

What's New...

RESEARCH NEWSLETTER

Summer 2010 Volume: 10 Number: 1

JFK Partners is an interdepartmental program of the departments of Pediatrics and Psychiatry of the University of Colorado School of Medicine located at the Anschutz Medical Campus in Aurora, Colorado. Designated as Colorado's University Center of Excellence in Developmental Disabilities (UCEDD) and Leadership Education in Neurodevelopmental Disabilities (LEND) Program, JFK Partners has collaborative relationships with numerous organizations that are a part of Colorado's developmental disability and special health care needs communities.

The purpose of JFK Partners is to provide:

- Interdisciplinary Pre-service Training
- Continuing Education
- Clinical Services
- Community Collaboration
- Research
- Dissemination



It has been a busy and exciting time in the field of research in developmental disabilities. Here is our "Top Ten" List of Research Efforts that are ongoing at JFK Partners and with our collaborators:


1. Recent efforts by the leadership of the Colorado Intellectual and Developmental Disabilities Research Center (IDDRC; Karl Pfenniger, MD, Corry Robinson, PhD, Gunter Scharer, MD) has lead to the creation of the Translational Nexus Registry, a participant database and bloodbank, which includes both behavioral and biological data on individuals with a variety of developmental challenges.
2. Thanks to the steadfast advocacy of parents, we are seeing more opportunities than ever to expand our research program here in Colorado. Funds allocated through the Combating Autism Act of 2007, as well as other sources, were awarded to local investigators to study:
 - Methods to train mental health practitioners to deliver a family-focused treatment program for youth with an Autism Spectrum Disorder and anxiety (Principal Investigator: Judy Reaven, PhD).
 - The use of videoconferencing to provide therapy and support to families living in rural Colorado (Principal Investigator: Susan Hepburn, PhD).

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- Nutrition and sleep in children with Autism Spectrum Disorder (Principal Investigator: Ann Reynolds, MD).
 - Factors that influence identification of children with Autism Spectrum Disorders in Latino families, in collaboration with Salud Clinic. There is also Protocol to provide accurate screening procedure in this population (Principal Investigators: Norbert Soke, MD, MPH and Susan Hepburn, PhD).
 - Continuing a large, longitudinal study of various developmental disorders into adolescence (Principal Investigator: Susan Hepburn, PhD).
3. We are proud to be a part of two national, multi-site studies:
- Study to Explore Early Development (a case control study of Autism, funded by the Centers for Disease Control to the Colorado Department of Public Health and Environment. Principal Investigator: Lisa Miller, MD, with a subcontract to JFK Partners; Principal Investigator: Corry Robinson, PhD)
 - Autism Treatment Network, funded by Autism Speaks to evaluate and improve provision of medical care to families of children with ASD (Co-Principal Investigators: Ann Reynolds, MD, Corry Robinson, PhD, Project Coordinator: Harriet Autsin, PhD).
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4. Neuroimaging studies are examining possible biological markers of autism (Principal Investigator: Don Rojas, PhD)
5. Psychophysiological studies are exploring some of the core social challenges of various developmental disorders, specifically automatic social-emotional responding that creates a sense of “connectedness” (Principal Investigator: Eric Moody, PhD).
6. Collaboration among geneticists, basic scientists, and behavioral investigators are expanding in studies of Down Syndrome, thanks to internal support from the CCTSI (Principal Investigators: Ellen Elias, MD, Corry Robinson, PhD).
7. Intervention studies are being conducted on:
- Efficacy of a family-focused, group treatment for anxiety in children and adolescents with ASD (Principal Investigators: Judy Reaven, PhD, Audrey Blakeley-Smith, PhD and Susan Hepburn, PhD).
 - Effectiveness of a peer mediated intervention in schools to promote social inclusiveness of children with developmental disabilities (Principal Investigator: Audrey Blakeley-Smith, PhD).
8. Pilot work is ongoing to develop studies of:
- Impact of a multi-media, parent-focused training package to promote independent toileting, feeding and hygiene routines in families of young children with disabilities (Principal Investigators: Susan Hepburn, PhD, Patti LaVesser, PhD, Steven Rosenberg, PhD).
 - Effect of a motor planning intervention on timing and fluidity of motoric responses involved in leisure and adaptive daily living (Principal Investigators: Lisa Dannemiller, PT, DSC, PCS and Patti LaVesser, PhD).



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9. Collaborations with researchers in the private sector are increasing, including the examination of the ability of the LENA system to identify children with ASD as early as possible by analyzing early speech sounds (Principal Investigator: Steven Rosenberg, PhD).
10. Ongoing support for the Leadership Education in Neurodevelopmental Disabilities (LEND) program and the Association of University Centers of Excellence in Developmental Disabilities (UCEDD); both directed by Corry Robinson, PhD, continue to provide the infrastructure for training, research, and service at JFK Partners. Trainees are actively engaged in research projects examining attentional issues in ASD and ADHD (Manteris); animal/human partnerships (Trujillo); Manual Task Analysis Discerns Limitations in Motor Skills in Children with Down Syndrome (Downey); improving ASD screening in Latino families (Soke); genetics of ASD (Davis); and neurobiological correlation of language function in ASD (Wilson).

