation Core Staff Coordinator

The Top Ten Reasons You Haven't Heard from Us in a While!

Reason #10: We're on-line at <http://www.waisman.wisc.edu/rpc>! If you have access to the Internet, you can learn a great deal about the Waisman Center on its web page. The Research Participation Core has its own special section that lists studies that are currently recruiting participants, with links to web sites that explain those research projects. You can also read about each investigator at the Waisman Center and review their research and academic publications. In addition, there is a section entitled "News & Note Worthy" which posts articles and announcements about Waisman Center research, training, service

and outreach. There have been several Waisman Center research studies summarized in newspaper articles this spring and several investigators received awards for their accomplishments. Remember, if you do not have a computer at home, you can gain access to the Internet at your public library. And don't be embarrassed to ask for help if you need it!

Reason # 9: We changed our name! While our former name was compatible with the technical language of science, we were always convinced that there was a better title for our work than Human Subjects Core. We considered many options and selected Research Participation Core. We hope you like it.

Reason #8: I've been on the move!

In the two-year construction period of the Waisman Center expansion project, I had to move my office 3 times! Let's just say that I am now better organized than ever.

Reason #7: We celebrated the Waisman Center's 30th Anniversary last fall! You can read about this event on the Waisman Center web page. We have provided you with an insert in this newsletter, "Milestones," a summary of a few Waisman Center accomplishments during its 30-year history.

Reason #6: We're compliant with HIPAA! Last spring, most everyone was made aware of new federal

regulations designed to protect the privacy of health information, referred to as HIPAA. (Did you know that this stands for the Health Insurance Portability and Accountability Act of 1996?). You probably have had to sign several forms at your health care providers' offices and have received several documents explaining the various organizations' privacy notices. I freely admit, although am somewhat embarrassed, that I carefully read all of those documents! Becoming knowledgeable about HIPAA has become an important part of my responsibilities working for the Research Participation Core because we maintain computerized registries containing personal information, and in certain cases, health information, to match individuals and families with research projects that are enrolling participants. Waisman Center administrators have spent much time meeting with University of Wisconsin-Madison administrators and attorneys to discuss how the Research Participation Core protects the confidentiality of individuals and families that we work with and safeguards the storage of information in our records. As a result, the consent form that new families sign to become registered with the Research Participation Core has been changed to be more informative and slightly longer. These changes reinforce our unwavering commitment to ensuring your confidentiality.

Reason #5: We got hooked on acronyms! From HIPAA to IRB to RPC! After making changes in our registration forms to meet HIPAA guidelines, we next obtained the approval of our IRB! Federal regulations mandate the approval of all federally funded

human research by an institutional review board (IRB), a committee of faculty members, scientists and/or physicians who review research proposals to ensure that participant rights are protected. The Research Participation Core is sort of an enigma – we don't conduct research ourselves, but we help connect families with research projects. Nevertheless, we have a University of Wisconsin-Madison IRB committee review our procedures and forms on an annual basis. This ensures that our procedures are in compliance with any changes in University or federal regulations. After typing "Research Participation Core" so many times in our reports, we decided to use the abbreviation "RPC".

Reason #4: We now offer our registration forms in Spanish! The number of Spanish-speaking individuals living in the state of Wisconsin has dramatically increased during the past several years. It is an objective of the RPC to provide information about its services and a consent form in a variety of accessible formats to everyone.

Reason #3: I went on an unexpected journey. A few months ago my 13-year-old son, Peter, became ill and was diagnosed with Crohn's disease, a chronic autoimmune disorder that results in inflammatory bowel disease. This experience has acutely reminded me of how a health problem, or developmental disability, can suddenly consume all the attention and energy of a family. I remember many stressful days spent talking with nursing staff over the phone and meeting with doctors during various appointments, all the while having that parental sense that "something is not right." It was only natural

for me to consult the "Family Village," an informational and networking web site co-sponsored by the Waisman Center. I was able to quickly get reliable information about Crohn's disease and its treatment, and discovered other sites where I could learn more about the illness and connect with other families. I have referred many families to this helpful web site <http://www.familyvillage.wisc.edu>, and I am thankful that it was there for my family during a time of crisis.

Reason #2: We've been busy with research! During the past year the RPC has helped 25 Waisman Center investigators recruit numerous participants for their studies. These studies have explored various developmental disabilities such as autism spectrum disorder, cerebral palsy, Down syndrome, fetal alcohol spectrum disorder, fragile X syndrome, language learning disabilities, and Williams syndrome. In addition, several investigators at the Waisman Center study the development of infants and children without special needs. If you are one of the many families who have taken the time to participate in a research project, we sincerely thank you. If you are registered with the RPC but have not been notified of a research study opportunity, this is not unusual. There may not be a match between the needs of our studies and your child's age or condition; however, you are likely to hear from us at some time.

Reason #1: We're reaching out! The RPC has recently attended a few state and local conferences, and used an exhibit table to enroll new families in our research participant registries. We ask that you help us spread the word about our research recruitment network to your friends and colleagues.

