

Message from the Research Director



Judy Reaven, PhD
Director of Research
Associate Director, JFK Partners

Dear Community Partners,

I am excited to welcome you to the new JFK Partners/ Developmental Pediatrics Research Newsletter! We are looking forward to regularly sharing with our readers information and updates about the many research projects of our faculty and students.

Spotlight!

In each issue of the Newsletter, you will see a Spotlight! section where we profile a particular area of research. In this issue, we are so pleased to spotlight Dr. Nicole Tartaglia, Developmental Behavioral Pediatrician, who shares information about her research.

Research Updates

We also have sections that provide updates for a number of research projects that are either ongoing or have been recently completed within JFK Partners / Developmental Pediatrics.

Study Recruitment

Don't miss our Recruitment Section where we list research projects that are actively recruiting individuals for participation.

Recent Publications

Many of those who have participated in our studies often ask about our research findings, so we have included a list of recent publications.

We hope to publish this Newsletter twice annually, so look for our next issue in March 2018! We would appreciate any feedback you have for us about this newsletter, as well as topics you are interested in hearing about in future editions. Share your thoughts with us here:

www.surveymonkey.com/r/2017news.

Sincerely,

"As a University Center of Excellence in Developmental Disabilities (UCEDD) and Leadership Education in Neurodevelopmental Disabilities (LEND) JFK Partners/ Developmental Pediatrics is dedicated to addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families."

*Sandra L. Friedman, MD, MPH
Section Head, Developmental Pediatrics
Director, JFK Partners*

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Spotlight!

An interview with Nicole Tartaglia, MD, Developmental Behavioral Pediatrician in Developmental Pediatrics

What do you study?

The primary goal of my research has been to better understand neurodevelopment and health in two groups of patients with genetic disorders - X&Y chromosome disorders and Fragile X syndrome.

The X and Y chromosomes (also called the sex chromosomes) are typically XY in males and XX in females. However, approximately 1 in 450 children are born with a difference in their X and/or Y chromosomes, resulting in conditions in males such as XXY (Klinefelter syndrome) or XYY, or Triple X syndrome (XXX) in females. Fragile X is a different condition resulting from a mutation in a single gene on the X-chromosome, and is passed on in families.

Both the X&Y chromosome disorders and Fragile X syndrome lead to difference in brain development that then lead to various degrees of developmental delays, learning/cognitive impairments, and increased risk for autism, ADHD, anxiety, and other behavioral challenges. In the initial phases of research, our team worked to better describe the conditions, such as the frequency of autism and ADHD and how the symptoms are different compared to each other (i.e. XXY vs. XYY), or in comparison to autism in children who do not have a sex chromosome difference. We also looked at medical and hormonal factors in these groups to evaluate how they influence development, behavior, and physical health.

How has your research helped families?

Our initial studies describing developmental profiles and features of ADHD or autism in X&Y variations have been very important for helping to guide evaluations for these patients. For example, prior to these publications, it wasn't always clear to families or medical professionals whether attention deficits were related to the genetic disorder or not, and attentional difficulties were often overlooked in some groups (such as XXY or XXX) because these patients usually don't show hyperactivity. So, these have really helped to guide families and professionals in seeking the right evaluations and treatments.

In our XYY research, we also identified many co-occurring conditions in XYY that hadn't been connected to the syndrome before, like tremor, white matter abnormalities in the brain, distinct facial features, a GI condition called eosinophilic esophagitis. These publications are important for guiding medical care.

Working with so many families in this research also shed light on how little many professionals and education systems understand about the conditions. Their experience and input inspired the development of our interdisciplinary clinic for X&Y chromosome variations called the *eXtraordinary Kids Clinic*. We are now helping other clinics use this model across the nation.

"Families who have children with these genetic disorders are usually very open to hearing about and participating in research. They remember when their child was diagnosed with a condition most people hadn't heard of, and they also recognize how much work we have to do to develop treatment programs and interventions for these conditions."



Nicole Tartaglia, MD
Associate Professor
Developmental Pediatrics
University of Colorado School of Medicine
Children's Hospital Colorado

How did you become interested in genetic research?

I have been interested in psychology, neuroscience, and genetics since being an undergraduate student at CU-Boulder. Once I decided on Pediatrics as my specialty in medical school, the steps to my current research interests have been guided by a combination of great mentors, an inspiring research team, and primarily by the needs of patients and families. I was planning on a career in Child Neurology, but then did a rotation at the Child Development Unit at the old hospital way back in 1999 when a great mentor, Dr. Randi Hagerman, pulled me into her Fragile X research. She convinced me about all the possibilities for research in Developmental Pediatrics.