We are especially grateful to families in our community, whose generosity of time spent with us is critical to pursuing these projects. We also appreciate the community organizations who support our efforts, including, but not limited to: The Autism Society of Colorado, Autism Speaks, Moms on the Spectrum, DAASM, Family Voices, El Grupo Vida, Roaring Fork Autism Network, the Parent Group of Grand Junction, and many more. Together, we strive to learn how to improve the quality of life for people with developmental disabilities and their families.

Respectfully,

Susan Hepburn, PhD

Director of Research



CADDRE: Study to Explore Early Development

FAMILY RESOURCES

Adams Camp Special Needs:

Therapeutic recreation

www.adamscamp.org

Arc of Colorado

www.thearcofco.org

Autism Speaks

www.autismspeaks.org

Autism Society of America

www.autism-society.org

Autism Society of Colorado

www.autismcolorado.org

Brain Injury Association of Colorado

www.biaincolorado.org

Colorado Dept. of Education

www.cde.state.co.us

Colorado Dept. of Human Services

www.cdhs.state.co.us

CO Fund for People with Disabilities

www.codisabilitytrust.org

The Study to Explore Early Development (SEED) is looking for children with Autism Spectrum Disorders to take part in a multi-site research study. SEED is a multi-site study being conducted by the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network set up and funded by the Centers for Disease Control and Prevention. For Colorado, the Colorado Department of Public Health and the Environment (CDPHE) is the grant recipient, Lisa Miller, MD, Principal Investigator. CDPHE contracts with JFK Partners for the direct work with families. Corry Robinson, PhD is the Principal Investigator for JFK's involvement.

The CADDRE Network is made up of six study sites, a central laboratory, and a data coordinating center. The six CADDRE study sites are located in California, Colorado, Georgia, Maryland, North Carolina, and Pennsylvania. SEED is the largest study to date of risk factors for Autism Spectrum Disorders (ASD) and other developmental disabilities. SEED will give researchers a better idea about the many things that increase the chances a child will have autism or other developmental problems. CADDRE began inviting families to participate in SEED in winter 2008. Staff at the CADDRE sites are working with partners in their respective communities to invite families to participate in SEED. Across the six sites, about 2,700 children and their parents will be invited to take part in the study. The study takes about 14 hours to complete and includes:

- Questionnaires
- Telephone interviews
- Allowing project staff to review the medical records of you and your child
- Participating in a child developmental evaluation
- Taking blood and cheek cell samples from you and your child
- Taking a small hair sample from your child
- Allowing project staff to complete a brief physical exam on your child
- Completing diaries about what your child eats for 3 days and recording the number and type of your child's stool for a week.



WHO CAN PARTICIPATE?

SEED will comprise children 2 through 5 years of age with ASD, with other developmental disabilities, and with typical development. You and your child may participate if:

- Your child was born between September 2005 and August 2006
- Your child was born in and currently lives in Arapahoe, Adams, Boulder, Broomfield, Denver, Douglas, or Jefferson County

For more information, contact Kristina Hightshoe at 303-724-7638 or at Kristina.Hightshoe@ucdenver.edu.



IDDRC-Translational Neuroscience Nexus Study

Council for Exceptional Children

www.ccc.sped.org

DAASM

<http://groups.yahoo.com/group/DAAM1>

Denver Options

www.denveroptions.org

Developmental Pathways

www.developmentalpathways.org

Disabled Resource Services

www.fortnet.org/drs

EI/Child Find

www.eicolorado.org

El Grupo Vida

www.elgrupovida.org

Empower Colorado

www.empowercolorado.com

Family Voices of Colorado

www.familyvoicesco.org

Imagine!

www.imaginecolorado.org

The Intellectual and Developmental Disabilities Research Center (IDDRC) at the University of Colorado is now actively recruiting families of children with various developmental disabilities to participate in a scientific registry, called the Translational Neuroscience Nexus. The Nexus project is a joint effort of the Colorado IDDRC, JFK Partners and specialty clinics at The Children's Hospital. It is a combined registry of clinical information and biological samples designed to advance research and treatment of intellectual and developmental disabilities. The Nexus is an essential tool for modern research to improve our understanding of intellectual and developmental disabilities and to develop new treatments. The Director of the Colorado IDDRC is Karl Pfenniger, MD a microbiologist at the University of Colorado. The Nexus project is led by Cordelia Robinson, PhD, the Director of JFK Partners, and Gunter Scharer, MD, FACMG, a geneticist at The Children's Hospital. All of the project leaders are Pediatric faculty.

WHO CAN PARTICIPATE?

Anyone between the ages of one month and 85 years of age who has a developmental or intellectual disability, or parents and siblings of those who have a developmental or intellectual disability are eligible to participate.

WHAT HAPPENS DURING THE RESEARCH?

There are two separate parts to this research, and each person decides in which part or parts they wish to participate.

1. The Registry: Information that is gathered from your routine clinic visits, and any hospital or emergency room visits you have at the University of Colorado Hospital or The Children's Hospital of Denver will be entered into the registry. If you have any past research records, we may also ask permission to put that information in the registry. We may send you a questionnaire from time to time to update our records. All information that is entered into the registry will be kept strictly confidential.