How Can You Participate in Waisman Center Research Studies?

Listed here are projects that currently need participants. For more information about specific studies, call or e-mail the individual listed. If you have general questions about research at the Waisman Center, contact Susan Vial at (608) 263-5192 or via e-mail at vial@waisman.wisc.edu.

Autism & Williams Syndrome: Brain Structure and Function

Led by Richard Davidson, Ph.D., this study uses functional magnetic resonance imaging (fMRI) techniques to monitor which areas of the brain are active when individuals look at pictures of faces. Eye movements will be recorded at the same time, to determine if individuals with Williams syndrome or autism scan or focus on faces differently than non-diagnosed individuals. The study is seeking participants who are between the ages of 12 and 35 years and who have either an autism spectrum diagnosis or Williams syndrome. Participants will spend 35 to 45 minutes in the fMRI scanner and the entire session lasts approximately 2 hours. Participants receive pictures of their brains at work and \$50 for completing the session, and can earn an additional \$30 for completing an optional scan.

Contact: *Kim Dalton, Ph.D.*
(608) 263-5609 or
kmdalton@facstaff.wisc.edu

Toddlers with Autism Spectrum Features: A Language Development Study

Headed by Dr. Susan Ellis Weismer and Dr. Morton Ann Gernsbacher,



Brennan Reich answers questions in a Waisman Center language study as his parents observe through a one-way window. Research projects need participants ranging in age from infancy to adulthood. Sometimes children are the participants and other times their parents or siblings are the participants.

the purpose of the Toddler Talk Project is to characterize early language abilities of toddlers (2 to 2-1/2 years old) with autism spectrum features, compared to toddlers with typical language and late-talking toddlers without autism. In-home assessments will be conducted with children living in Southeastern Wisconsin, beginning in July of 2004.

Contact: *Chris Hollar*
(608) 263-3123 or
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Fragile X Syndrome: Language and Communication in Adolescents

Leonard Abbeduto, Ph.D., is investigating the developmental course of language and communication skills in adolescents with fragile X syndrome. This study seeks to identify biological, environmental and psychological

factors that affect the development of communication skills and determine whether there are developmental challenges specific to fragile X syndrome. Participants should be adolescents between the ages of 11 and 15 who have fragile X syndrome, who use spoken language as their primary means of communication, and whose families are native English speakers. Participation involves completion of language-related tasks, blood draw for genetic analysis, and parent questionnaires and activities. This study requires 4 separate visits to the Waisman Center, approximately 1 year apart, with each visit consisting of 2 days of testing sessions. Travel costs for families will be reimbursed. Families receive \$25 per visit and adolescents are given a certificate of achievement and a gift.

Contact: *Len Abbeduto, Ph.D.*
(608) 263-1770 or
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Language Learning Disabilities: Cognitive Problem Solving

This study, led by Julia Evans, Ph.D., is designed to examine problem solving and mathematical reasoning abilities. Your child may be eligible to participate if he or she has difficulty with the following tasks: remembering things you tell him or her, following directions or explaining things, and understanding school assignments. Participants should be between the ages of 7 and 9 years and have either language learning disabilities or have typically developing language.

*Contact: Beth Simon
(608) 265-2642 or
childlang@waisman.wisc.edu*

Structure and Function of the Brain

Using magnetic resonance imaging (MRI), Andrew Alexander, Ph.D., is investigating brain development and structure in healthy children. The study consists of four sessions that are repeated each year for three years. Total time for the four sessions is 3 to 4 hours per year. The series of sessions include evaluations of the child's emotional maturity, physical maturity, an MRI practice session, and the experimental MRI session. Participants should be between 10 and 12 years old without any known brain disorders, lesions or trauma. Child participants will be paid \$50 for completing each scan session and receive a \$50 bonus for completing all three sessions. The study will be used as a comparative template for imaging studies of children with developmental disorders.

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Published by the Research Participation Core. If you would like your name added to or removed from our mailing list, please contact us.

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WAISMAN CENTER, UNIVERSITY OF WISCONSIN-MADISON

Dedicated to the advancement of knowledge about human development, developmental disabilities, and neurodegenerative diseases.

M I L E S T O N E S

—**1963**

Dedication of the Joseph P. Kennedy Jr. Memorial Laboratories on the UW-Madison campus, the precursor to the Waisman Center.



—**1965** Selection of UW-Madison by the National Institute of Child Health and Human Development (NICHD) as one of the first two sites in the United States for a multidisciplinary center devoted to the study of human development and mental retardation.

—**1968** Designated as a University Affiliated Facility with the passage of the Developmental Disabilities Act, one of 10 initial programs—now, one of 61 in the United States. Began providing interdisciplinary training and clinical services two years later in temporary quarters on campus.

—**1971** Became the first University Affiliated Facility to develop a computer system for client data collection.



—**1973** Dedication of the Waisman Center, which was named for Harry A. Waisman, a biochemist, pediatrician, and pioneer in mental retardation research.