During my Developmental Pediatrics fellowship at the UC-Davis MIND Institute, I became very involved in research on sex chromosome variations. For one study, I met with families who had sons with XXYY in different parts of the US, Canada, the UK, Australia, and even Japan. I collected medical records, did some testing on the boys/men, and really “heard their story.” It was a great opportunity to meet families with the same condition from all over the world, and to realize that so many of the struggles and challenges parents face are similar no matter where they live.

What are you working on right now?

We are starting a very exciting program called the eXtraordinary Babies Study that will evaluate the early health and development of infants and children with sex chromosome disorders. This study follows babies, who were diagnosed with a sex chromosome disorder before being born, from 2-3 months of age every 6-12 months as they grow up. This is an amazing opportunity to learn about the variability in these conditions from a young age. In the study, we will closely evaluate and track developmental skills, medical problems, hormone levels, body composition, and other important factors such as family history, interventions, and family quality of life.

In the Fragile X LEARN trial (funded by NIH NeuroNext program), we are one site of a study looking to see if a specific medication can lead to improvements in language and cognitive outcomes. There are a lot of new studies on the horizon looking at different medications targeting the biological abnormalities in Fragile X and autism.

We are also part of a large CDC study the FORWARD study. In this study families seen in Fragile X clinic participate in a national database of Fragile X families that now has more than 1000 participants. This data allows us to understand development, health problems, medication treatments, and interventions throughout the lifespan. Our site was also selected to conduct additional research looking much more closely at development, social, and motor skills in Fragile X, as well as to explore strategies to improve participation of minorities in research.

Research Updates

Growing up with an extra X or Y: The TRIXY study

Principal Investigator: Nicole Tartaglia, MD, MS

Development can vary in children with an extra X or Y chromosome. It is therefore important to identify children with developmental differences so that appropriate interventions and supports can be provided as soon as possible. We have limited knowledge about development in these areas in young children with an extra X or Y chromosome, and there is still a lot for us to learn. In this study we are hoping to identify early markers to know which children are at higher risk for behavior differences. With this knowledge, we hope to understand risk and protective factors so that we can provide better care for infants with a diagnosis of XXY, XXX or XYY. Funded by a grant awarded to Sophie van Rijn, PhD at Leiden University. See Study Recruitment Section about how to join this study.

The aV1ation Study

Principal Investigator: Nicole Tartaglia, MD, MS

This is a Phase II Double-Blind, Placebo-controlled Study to Investigate the Safety and Efficacy of RO5285119 in Children and Adolescents Age 5-17 with Autism Spectrum Disorder (ASD). People with autism spectrum disorder (ASD) often suffer from secondary conditions too (such as sleeping problems, anxiety and attention issues). Although there are medications available to help manage such secondary conditions, we've yet to find any that address the social and communication skill issues at the heart of autism. This study is seeking children and adolescents (aged 5 to 17) with 'high-functioning' ASD to participate in the aV1ation study. The aV1ation study will test an investigational medicine that blocks a hormone receptor in the brain (the vasopressin receptor) linked to the control of socialization, stress, anxiety and aggression. The goal of the study is to investigate if this medication leads to improvements in socialization, anxiety, or other aspects of behavior in children and adolescents with ASD. This study is sponsored by Hoffman-La Roche, LTD.

Program Update

Facing Your Fears (FYF) Program: Group Treatment for Children & Adolescents with Autism Spectrum Disorder and Anxiety

Principal Investigator: Judy Reaven, PhD
Judy.Reaven@ucdenver.edu

Children with ASD are at high risk for developing psychiatric symptoms and anxiety disorders are among the most common co-occurring conditions ¹. Anxiety significantly interferes with peer relationships, family functioning and school performance.

Cognitive behavior therapies (CBT) are evidence-based practices for neurotypical youth with anxiety ². Facing Your Fears (FYF) is one such CBT program ³, and is a 14-week family-focused group treatment (1½ hours each session) developed to manage anxiety in children ages 8-14 years with ASD ⁴.

Our group has conducted five treatment trials on the clinic-based FYF program (all in Colorado), including one randomized controlled trial. Results from all of these studies demonstrated significant reductions in anxiety symptoms following treatment. Of the five treatment trials, two were pilot studies, one adapting FYF for adolescents with ASD 13-18 years ³ and the other modifying FYF for telehealth delivery ⁵.