2. The Bio Bank: If you are willing to provide a blood or DNA sample we will call you to schedule a visit to The Children's Hospital where the sample will be collected. This sample will provide genetic and biochemical information to associate with clinical information. Research will be conducted on de-identified samples or you will be asked for permission for active participation in a study.

If you have any questions or comments regarding the Nexus registry, please contact Sondra Rosendahl, MS, IDDRC Nexus Coordinator, 303-724-2349 sondra.rosendahl@ucdenver.edu.



Empathy and Autism: A Study to Understand Emotional Mimicry in Children with Autism

MH Down Syndrome Assoc.
www.mhdsa.org

Mile High United Way
www.unitedwaydenver.org

Moms on the Spectrum
www.bigtent.com

Pathways Resource Guide
www.pathwaysresourceguide.org

PEAK Parent Center
www.peakparent.org

Roaring Fork Autism Network
www.rfautism.org

Rocky Mountain ADA Center
www.adainformation.org

Parent to Parent
www.p2p-co.org

Wrightslaw
www.wrightslaw.com

SpecialOlympics
www.specialolympicsco.org

For most people, it is very easy to understand what other people are feeling. The social and emotional connection that most of us develop with others is easy and natural, and helps us forge strong social bonds with our loved ones. However, children with autism sometimes have difficulty understanding the emotions of others. This may be due to difficulty in how their brains interpret the emotional expressions of others and can lead to problems making strong emotional connections with others. Psychologists call this ability “empathy,” and a growing body of scientific evidence suggests that this may be a fundamental part of social development. Unfortunately, research also suggests that children with autism may not experience empathy in the same way that typically developing people do. For example, someone with autism may think that a person whose mouth is shaped like a “U” (with the corners upturned) may look very odd. Typically developing individuals would quickly determine that the same person is smiling and infer that he or she feels happy.



Although empathy appears to be very important for social development, little is known about exactly how it contributes to social development. Moreover, how empathy is experienced by those with autism and how it influences the symptoms of autism has only been explored in the last few years. Researchers at JFK Partners in collaboration with Daniel McIntosh, PhD of University of Denver, have begun a three year project to try to develop a better understanding of empathy in children with autism. This study uses state-of-the-art psychophysiological recordings to understand how the brains of children with autism experience the facial expressions they see. Psychophysiology uses advanced computer systems to track the body’s responses to visual inputs. In this study, children wear tiny sensors on their arm, face and neck to track their reactions to a series of video clips. This helps us understand how their brains interpret the emotional expressions. The information from this study will help psychologists develop more advanced understanding of how children, both with and without autism, develop socially and emotionally. Moreover, this study will provide the knowledge necessary to create more appropriate treatments for children with autism that focus on their social strengths.

This study is currently accepting new participants, and we are interested in exploring empathy in children with Autism, Down Syndrome, Williams Syndrome, or any other developmental disability of known or unknown causes. We are seeking children between the ages of 6 and 17, with a variety of developmental histories, including typically developing children, to participate. The only requirements are that participants must 1) be verbal enough to understand basic instructions, 2) be able to sit still for approximately 10 minutes at a time, and 3) have normal or corrected vision so they can see the videos. Each child will receive an assessment of their cognitive functioning and social communication ability, and the family will receive a written feedback of those findings. On a separate visit the child will participate in the psychophysiology experiment. Both visits last about 2 hours.

If you are interested in participating in this study, please contact Eric Moody, PhD at 720-258-6464, or eric.moody@ucdenver.edu.



Autism Treatment Network and AIR-P

The Autism Treatment Network (ATN) is the nation's first network of clinics, physicians, and researchers dedicated to improving the care of children and adolescents with autism. A program funded by Autism Speaks, ATN, and its clinicians are dedicated to finding treatments to better manage the health of children with autism and to sharing their increasing knowledge across the wider autism community. The goals of ATN are to improve comprehensive, multidisciplinary medical care to children with an Autism Spectrum Disorder; increase the understanding of medical conditions in children with ASD; and develop standards of care and treatment guidelines for those conditions. ATN researchers and clinicians are also working to develop clinical practice guidelines and algorithms for identifying and treating conditions that often affect individuals with autism: Guidelines currently being developed are for insomnia, EEG, and constipation. The ATN Behavioral Sciences Committee has begun to develop a set of toolkits to assist parents and physicians in five key areas:

- Transition to Adulthood
- Treatment for Behavioral issues
- An Applied Behavior Analysis (ABA)-specific toolkit
- Feeding and Diet (selectivity)
- Toileting

Families are eligible to participate in the ATN with a child between the ages of 2 and 18 who have recently received a diagnosis at one of our sites of an Autism Spectrum Disorder, including PDD-NOS and Asperger's Syndrome. Families that agree to participate will take part in a clinical evaluation. The information gathered from the clinical evaluation will be made anonymous for confidentiality and entered into a secure database. Families will also update researchers on their child's progress every year until adulthood so that we can track outcomes and find out what treatments are working.