—**1973** Established a biomedical research unit at the Waisman Center, representing a new focal point for brain research on the UW-Madison

campus. First unit coordinator was Clinton N. Woolsey, an acclaimed neuroscientist who, along with Harry Waisman, was a driving force in the establishment of the Waisman Center.



—**1975** Initiated one of the first genetics counseling training programs in the United States—the only one in the state of Wisconsin to this day.

—**1975** Establishment of the Friends of the Waisman Center by Harvey A. Stevens, the first program administrator of the Waisman Center.

—**1976** Established an international collection of art by people with developmental disabilities, featuring more than 150 artworks from 15 countries.

—**1979** Established the Communication Aids and Systems Clinic (CASC) to provide state-of-the-art augmentative and alternative communication services. A joint venture with UW-Hospitals and Clinics, CASC was one of the very early programs in the country with this focus.

—**1979** Opened the Waisman Early Childhood Program, a model school for children with diverse developmental needs.



—**1982** Appointment of Terrence R. Dolan, Ph.D. as director of the Waisman Center, a role he held for 20 years.

—**1983** Naming of an X-linked form of mental retardation the “Waisman Syndrome,” after Harry Waisman.

—**1983** Developed PEPPER, the first computer program designed to categorize the various factors contributing to speech disorders and to identify useful therapies. Currently, PEPPER (Programs to Examine Phonetic and Phonologic Evaluation Records) is used as a research tool in the quest for the genetic origins of childhood speech sound disorders.

—**1985** Developed the first edition of SALT (Systematic Analysis of Language Transcripts), a new method for quickly analyzing speech and language—a standard for researchers and clinicians to this day.

—**1986** Initiated the Children's Theatre, an outreach performance series for young children and their families that draws thousands of people to the Center each year.



—**1989** Discovered a highly successful strategy for gene transfer that is the basis for many clinical trials of DNA vaccines and gene therapies.

—**1989** Expanded community outreach and training programs in response to new Birth to 3 Early Intervention federal legislation.

—**1990** Developed a training curriculum in conjunction with UW-Extension that has been used over the years by thousands of service providers who work with people who have developmental disabilities.

—**1992** Initiated the Alvin L. Berman & Ruth Bleier Memorial Student Research Award, given by the Friends of the Waisman Center, commemorating the contributions of these Waisman Center scientists.

—**1994** Organized a Constituent Advisory Committee to formally solicit advice from individuals with developmental disabilities and their families regarding programs and services.

—**1995** Incorporation of accessibility features developed at the Trace Center in Windows 95, the first time such features are built into a PC-based system.

—**1995** Established the NICHD-funded Waisman Center Post-Doctoral Training Program in Developmental Disabilities, an important initiative that expanded the Center's commitment to advanced research training.

—**1996** Established a state-wide twins database, the first of its kind and a resource for multiple research projects related to behavioral genetics and early childhood development.

—**1996** Established the Board of Visitors, an external advisory group to the Waisman Center.

—**1996** Opened the Family Village, an award-winning internet site and one of the first resources on the web designed for families and people affected by disability.



—**1996** Demonstrated that infants can keep track of statistical properties of sounds to learn language.

—**1997** Provided new evidence that, in individuals with Down syndrome, language skills once thought to plateau in childhood continue to develop into adulthood.

—**1998** Established a Waisman Center community outreach site dedicated to community training on the inclusion of people with developmental disabilities.

—**1999** Publication of the book *Improving the Communication of People with Down Syndrome*, integrating two decades of research on Down syndrome conducted in nine Waisman Center laboratories.

—**2000** Established the Waisman Resource Center, a statewide source of information and assistance for families and providers about children who have special health care needs.

—**2001** Identified the gene responsible for Alexander disease.

—**2001** Provided new evidence that Down syndrome and fragile X syndrome are characterized by different language and cognitive challenges.

—**2001** Completion of a \$25 million addition, including the six-story William F. and Betty Jo Heckrodt Translational Research Tower and the Judith B. Ward Early Childhood Wing.



Craig Dugan

—**2001** Provided new evidence, through a longitudinal study, of the factors leading to life-long psychological well-being in families who have a son or daughter with a developmental disability.

—**2001** Established the W. M. Keck Laboratory for Brain Imaging and Behavior, one of the most comprehensive and sophisticated brain imaging centers in the world.



Jeff Miller

—**2002** Appointment of Marsha Mailick Seltzer, Ph.D. as Waisman Center director.

—**2003** Developed new stem cell approaches for treating conditions such as Parkinson's disease and ALS.

—**2003** Conducted first test in the United States of a child with dual cochlear implants.

—**2003** Patented a new test that assesses hearing in children in complex environments.

—**2003** Provided compelling new evidence from the Chicago Longitudinal Study that preschool programs have positive life-long effects on high school graduation rates, prevention of delinquency, and self-sufficiency in adulthood.

—**2003** Partnered with Madison Metropolitan School District to establish a pilot four-year old kindergarten program.

—**2003** As of this year, provided services and supports to 60,000 individuals with developmental disabilities and their families and training to 6,000 university students.



Bob Rashid