¹ Simonoff et al. 2008; ² Olatunji et al. 2010; ³ Reaven et al. 2012; ⁴ Reaven et al. 2011; ⁵ Hepburn et al. 2015

Research Updates

Facing Your Fears Adapted for Schools

Principal Investigator: Judy Reaven, PhD
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We have worked to implement FYF beyond clinic settings, and have begun to modify this program for use in elementary and middle schools. Our preliminary work in this area was conducted in Singapore with verbally fluent students ages 13-15 with ASD and anxiety (Drmic et al. 2017). Given the encouraging results (significant reductions in youth anxiety), we applied for grant funding to modify and deliver FYF in public schools in Colorado, specifically targeting low-resource schools (elementary and middle schools) and underrepresented racial/ethnic minority students with ASD or other special learning needs and anxiety. We were just awarded a three-year HRSA grant to modify FYF in three major public schools districts in the Denver Metro area (PI: Judy Reaven). Look for details regarding this exciting new project in subsequent issues of our newsletter. Funding: NIMH, R41MC31075.

Facing Your Fears Adapted for Adolescents with ASD and ID

Principal Investigator: Audrey Blakeley-Smith, PhD
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Our research team is also exploring the effectiveness of a family focused, modified group cognitive behavioral therapy treatment for adolescents with Autism Spectrum Disorders, intellectual disabilities, and anxiety. This treatment is an adapted version of the Facing Your Fears program. The intervention program targets anxiety and helps families develop strategies for their teens to face fears. We have just started our fourth group and will run three or four more groups in the upcoming months. See Study Recruitment Section about how to join this study. Funding: Organization of Autism Research (OAR).

For more information about Facing Your Fears, check out our website at:

<http://www.FacingFears.org>

Training Clinicians to Deliver FYF

Principal Investigator:
Judy Reaven, PhD
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In efforts to implement FYF beyond our clinic setting, we have conducted a multi-site randomized trial, in five sites across North America, to determine the optimal training necessary in order to deliver FYF and obtain positive treatment outcomes for participating youth with ASD and anxiety. Results will be shared in subsequent issues of our newsletter. Funding: NIMH, #5R33MH089291



Judy Reaven (Above) and Audrey Blakeley-Smith (Below) training clinicians to deliver FYF in other states and countries. Photos from recent training in Buenos Aires, Argentina.



Research Updates

Relationship Between Treatment Acceptability & Treatment Response

Caitlin Walsh, PhD / Caitlin.Walsh@childrenscolorado.org

An area that has not been widely studied is the relationship between acceptability of CBT and treatment response. This study focuses on parent, child, and clinician acceptability of the Facing Your Fears program for youth with ASD and anxiety. Results indicated that parents rated acceptability as higher for the overall treatment compared to children, although both groups found FYF to be an acceptable intervention. Children and parents rated graded exposure (facing fears) as more acceptable than psychoeducation. Parent and child acceptability ratings for exposure were predictive of lower child anxiety levels post-treatment.

This is the first study in the ASD literature to demonstrate that there is a relationship between the acceptability of a treatment and a reduction in child anxiety symptoms. This study was recently submitted to the Journal of Contemporary Psychotherapy for a special issue on Treatment for Autism Spectrum Disorder. Funding: Natl Institute of Mental Health, #5R33MH089291

Key Study Questions

This project seeks to address three key questions:

- 1) What are meaningful family-focused outcomes of early intervention?
- 2) How do we measure these outcomes?
- 3) How do parent mediated interventions impact family outcomes in addition to child outcomes?

Family Involvement

All aspects of this study have been overseen by a Consumer Advisory Council (CAC), comprised of parents of children with ASD who have already participated in early intervention.

Parent Mediated Interventions in Autism: The Search for Meaningful Outcomes

Principal Investigator: Elizabeth Griffith, PhD
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The primary goal of this study is to partner with families to redefine “success” in parent mediated interventions with very young children with ASD to include impact on family well-being, parental health and cognition, and parent-child interactions.

We believe that understanding these meaningful and functional outcomes will lead to improved interventions and therefore child and parent well-being, as well as influence the ways that intervention outcomes research is conducted.

The study has already 1) explored themes in family narratives, through interviews and focus groups, related to their experiences of parent mediated early interventions, and 2) used these themes to guide selection of measures of meaningful parent and family outcomes going forward.