With 14 different ATN Centers, each collecting comprehensive information about over 100 children per year, this will be the largest effort of its kind to look at the variety of factors associated with autism, from family history to medical issues. It is our hope that through this effort, we'll be able to greatly accelerate our understanding of Autism Spectrum Disorders and by doing so develop better diagnosis and treatment protocols.

THE AUTISM INTERVENTION RESEARCH NETWORK ON PHYSICAL HEALTH (AIR-P)

The Autism Intervention Research Network on Physical Health (AIR-P) is a grant awarded by HRSA's Maternal Child and Health Bureau (MCHB) to the ATN, under the leadership of the ATN Clinical Coordinating Center based at Mass General, to bring a major research focus to the extraordinary infrastructure provided by the ATN registry. The AIR-P has three main objectives: 1) to carry out research on evidenced based practices for interventions; 2) to develop evidenced based practice guidelines for clinical care; and 3) to disseminate toolkits, research findings, and clinical consensus guidelines to pediatricians, other primary care providers, specialty physicians and families. A key priority of the AIR-P Network is to educate parents, professionals and the community about our clinical work and research activities in order to further advance and optimize the care of our children. The ATN site at The Children's Hospital in Denver is participating in studies involving sleep education for parents of children with ASD, diet and nutrition in children with ASD, the prevalence of Creatine Deficiency Syndromes in children with ASD, and the role of maternal cholesterol metabolism in the mothers of children with ASD.

If you are interested in learning more about these studies, please contact Harriet Austin at 720-777-6602 or austin.harriet@tchden.org



Down Syndrome and Autism Study

NEW DEVELOPMENTS

Dr. Ellen Elias and Dr. Kathleen Gardiner, geneticists affiliated with the IDDRC, are working with Corry Robinson, PhD and Susan Hepburn, PhD to expand the behavioral study and include a genetics component. Families of children with Down Syndrome who have enrolled in the Nexus registry are being asked to participate. The primary question of this study is genetic linkages that can be identified for further study to help explain why the co-occurrence happens in some but not in others.

The DS - Autism Connection is hosting some community outreach events in the next several months. See the websites listed at the end of the article for more information.

2010 Fall Conference: What Happens When Down Syndrome and Autism Connect?

Friday, October 8th 9:00 a.m.-3:00 p.m

Anschutz Medical Campus Education 2 South 1st Floor, Room 1102 13121 E. 17th Avenue Aurora, CO 80045

To register, please contact Robin Zaborek at Robin@autismcolorado.org or call 720-214-0794 x17.

Clinical psychologists and epidemiologists at JFK Partners, University of Colorado School of Medicine, and the Colorado Department of Public Health and the Environment collaborated with the Mile High Down Syndrome Association to complete a study about the connection between Autism and Down Syndrome. The study was funded by a three-year grant from the Association of University Centers on Disability (AUCD) and the Centers for Disease Control (CDC). Some of the results of this study were recently published in the Journal of Developmental and Behavioral Pediatrics.

Understanding how often the co-occurrence of Down Syndrome and Autism happens is important for improving assessment and intervention efforts. Clinical experience has shown that children with both conditions do not respond in the same way to educational interventions as children with Down Syndrome without Autism. The challenges of raising a child with both Down Syndrome and Autism are different, and some families have told us that it has been difficult for them to find support and help in their communities.

THE STUDY

Almost 150 families of children with Down Syndrome from 10 counties in the greater Denver area volunteered their time to participate in this study. Some families completed a telephone interview and others participated in a comprehensive developmental evaluation.

WHAT ARE THE RESULTS?

1. Using a conservative definition of Autism, our research team found that approximately 7% of children with Down Syndrome meet criteria for Autistic Disorder, and an additional 18% meet criteria for Autism Spectrum Disorder; meaning that they showed some, but not all of the symptoms associated with Autism. This finding suggests that the risk for Autism is at least seven times greater for a child with Down Syndrome than for a child in the general population.
2. Our findings suggest that approximately one out of four children with Down Syndrome require the kind of interventions usually recommended for children with Autism. These interventions might include working on imitation, sharing attention, improving the use of eye gaze and gestures to communicate with others, practicing appropriate transitions between activities and learning how to replace problem behaviors, such as tantrums, self injury, or aggression, with a more appropriate alternative behavior, such as communicating one's needs.

COMMUNITY OUTREACH

For more information on the connection between Autism and Down Syndrome, or to request a flyer please visit one of these websites:

www.mhdsa.org

www.autismcolorado.org/index.php/ds-autism-connection

Telehealth Delivery of a Family Focused Intervention Program for Children with ASD and Anxiety

Children with autism are an underserved population in several aspects of healthcare; including: general pediatric services, specialized medical care, and mental health services. Health insurance coverage is not adequate to meet the health care needs of children with this complex neurodevelopmental disorder, and cost-effective service delivery models are greatly needed. Families of children with autism living in rural areas experience even more significant obstacles to medical care, particularly in access to mental health services. Rural children with special needs are more likely to be diagnosed later than children in urban areas. Services are more difficult to obtain and coordinate in rural areas, and wait periods for mental health treatment can be exceedingly long.