The themes from this first Phase of the study included: the parent-mediated intervention they participated in helped them understand how ASD impacted their child’s development and improved their relationship with their child. Parents described improved overall family functioning; however, this type of intervention also highlighted differences in parenting beliefs between caregivers, and added another appointment to juggle. Finally, families described feeling that most interventions they experienced were a “series of short-term therapies for a long-term condition”, but that the interventions lead to better understanding the life-long nature of ASD.

We are currently in Phase 2 of the study and examining the selected measures of meaningful outcomes, guided by the themes gathered in the first Phase, both before and after a parent-mediated intervention based upon the strategies of the Early Start Denver Model (ESDM). Data collection for this Phase of the study will continue through the end of August 2018. Funding: Maternal Child Health Bureau, R40MC27703.

Crisis Plan Intervention

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN
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For a number of years medical students in the LEADS program have focused on Crisis Intervention for people with a dual diagnosis of intellectual disability and mental illness or behavioral disability. The current project has involved developing a template for a crisis plan for these individuals and their families. As part of this research study, we work with families to complete a crisis plan using an approved template and crisis resource guide. This protocol is open to parents of a dually diagnosed individual of any age who lives with his or her parents. See the Study Participant table for more information on how to enroll.

Research Updates

The Good Tastes Study

Principal Investigator: Susan Johnson, PhD
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Some children react more to bitter taste than others. This research will study children's response to bitter tasting vegetables. This study is designed to learn more about infants' and toddlers' responses to bitter tasting vegetables. Also, we hope to learn more about parents' experiences of offering vegetables to their children and their thoughts and feelings about their child's responses. We are currently enrolling children and their families. See the Study Recruitment Page for more information about enrollment. Funding: The Sugar Association



Evaluation of Inclusive Higher Education Pilot Program

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN
Cordelia.Rosenberg@ucdenver.edu

Dr. Rosenberg leads the program evaluation for the Colorado Inclusive Higher Education (IHE) Pilot program, which began its second of four years on July 1, 2017. This program is authorized through [Senate Bill 196](#). The three schools participating are Arapahoe Community College, University of Colorado at Colorado Springs, and University of Northern Colorado. JFK Partners is conducting the evaluation activities which involve documentation of program activities, policies and outcomes against nationally accepted program standards. Evaluation also includes interviews or surveys of key stakeholder groups including enrolled students, parents, faculty, peer mentors and typical students. More information can be found on the IN! website at www.inclusivehighered.org. Funding: State of Colorado, Senate Bill 196.

SPARK for Autism Study

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN
Cordelia.Rosenberg@ucdenver.edu

JFK Partners and Children's Hospital Colorado are pleased to be the clinical site in Colorado for the SPARK for Autism project. The mission of SPARK - an online research partnership involving 50,000 individuals with autism and their families — is simple. We want to speed up research and advance understanding of autism. SPARK is a landmark online research partnership that will transform the autism research landscape by building a national cohort of 50,000 individuals with autism and their families, making it the largest autism genetic research cohort in the US. Because autism is a spectrum disorder, large numbers are critical to tease out common genetic causes and potential targets for treatments and interventions. However, participation in autism research studies to date has been low, which ultimately hinders the progress of our understanding of autism. SPARK will change that by connecting researchers to a well-characterized and large cohort of individuals and their biological families. This first of its kind study is designed to encourage all in the autism community to participate. Registering for SPARK can be done entirely online, in the convenience of one's home at no cost, making it more accessible to all individuals in the autism community, even if they are not close to a major research center. Funding: Simons Foundation, #390284. Visit the Colorado SPARK Study website at www.jfkpartners.org/SPARK.

Study to Explore Early Development (SEED 3)

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN
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JFK Partners is excited to begin the third phase of the national SEED study, which is funded by the Centers for Disease Control (CDC). SEED is one of the largest epidemiological studies to date that is designed to compare children with autism spectrum disorder (ASD) and other developmental disabilities to children without these conditions. SEED will help identify factors that might put children at risk for ASD and help improve services and treatments for children with ASD. SEED 3 is open to enrollment by invitation only. You can visit the Colorado SEED Study website at www.coloradoseed.org. Funding: CDC, National Center for Birth Defects and Developmental Disabilities, #5U01DD00120.

Research Updates

The Impact of Natural Environments on Symptom Expression in Children with ASD

Principal Investigator: Eric Moody, PhD
Eric.Moody@ucdenver.edu

Cortisol is a stress response hormone and is associated with expressions of core ASD symptoms and poorer performance on executive function (e.g. planning) tasks. Previous studies indicate that exposure to natural environments decreases cortisol production in the typical population however, there is little information whether natural environments impact children with autism in the same way. We have received a new grant from the U.S. Forestry Service to study this. We are in partnership with Georgia State University and Happy Dog Ranch, a local non-profit ranch dedicated to rescuing displaced animals, and supporting families affected by any disability, to explore this further. Children with autism will go on walk through Chatfield State Park, located adjacent to Happy Dog Ranch. Cortisol and cognitive tasks will be completed before and after the walk, and this will be compared to a control condition where children walk on a treadmill. This will help us better understand the impact of natural environments on children with autism and how to improve their stress and wellbeing. See the [Study Recruitment Page](#) for more information about enrollment. Funding: U.S. Forest Service.

Transition Education for Individuals with Intellectual or Developmental Disability

Principal Investigator: Eric Moody, PhD
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Ensuring adequate continuity of care during the transition from pediatric to adult services for a child with special health care and/or mental health needs can be challenging for both families and providers. Despite national guidelines and resources to support transitions to adult care, many families and healthcare providers report that they have little opportunity ensure successful transitions. To better understand the national landscape, we are surveying primary care providers to better understand their barriers to supporting their patients through a transition to adult care. This voluntary survey, which will be sent to primary care physicians, specialists and other providers across the country. We will identify the use and barriers to having an established transition plan for patients in place. This will guide future programs and policy work.

DBPNet

Sandra L. Friedman, MD, MPH is the site lead for Colorado for the **Developmental Behavioral Pediatrics Research Network** (DBPNet). We are one of 14 sites of clinical practices with developmental-behavioral pediatrics or neurodevelopmental disabilities and post-doctoral fellows in developmental-behavioral pediatrics.

Two studies are in the planning stages:

1. A Retrospective Description of the Effectiveness and Adverse Effects of Stimulants and Alpha-2 Agonists Used by Developmental-Behavioral Pediatricians for the Treatment of ADHD in Preschool Age Children
2. An ADOS Study, not officially titled as yet. It will be a prospective study to determine the frequency with which results of the ADOS-2 alters the diagnostic conclusion of developmental-behavioral pediatricians.

Progress for these studies will be shared in future Research Newsletters.

Research Updates

Parents and Child Care Providers Partnering to Support Social & Emotional Health & Development of Young Children

Principal Investigator: Lorraine Kubicek, PhD / Lorraine.Kubicek@ucdenver.edu

Findings from both clinical work and research suggest that one of the most powerful ways to promote young children's social emotional health and prevent and/or mitigate the effects of toxic stress is through nurturing early caregiver-child relationships. Both the **Partners in Parenting Education (PIPE)** and **Emotional Beginnings (EB)** curricula provide parents and child care providers with training to develop sensitive, responsive, and dependable caregiver-child relationships that can support and encourage optimal child development, health and well-being. The goal of this project is to design a program that blends these two **How to Read Your Baby** curricula and fosters collaboration between parent and child care providers while promoting parents as their child's first teacher. This project is a partnership with Early Learning Ventures, an Early Head Start Partnership grantee, How to Read Your Baby, a Colorado based non-profit that promotes emotionally responsive caregiving through the PIPE and EB curricula, and JFK Partners. Funding: CCTSI Community Engagement Partnership Development Grant, University of Colorado Anschutz Medical Campus.

Stage 1

In Stage 1, 858 teachers completed screens on 4,183 students included in our stratified random sample of 5,521 students.

Stage 2

In Stage 2, *parents* completed diagnostic interviews for a subsample of this population of students, 600 who scored low and 600 who scored high on the screen.

Prevalence, Treated Prevalence and Co-Occurrence of Internalizing, Externalizing and Tic Disorders in Colorado School-Aged Youth

Principal Investigator: Lorraine Kubicek, PhD
Lorraine.Kubicek@ucdenver.edu

The specific aims of this study were to assess the prevalence, treated prevalence, and co-occurrence of internalizing, externalizing, and tic disorders in Colorado school-aged youth (ages 5-17 years).

Two hundred and thirty eight interviews were conducted through February 29, 2016, 46% with parents of girls and 54% with parents of boys. The students are 58% Hispanic or Latino, 28% White, 25% Black or African American, 4% American Indian or Alaska Native, 2% Asian, 0.4% Native Hawaiian or Other Pacific Islander, and 3% Other (some reported more than one race/ethnicity).