POTENTIAL FOR TELEHEALTH DELIVERY OF INTERVENTIONS

Telehealth delivery (using the internet to connect families with specialty clinicians) has the potential to be a cost-effective approach to disseminating this highly specialized mental health intervention to underserved families, particularly those in rural areas. Described as a method for reducing the limitations of time and distance in the provision of medical care, telehealth programs have been demonstrated to be effective in supporting the delivery of parent education, family therapy, and psychological consultation for persons with a broad array of mental health problems.

TELECOPEX PROJECT

Our project is funded for 2 years by the Human Resources and Services Administration (HRSA), which is part of the Department of Health and Human Services. The mission is to develop and test novel methods for reaching underserved populations. Funding allocated within the Combating Autism Act was made available to five intervention projects around the country, including this one. Our project focus is using videoconferencing to link clinicians with families of children with Autism Spectrum Disorder. Videoconferencing provides real-time, clinician/patient interaction through the use of video calls, such as with Skype or OoVoo. This technology has been used with success in the provision of mental health services to complex patients living in rural areas. The live interface allows for direct observation of parent/child interactions and is quite conducive for interventions that utilize parent coaching techniques. A literature review on the use of videoconferencing in the delivery of mental health services concluded that the technology is affordable, easy to use, reliable, and readily available, even in rural areas. Their review also suggested that the current research supports high satisfaction in the technology for both clinicians and their patients. Clinician -- patient communication was also reported to be “very good” to “excellent” across most studies. There are a lot of possibilities in trying to develop ways to support families through this kind of interaction, and we have much to learn about how comfortable families feel with technology, how best to coach families and clinicians on how to use new technologies, and what concerns or reservations families may have about interacting with a clinician over a video call. We are also working on effective ways to modify our clinical interventions for delivery through videoconferencing. We plan to explore different kinds of interventions, such as educational, therapeutic, and therapy for individuals and for small groups of families. We are currently developing an online course and support materials as well. Parent groups in rural Colorado have been very helpful in this effort—we are especially grateful to Allison Johnson and Jill Frazier, parent leaders in Carbondale and Grand Junction.



If you are interested in learning more about this study, or are interested in participating in a focus group, please contact Kristen Kaiser at 303-724-4772 or kristen.kaiser@ucdenver.edu.

The Strong Start Study: Strengthening Young Families Affected by Substance Abuse in Denver

The Strong Start study will work with pregnant women in substance abuse treatment and their babies to increase protective factors within the families to promote mothers' sobriety and optimal child development. Strong Start will use High Fidelity Wraparound with women to help create systems of support from their families, friends and community. Using High Fidelity Wraparound is an approach to working with families that improves mothers' abilities to pursue life goals by helping them learn to make effective use of their resources in order to address their needs and the needs of their children.

The award of the Strong Start Study for research on prevention of child maltreatment is a great opportunity to contribute to knowledge needed in this area, especially given the heightened risk of devel-

opmental concerns for infants who have experienced prenatal exposure to alcohol and other drugs. Strong Start's partners include Early Intervention Colorado of the Division of Developmental Disabilities, and Women's Treatment for Substance Use Disorders of the Division of Behavioral Health, both within the Colorado Department of Human Services.

This grant is one of four projects selected by The Center for the Study of Social Policy (CSSP) to implement new models and evaluate their effectiveness. CSSP is a public policy, research and technical assistance organization. Headquartered in Washington, D.C., CSSP works with state and federal policy makers and with communities across the country. They rely on data, extensive community experience and a focus on results to promote smart policies that improve the lives of

children and their families and achieve equity for those too often left behind. This research is part of the National Quality Improvement Center on Early Childhood, a five-year project launched in late 2008 to develop and disseminate new knowledge about programs and strategies that prevent child maltreatment and optimal development of infants and children younger than five. The U.S. Department of Health and Human Services' Children's Bureau awarded \$10 million to CSSP to develop the Center with its partners ZERO to THREE: National Center for Infants, Toddlers, and Families; and the National Alliance of Children's Trust and Prevention Funds. **For more information, visit www.cssp.org, or contact Kay Teel, PhD at kay.teel@ucdenver.edu.**

Collection of Recorded Speech Samples in the Assessment and Treatment of Child Speech and Language Disorders-The Lena System

This study is examining the usefulness of the LENA system in developing more effective treatments for young children with Autism Spectrum Disorders and language delays. The LENA system provides clinicians with information about children's natural language environment by recording and analyzing speech samples from children and the people around them.

Participants are children from monolingual English-speaking households between the ages of 18-60 months, including children who are typically developing, children with developmental delays who are in speech therapy at JFK, children diagnosed with ASD who are in speech therapy at JFK, and children on JFK's waitlist for a formal evaluation and diagnosis. Only one child per family may be enrolled in this study. **For more information please contact Rene Charlifue-Smith at 303-724-7632 or renee.charlifue-smith@ucdenver.edu.**