Parent reports indicated that 18% of the students have ongoing physical health problems that have been diagnosed by a health care worker, 10% are limited in activities in some way due to physical, mental or emotional problems, and 2% have health problems that require the use of special equipment. Almost all of students have health care coverage. Most who do are covered through Medicaid or the Children's Health Insurance Program (CHIP Plus).

A number of additional presentations/manuscripts focused on our local Colorado data are in preparation.

Funding: Centers for Disease Control and Prevention (CDC) as a sub-contract through the University of South Carolina School of Medicine, Disability Research and Dissemination Center.

Colorado Project LAUNCH (Linking Actions for Unmet Needs in Children's Health)

Principal Investigator: Lorraine Kubicek, PhD
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The purpose of Project LAUNCH is to promote the wellness of young children (birth to 8) by addressing the physical, social, emotional, cognitive, and behavioral aspects of their development. This initiative is grounded in the public health approach, working toward coordinated programs that take a comprehensive view of health and promote the well-being of all young children. Grantees implement five core prevention and promotion strategies: (1) screening and assessment in a variety of child-serving settings, (2) enhanced home visiting through increased focus on social and emotional self-being, (3) mental health consultation in early care and education, (4) family strengthening and parent skills training, and (5) integration of behavioral health into primary care settings. The long term goal of Project LAUNCH is to ensure that all children enter school ready to learn and able to succeed. Project LAUNCH seeks to improve and strengthen our early childhood system by increasing the coordination of key child-serving systems, the expertise of behavioral health providers in primary care and other local programs, and access to and availability of evidence-based prevention and wellness promotion practices that support young children and their families. JFK Partners leads the Evaluation Team and works in collaboration with Early Childhood Partnership of Adams County, Colorado Department of Human Services' Office of Early Childhood, and Colorado Department of Public Health and Environment on Colorado Project LAUNCH. Funding: Substance Abuse and Mental Health Services Administration (SAMHSA).

Recent Publications

For copies of the listed publications, please contact the Principal Investigator listed below.

Parent Mediated Interventions in Autism: The Search for Meaningful Outcomes

Principal Investigator: Elizabeth Griffith, PhD
Elizabeth.Griffith@childrenscolorado.org

Wainer, AL, Hepburn, S, Griffith, EM. (2017) Remembering parents in parent-mediated early intervention: An approach to examining impact on parents and families. *Autism*, 21(1), 5-17. <https://doi.org/10.1177/1362361315622411>

Facing Your Fears (FYF) Program: Group Treatment for Children & Adolescents with Autism Spectrum Disorder and Anxiety

Principal Investigator: Judy Reaven, PhD
Judy.Reaven@ucdenver.edu

Drmic, IE, Aljunied, M, Reaven, J. (Jan, 2017). Feasibility, acceptability and preliminary treatment outcomes in a school-based CBT intervention program for adolescents with ASD and Anxiety in Singapore. *Journal of Autism and Developmental Disorders*. Online publication. <https://doi.org/10.1007/s10803-016-3007-y>

Reaven, J., Blakeley-Smith, A., Beattie, TL, Sullivan, A, Moody, EJ, Stern, JA, Hepburn, SL, Smith, IM. (2015). Improving transportability of a cognitive-behavioral treatment intervention for anxiety in youth with autism spectrum disorders: Results from a US-Canada collaboration. *Autism*, 19(2), p. 211-222. <https://doi.org/10.1177/1362361313518124>

Reaven, J., and Wainer, A. (2015). Children and adolescents with ASD and co-occurring psychiatric conditions: current trends in intervention. In R. M. Hodapp, & D. J. Fidler (Eds.), *International Review of Research in Developmental Disabilities* (pp. 45–90). ISBN: 9780128021811. Elsevier Inc. Academic Press.

Efficacy of Crisis Plans for Individuals with Neurodev & Behavioral Dual Diagnosis

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN
Cordelia.Rosenberg@ucdenver.edu

Claus, D. and Rosenberg Robinson, C. (2017). [Crisis Resource Guide](#). JFK Partners and LEADS Program: Aurora, CO

Study to Explore Early Development

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN
Cordelia.Rosenberg@ucdenver.edu

Wiggins, Barger, Moody, E.J., Soke, Pandey, Levi (2017). The ADOS Calibrated Severity Score Best Measures Autism Diagnostic Symptom Severity in Pre-School Children. *Journal of Autism and Developmental Disabilities*, <http://doi.org/10.1007/s10803-017-3072-x>

Moody, Reyes, Ledbetter, Wiggins, DiGuseppi, Alexander, Jackson, Lee, Levy & Rosenberg (2017). Screening for Autism with the SRS and SCQ: Variations across Demographic, Developmental and Behavioral Factors in Preschool Children. *Journal of Autism and Developmental Disabilities*. <http://doi.org/10.1007/s10803-017-3255-5>; <http://rdcu.be/vq5Y>

Emotional Mimicry in Children with Autism

Principal Investigator: Eric Moody, PhD
Eric.Moody@ucdenver.edu

Moody, E.J., Reed, C.L., Bommel, T.V., App, B., & McIntosh, D.N. (2017). Emotional Mimicry Beyond the Face? *Social Psychological and Personality Science*. <http://doi.org/10.1177/1948550617726832>.

Recent Publications

For copies of the listed publications, please contact the Principal Investigator listed below.

Prevalence, Treated Prevalence and Co-Occurrence of Internalizing, Externalizing and Tic Disorders in Colorado School-Aged Youth

Principal Investigator: Lorraine Kubicek, PhD
Lorraine.Kubicek@ucdenver.edu

Reyes, N., Moody, E., Kaparich, K., Davidon, S., Rosenberg, S., & Kubicek, L. (2017, May). *Child and parent factors that influence Social Communication Questionnaire Scores: An examination of an English- and Spanish-speaking sample*. Presented at the 16th annual International Meeting for Autism Research (IMFAR) Conference. San Francisco, CA.

X&Y Chromosome disorders

Principal Investigator: Nicole Tartaglia, MD, MS
Nicole.Tartaglia@childrenscolorado.org

J Ross, H Kushner, K Kowal, M Bardsley, S Davis, A Reiss, N Tartaglia, D Roeltgen "Androgen Treatment Effects on Motor Function, Cognition and Behavior in Boys with Klinefelter Syndrome," *The Journal of Pediatrics*, 2017, Mar, epub ahead of print (PMID 28285751) <http://doi.org/10.1016/j.jpeds.2017.02.036>

N Tartaglia, R Wilson, J Miller, J Rafalko, L Cordeiro, S Davis, D Hessler, J Ross "Autism Spectrum Disorders in Males with Sex Chromosome Aneuploidy: XXY/Klinefelter syndrome, XYY, and XXYY," *Journal of Developmental-Behavioral Pediatrics*, 2017, Apr 38(3): 197-207 (PMID 28333849) <https://doi.org/10.1097/DBP.0000000000000429>

N. Tartaglia, S Howell, R Wilson, J Janusz, R Boada, S Martin, JB Frazier, M Pfeiffer, K Regan, S McSwegin, P Zeitler. The eXtraordinary Kids Clinic: an interdisciplinary model of care for children and adolescents with sex chromosome aneuploidy, *Journal of Multidisciplinary Healthcare*, 2014, 8, 323-334. <https://doi.org/10.2147/JMDH.S80242>

S. Davis, S Howell, R Wilson, T Tanda, J Ross, P Zeitler, N Tartaglia, "Advances in the interdisciplinary care of children with Klinefelter syndrome," *Advances in Pediatrics*, 2016 Aug 63(1): 15-46. (PMID 27426894) <https://doi.org/10.1016/j.yapd.2016.04.020>

Fragile X Studies

Principal Investigator: Nicole Tartaglia, MD, MS
Nicole.Tartaglia@childrenscolorado.org

J Liu, R Hagerman, R Miller, L Craft, B Finucane, N Tartaglia, E Berry-Kravis, S Sherman, S Kidd, J Cohen, "Clinicians Experience with the Fragile X Clinics and Research Consortium," *American Journal of Medical Genetics Part A*, 2016, Dec 170(12): 3138-3143. <https://doi.org/10.1002/ajmg.a.37948>

ABC Dy, F Tassone, M Eldeeb, MJ Salcedo-Arellano, N Tartaglia, R Hagerman, "Metformin as a Targeted Treatment in Fragile X Syndrome," *Clinical Genetics*, 2017, Apr 24, epub ahead of print. <https://doi.org/10.1111/cge.13039>

Autism

Principal Investigator: Nicole Tartaglia, MD, MS
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Study Recruitment