Overview of Current Projects of JFK Partners and Collaborators

Project Name	Focus of Study	Who is Eligible	Contact Information
Cognitive Behavioral Group Therapy for Anxiety Symptoms in Children and Adolescents with High-Functioning Autism Spectrum Disorder. Judy Reaven, PhD; Audrey Blakeley-Smith, PhD; Susan Hepburn, PhD Funded by NIH COMIRB # 03-245	To examine the effectiveness of an original, manualized, family-focused, cognitive behavioral group treatment package designed to reduce anxiety symptoms in young people with ASD	Adolescents (ages 14-19) with ASD, verbally fluent, having difficulties coping with fear, worry or anxiety.	Brian Wolff 303-724-7645 brian.wolff@ucdenver.edu
Making Friends: A School-based Program. Audrey Blakeley-Smith, PhD; Susan Hepburn, PhD Funded by OAR COMIRB # 07-0624	To study the effectiveness of a peer-mediated intervention in a public school setting, with the goals of increasing social opportunities for students with ASD and assisting peers to appropriately interpret the behaviors of their classmates with ASD.	School-aged children with ASD and their peers in the Littleton Public Schools.	Audrey Blakeley-Smith 303-724-7630 audrey.blakeleysmith@ucdenver.edu
Center for Autism and Developmental Disabilities Research and Epidemiology: Study to Explore Early Development (SEED). Lisa Miller, MD, MSPH; Cordelia Robinson, PhD Funded by CDC COMIRB # 06-0066	To conduct surveillance of autism and other developmental disabilities; to establish a multi-site collaborative epidemiologic study initially focused on autism; and to conduct site-specific, investigator initiated studies on autism. Our site has initiated studies on comorbid mental health conditions, GI functioning, sleep, and dysmorphology.	Children with a diagnosis of ASD and/or other developmental delay and born between May 2005-August 31st-2006. English or Spanish speaking families are eligible. Your child was born and currently lives in Arapahoe, Adams, Boulder, Broomfield, Denver, Douglas or Jefferson counties.	Kristina Hightshoe 303-724-7638 kristina.hightshoe@ucdenver.edu
GAMMA Band Dysfunction as a Local Neuronal Connectivity Endophenotype in Autism. Don Rojas, PhD; Susan Hepburn, PhD Funded by NIH COMIRB # 07-0675	To examine brain differences in people with and without Autism Spectrum Disorder through neuroimaging protocols. Of particular interest are regions of the brain involved in language.	Must either be diagnosed with ASD or be a parent or a sibling of a person with ASD. Parent or sibling can have no neurological illness. Participants must be between 5-55 years old, have normal hearing. Have no permanently implanted metal objects (such as braces or a pacemaker.)	Alissa Wallace 303-724-4993 alissa.wallace@ucdenver.edu
Emotional Mimicry in Neurodevelopmental Disorders. Eric Moody, PhD; Daniel McIntosh, PhD; Susan Hepburn, PhD Funded by NIMH COMIRB # 08-0846	To study automatic social and emotional responses in persons with various developmental disabilities in an effort to identify potential biological markers that may facilitate identification of infants with autism.	Children between the ages of 5-17 years of age. We are seeking children with ASD and other developmental disabilities and typically developing children. Siblings are welcome. All children must be verbal enough that they can understand and follow basic directions. They should be able to sit calmly for 5-10 minutes at a time and have normal or corrected vision.	Eric Moody. 720-258-6464 eric.moody@ucdenver.edu
Autism Treatment Network: Cooperative Multi-Center Program for Comprehensive Care and Treatment of Autism. Ann Reynolds, MD. Funded by Autism Speaks COMIRB# 07-0673	The ATN is the nation's first network of hospitals and physicians dedicated to improving medical care for children and adolescents with autism. ATN doctors are dedicated to finding better ways to manage the health of children with autism and sharing their increasing knowledge across the wider medical community by collecting extensive information about children diagnosed with autism.	Families with a child between the ages of 2 and 18 who have recently received a diagnosis at one of our sites of an Autism Spectrum Disorder, including PDD-NOS and Asperger's Syndrome.	Harriet Austin. 720-777-6602 austin.harriet@tchden.org
Policy and Procedures of the Intellectual Developmental Disorders Research Center (IDRC) Translational Neuroscience Nexus (TNN) for the Study of Intellectual and Developmental Disorders. Cordelia Robinson, PhD; Gunter Scharer, MD; Renata Gallagher, MD, PhD; Matthew Taylor, MD, PhD; Ann Reynolds, MD COMIRB # 07-1260	The proposed Translational Neuroscience Nexus (Nexus) is a database, patient registry, and biological sample bank focused on neurological and behavioral disorders. its major goal is to advance research on intellectual disabilities (I) by linking human neurological/ behavioral phenotypes to biological samples, especially DNA and (ii) by facilitating access to appropriate patient cohorts for clinical trials.	Children and adults with a diagnosed developmental disability age 31 days to 85 years	Sondra Rosendahl 303-724-2349 sondra.rosendahl@ucdenver.edu

Overview of Current Projects of JFK Partners and Collaborators

Project Name	Focus of Study	Who is Eligible	Contact Information
Telehealth Delivery of a Family-Focused Intervention Program for Children with ASD and Anxiety. Susan Hepburn, PhD; Judy Reaven, PhD; Audrey Blakeley-Smith, PhD; Brian Wolff, PhD; Larry Edelman, MA; Kristen Kaiser, MA; Dina Johnson, BS Funded by HRSA COMIRB # 09-1004	The goals of this project are to develop and evaluate the use of videoconferencing to deliver a promising mental health intervention to families of children with ASD who are geographically removed from specialty medical centers. Given the obstacles faced by rural families of children with autism as they seek specialized care, finding innovative ways to link specialists with families of psychiatrically complex youth with ASD is an important research goal.	Families of children, ages 8-14, who have a diagnosis of an Autism Spectrum Disorder and struggle with exaggerated fears, constant worrying, and anxiety that interferes with family life. Families who live an hour or more from the Metro Denver area in a community with internet access. Families who are willing to partner with our Clinical Research Team to pilot our treatment program with new technology. Study team will provide families with technology needed for the project.	Kristen Kaiser 303-724-4772 kristen.kaiser@ucdenver.edu
Training Clinicians to Provide Cognitive Behavioral Therapy to Children with High Functioning ASD and Anxiety. Judy Reaven, PhD; Audrey Blakeley-Smith, PhD; Susan Hepburn, PhD. Funded by NIH COMIRB # 09-0978	This project provides training to clinicians working with children with high-functioning Autism Spectrum Disorders and anxiety in using Cognitive Behavior Therapy. Three sites in the U.S. have been selected to receive training in the Face Your Fears manualized intervention model using three different training methods. An optimal training model will be developed with the results of data collected during training at the three sites.	We are not recruiting locally, but are developing training materials which will be implemented across the state in the future.	Brian Wolff 303-724-7645 brian.wolff@ucdenver.edu
Creatine Deficiency Study in Children with ASD: An Autism Treatment Network Study. Anne Reynolds, MD; Chun-Hui Tsai, MD Funded by AIR-P of HRSA COMIRB # 09-1202	The Colorado ATN site is collaborating with other ATN sites to identify children with an Autism Spectrum Disorder who might have a Creatine Deficiency Syndrome (CDS). CDSs are associated with developmental delays, autistic symptoms and seizures, but the prevalence and variation in characteristics of CDS has not been well studied in autism.	Families with a child between the ages of 2 and 17.5 who have recently received a diagnosis at one of our sites of an Autism Spectrum Disorder, including PDD-NOS and Asperger's Syndrome, and families who are already enrolled in the ATN Registry.	Harriet Austin. 720-777-6602 austin.harriet@tchden.org
Diet and Nutrition in Children with ASD: An Autism Treatment Network Study. Ann Reynolds, MD Funded by AIR-P of HRSA COMIRB # 09-0684	The Colorado ATN site is collaborating with other ATN sites across the country to describe the nutritional intake of children ages 2 through 11 years who have an Autism Spectrum Disorder. The study will examine the association between nutritional status, serum iron and vitamin D levels as well as sleep and gastrointestinal function.	Families with a child between the ages of 2 and 11 who have recently received a diagnosis at one of our sites of an Autism Spectrum Disorder, including PDD-NOS and Asperger's Syndrome, and who are already enrolled in the ATN Registry.	Harriet Austin. 720-777-6602 austin.harriet@tchden.org
Sleep Education Program for Parents of Children with Autism Spectrum Disorders. Ann Reynolds, MD Funded by AIR-P of HRSA COMIRB # 10-0275	This research project, part of the Autism Treatment Network (ATN), provides parents with tools to help their 2 to 10 year old child fall asleep.	Families with a child between the ages of 2 and 10 who are already enrolled in the ATN Registry, and meet other eligibility requirements of the study.	Harriet Austin. 720-777-6602 austin.harriet@tchden.org
Social Cognition and Comorbidity of Children with Autism Spectrum Disorders and Attention Deficit/Hyperactivity Disorder. Elyse Manteris, Susan Hepburn, PhD COMIRB # 10-0380	This research project will study the ways in which children with ASD and ADHD think about, understand, and process information in their environment, and how this may differ from typically developing children.	Families with a child who is between the ages of 7-11 years old and is typically developing, or has a diagnosis of an autism spectrum disorder or attention-deficit hyperactivity disorder.	Elyse Manteris 303-919- 8459 elyse_manteris@hotmail.com
Manual Task Analysis Discerns Limitations in Motor in Children with Down Syndrome Principal Investigator and Co-Investigators: Joanne Valvano PT, PhD; Mary Jane Rapport PT, PhD; Patricia Winders PT; and James Carollo PhD, PE	To investigate coordination and grip strength in the upper extremities of children with Down syndrome during performance of functional reach and grasp activities compared to typically developing children.	Children will participate in two sessions conducted at the Center for Gait and Movement Analysis at The Children's Hospital. One session will be an intro and one session will include data collection.	Jessica Davis 720-777-0931 Davis.Jessica@tchden.org

Recent Awards at JFK Partners



Audrey Blakeley-Smith, PhD, Assistant Professor of Psychiatry/Pediatrics at JFK Partners, Autism and Developmental Disabilities Clinic.

Eric Moody, PhD, Post Doctoral Fellow at JFK Partners, Department of Psychiatry.



Lisa B. Wilson, Pre-doctoral Fellow at UC Denver School of Medicine.

Judy Reaven, PhD, Director of Clinical Service at JFK Partners.