Project Name	Who is Eligible	Contact Information
<p>Facing Your Fears Adapted for Adolescents with ASD and ID COMIRB # 15-2459</p> <p>PI: Audrey Blakeley-Smith, PhD</p>	<p>1) Individuals aged between 12-21 years 2) Confirmed diagnosis of an autism spectrum disorder 3) Cognitive abilities in the intellectual disabled range</p>	<p>Allison Meyer, PhD 303-724-7656 allison.t.meyer@ucdenver.edu</p> <p>or</p> <p>Audrey Blakeley-Smith, PhD Audrey.blakeleysmith@ucdenver.edu</p>
<p>Efficacy of Crisis Plans for Individuals with Neurodevelopmental and Behavioral Dual Diagnosis</p> <p>COMIRB # 17-0845</p> <p>PI: Cordelia Robinson Rosenberg, PhD, RN</p>	<p>We are enrolling parents of an individual who has both a neurodevelopmental diagnosis AND a psychiatric or behavioral diagnosis.</p> <p>1) Individual with dual diagnoses must be between 8-50 years of age 2) Individual must live in the state of Colorado 3) Individual with dual diagnoses must have experienced one or more of the following events: (a) 911 call; (b) Emergency Department admission for mental health reasons; or (c) other urgent mental health intervention. 4) Parent or caregiver must be willing/able to complete the Crisis Plan and follow up surveys.</p>	<p>Angela Rachubinski, PhD 303-724-7366 Angela.Rachubinski@ucdenver.edu</p>
<p>Good Tastes Study COMIRB # 15-2437</p> <p>PI: Susan L. Johnson, PhD</p>	<p>Children must be between 6 and 24 months of age, have been born at term (at least 37 weeks gestation) and not have allergies or medical conditions. Parents must live within 75 miles of the University of Colorado Denver Anschutz Medical Campus and be between 18 – 50 years of age.</p>	<p>Kameron Moding 303-724-2922 Kameron.Moding@ucdenver.edu</p>
<p>SPARK for Autism COMIRB # 16-0126</p> <p>PI: Cordelia Robinson Rosenberg, PhD, RN</p>	<p>SPARK is open to individuals of all ages with a professional diagnosis of ASD living in the United States. ASD includes Asperger syndrome, autism/autistic disorder and pervasive developmental disorder-not otherwise specified (PDD-NOS). Participants are welcome to invite biological parents and full biological siblings (with and without ASD) to participate as well.</p>	<p>Jeanette Cordova 303-724-0473 SPARK@ucdenver.edu sparkforautism.org/JFKPartners</p>
<p>Impact of Natural Environment on Symptom Expression in Children with ASD - COMIRB # 17-0848</p> <p>PI: Eric Moody, PhD</p>	<p>Children ages 5-17 with or without autism spectrum disorder and their caregivers are invited to participate.</p>	<p>Eric Moody 303-724-7679 Eric.Moody@ucdenver.edu</p>
<p>The aV1ation Study COMIRB#16-2631</p> <p>PI: Nicole Tartaglia, MD, MS</p>	<p>1) Males or females with ASD 2) 5 - 17 years of age at enrollment. Current priority group is 13-17 yrs. 3) Full scale IQ greater than 70 4) No previous diagnosis of intellectual disability</p>	<p>Nana Welnick 720-777-8608 Nanastasia.welnick@childrenscolorado.org</p>
<p>Growing up with an extra X or Y: The TRIXY study COMIRB#16-1710</p> <p>PI: Nicole Tartaglia, MD, MS</p>	<p>1) Children must be between the ages of 1 years and 5 years old at enrollment 2) Confirmed diagnosis of 47,XXY, 47, XYY or 47, XXX or typically developing children 3) Additional screening criteria</p>	<p>Lisa Cordeiro, MS, CSP 720-722-1515 trixy@ucdenver.edu</p>

Upcoming Opportunities

Please be on the lookout for our next Research Newsletter in March 2018. We aim to provide updates on current research and will highlight new ways to get involved. We plan to debut a new research database next year for members of the community who might like to be involved in research. This database will be not only used to let the public know about studies on topics they are interested in, but also for parents to let us know if they would like to be part of a parent panel, focus group, or other opportunities at JFK Partners / Developmental Pediatrics. If you have an idea, please don't hesitate to let us know!
www.surveymonkey.com/r/2017news.

JFK Listserv

If you would like to hear about all of the ongoing opportunities at JFK Partners, please join our listserv by sending an email to: Listserv@Lists.UCDenver.edu with "Listserv Command" in the Subject Line and "SUBSCRIBE JFKPARTNERS" in the text of your email. If you have trouble, please email Dina.Johnson@ucdenver.edu.

We invite you to follow us on Facebook or Twitter @JFKPartners



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