- The Organization for Autism Research (OAR) has established an annual award in memory of Dr. Ted Carr, who died unexpectedly earlier this year. Audrey Blakeley-Smith, PhD, Assistant Professor of Psychiatry/Pediatrics at JFK Partners, received the award for her work in “Peer-Mediated Intervention for Elementary School Students with Autism Spectrum Disorders,” which was found to exemplify Dr. Carr’s passion to improve the quality of life for persons on the Autism Spectrum and their families.
- Eric Moody, PhD of JFK Partners, Department of Psychiatry, was awarded a National Research Service Award (NRSA) Postdoctoral Fellowship to study emotional processing in those with Autism. This prestigious award supports Dr. Moody’s advanced training in biostatistics, epidemiology, autism assessment, and family support issues.
- Autism Speaks recently awarded eight Dennis Weatherstone Pre-Doctoral Fellowships to promising young investigators in ASD services (funded by the Stavros Niarchos Foundation). Lisa B. Wilson, a graduate student in neuroscience, was awarded with the fellowship at UC Denver School of Medicine. With mentors Donald Rojas, PhD and Susan Hepburn, PhD, Ms. Wilson will use advanced imaging techniques including magnetoencephalography and magnetic resonance imaging to examine how language is processed in parents of children with autism and adults with autism. Ms. Wilson’s training in autism research was previously supported by a grant from the CCTSI, which provides infrastructure support to researchers at UC Denver.
- Judy Reaven, PhD, Director of the Clinical Services at JFK Partners, received the Dane Prugh Award for Outstanding and Inspirational Teaching in Child Psychiatry. Dr. Reaven has received this award once before for her clinical teaching and seminar work.



Congratulations and Recent Publications...



CONGRATULATIONS...

- Judy Reaven, PhD, Audrey Blakeley-Smith, PhD, Shana Nichols, PhD and Susan Hepburn, PhD on the publication of the Face Your Fears Treatment Manual by Brooks Publishing.
- Lila Kimel, PhD long time trainee and research associate at JFK Partners on obtaining her license to practice psychology.
- Eileen Leuthe, PhD JFK Partners Post-Doctoral Fellow on her license and new appointment as a psychologist at the Child Development Unit/Department of Pediatrics.
- Norbert Soke, MPH, MD for his acceptance into a PhD program in Epidemiology at the Colorado School of Public Health.
- Ann Reynolds, MD for her promotion to Associate Professor of Pediatrics.
- Nikki Withrow, Don Rojas, PhD, Judy Reaven, PhD, and Ann Reynolds, MD for their impressive presentations at the Autism Speaks Science Night.
- Ben Yerys, PhD former trainee from JFK Partners on his receipt of a K-award.
- Athena Lickel, a former research assistant at JFK Partners for completing her internship in Clinical Psychology.
- Patti LaVesser, PhD, Dylan Carelli and Alyson Hatten for their presentation acceptance at The Association for Persons with Severe Handicaps (TASH) conference.
- Dina Johnson for her acceptance into the eLearning Technology Masters program at UCD.

RECENT PUBLICATIONS...

Blakeley-Smith, A. (2009). Environmental Fit: A Model for Assessing and Treating Problem Behavior Associated with Curricular Difficulties in Children with Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 24(3), 131-135.

Reaven, J. (2009). Children with High Functioning Autism Spectrum Disorders and Co-Occurring Anxiety Disorders: Implications for Assessment and Treatment. *Journal for Specialists in Pediatric Nursing*, 14(3), 192-199.

Robinson, C. (2009). What Nurses Need to Know About the "Other ASD," *Journal for Specialists in Pediatric Nursing*, 14(3), 155-156.

DiGuseppi, C., **Hepburn, S., Davis, J.,** Fidler, D.J., Hartway, S., Raitano Lee, N., **Miller, L.,** Rutenber, M., **Robinson, C.** (2010). Screening for Autism Spectrum Disorders in Children with Down Syndrome. *Journal of Developmental and Behavioral Pediatrics*, 31(3) 181-191.

Toilet Training for Children with Special Needs

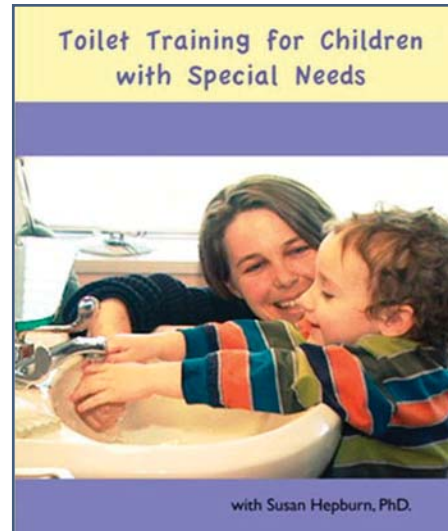
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Phone ordering: 1-800-232-8902

Questions about this product can be directed to:
Dina Johnson at JFK Partners 303-724-7673
or dina.johnson@ucdenver.edu.

This product was developed in collaboration between JFK Partners, University of Colorado School of Medicine and Developmental Pathways. Supported in part by the Administration on Developmental Disabilities UCEDD Grant (#90DD0632) and the Maternal and Child Health Bureau LEND Grant (#1T73MC11044).



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