

CART Connection Fall 2016, Vol. 9

News from the UCLA Center for Autism Research and Treatment

Did you know?

Many children who were diagnosed with ASD had notes about their development in their health and special education records by 3 years old. Still, less than half of children with ASD received a developmental evaluation by 3 years old. This lag between the first concern and first developmental evaluation may affect when children are being diagnosed and receiving the service they need. -Center for Disease Control and Prevention (CDC 2016)

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Multisite Studies Enable Scientific **Research Collaboration**



Across the nation, research centers are increasingly participating in multisite studies. These collaborative endeavors have many advantages. Multisite studies provide investigators the opportunity to research different programs using a shared study design and methodology, and give more families around the country the opportunity to participate in research. Multisite studies are also important because as different centers participate, results obtained may be more easily generalized. The UCLA Center for Autism Research and Treatment (CART) participates in many multisite studies, three of which are highlighted here:

ABC-CT

The Autism Biomarkers Consortium for Clinical Trials (ABC-CT) is a multi-site, longitudinal study that aims to identify biomarkers, or biological signatures, of autism spectrum disorder (ASD) using advanced methods such as eye tracking and electroencephalography (EEG). Currently, most of our understanding of ASD is based on measurements of behavior, even though we believe that there is a brain basis for the symptoms that define ASD. These brainbased biomarkers can help us not only understand why where are so many

Multisite Studies, continued on page 2

Mission Statement

The mission of the UCLA Center for Autism Research and Treatment is to continue to play a leading role, both nationally and internationally, in efforts to develop an improved understanding of the biological basis of autism, so as to improve diagnosis and to develop new, more effective treatments for autism spectrum disorders across the lifespan. We hope to achieve these goals by fostering a strong collaborative environment for basic and applied research, as well as a challenging, but supportive environment for trainees.



CART administrative staff: Kenneth Tran, Monica Belli, and Consuelo Garcia with UCLA's Joe Bruin

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individual differences between children with ASD, but they also can be used as more sensitive measures of response to treatments in clinical trials. This study, funded by the National Institutes of Health, involves five collaborating sites, all of which have tremendous expertise in autism research: University of California, Los Angeles, Yale University, Duke University, Harvard Medical School, and University of Washington and will be conducted over a 4 year period.

We are currently recruiting school-aged children (6 - 11 years) with ASD and a comparison group of typically developing children. Children will be assessed across three time points with behavioral assessments, EEG and eye tracking tasks. Benefits to participation include \$100 compensation per visit (\$300 total) and a detailed feedback letter from a clinician summarizing the behavioral assessment scores. Most importantly, this study provides families with an opportunity to be involved with an exciting, truly innovative national research endeavor!

If you're interested in participating in this exciting research endeavor with your child, please contact the Jeste Lab at (310) 825-0180.

AIR-B

School transitions can be stressful for children with ASD, their parents and teachers. Small transitions are common, occurring each year as children move between grades, but major transitions may hold even greater importance. These occur when moving from one level of school to another: from preschool to Kindergarten, from elementary to middle school and middle to high school. Nearly all parents and children find these stressful, but for children with ASD, critical gains may be lost if interventions are not successfully in place before, during and after these transitions. We recognize that children with ASD may need targeted transition interventions in order to support their success during these times. The Autism Intervention Research Network for Behavioral Health (AIR-B), a team of researchers across 5 Universities (UCLA, Drexel University, UC Davis, University of Pennsylvania, and University of Rochester) has begun the development of just such an intervention. An important measure of change for this intervention is social network mapping of the levels of communication and cooperation between all members of the child's transition team. These maps are the brainchild of Dr. Elizabeth McGhee Hassrick and Dr. Kathleen Carley who have developed the Social Dynamics of Intervention tool. AIR-B investigators are currently piloting the tool with families who are transitioning to new levels of schooling. We are following families from the end of school, over the summer and through the transition to the new school. Once we better understand the challenges the families and teachers face, we will be better able to design an intervention to help in these transitions.

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The Kasari Lab's AIR-B team

The goal is for the social networks to have stronger connections over time, thus insuring the students will have the necessary supports in place to make a positive transition.

SPARK for Autism

UCLA joins launch of SPARK, the nation's largest autism research study. This groundbreaking initiative combines webbased registry with DNA analysis to accelerate autism research and speed discovery of treatments.

SPARK is an online research initiative designed to become the largest autism study ever undertaken in the United States. Sponsored by the Simons Foundation Autism Research Initiative (SFARI), SPARK will collect information and DNA for genetic analysis from 50,000 individuals with autism — and their families — to advance our understanding of the causes of this condition and to hasten the discovery of supports and treatments. The SPARK effort is being led locally by Dr. Amanda Gulsrud and her team at CART.

Autism is known to have a strong genetic component. To date, approximately 50 genes have been identified that almost certainly play a role in autism, and scientists estimate that an additional 300 or more are involved. By studying these genes, associated biological mechanisms and how genetics interact with environmental factors, researchers can better understand the condition's causes, and link them to the spectrum of symptoms, skills and challenges of those affected.

There is no cost to participate in SPARK, and registering for this first-of-its-kind initiative can be done entirely online in the convenience of one's home and at no cost. DNA will be collected via saliva kits shipped directly to participants. Once the SPARK participant's family has returned their saliva samples and provided some medical and family history information, the SPARK participant will receive up to a \$50 gift card. SPARK will provide access to online resources and the latest research in autism, which may provide participants and families with valuable information to help address daily challenges. Karie del Solar and her family recently participated in SPARKforAutism. She said, "I was so excited when I found out about SPARK. Genetic testing was recommended for my family, but I found the process daunting and it inevitably fell to the back burner. I was so surprised at how easy the sign up process was, and was so relieved to find out that we only had to collect saliva to participate in the study - no making appointments for blood work - just a quick saliva sample! I feel happy that my family was able to be a part of this amazing effort and feel comforted in knowing we will continue to benefit from this study as I will continually be updated on any research findings that can be helpful to my family."

Anyone of any age with a professional diagnosis of ASD who is interested in learning more about SPARK or in participating can visit www.SPARKforAutism. org/UCLA, or call us at (310) 206-7478, or email at: jbecerra@mednet.ucla.edu.

The Multidisciplinary Advocacy Needs of the Disabled: A Legal Perspective

By Ariana Cernius



Ariana Cernius (3L, UCLA Law School; older sister of a 22-year-old brother with autism)

David's* innocence and vulnerability punctuate his need for understanding and support. He was diagnosed with mental retardation in third grade, and started receiving special education and Supplemental Security Income (SSI). But the Social Security Administration (SSA) terminated David's benefits at age 21 and Mark, the step-grandfather who raised David since birth, brought him to Bet Tzedek Legal Service's Government Benefits Unit for help appealing the termination.

Accurately characterizing David's disability was essential to his appeal. David's school and medical records documented his mental retardation, inability to complete simple tasks like dishwashing because of his childlike wonder at soap bubbles, his 1stgrade reading level at age 17, and his lack of adaptive skills like self-care. However, I discovered David had never been given an IQ test, a statutory requirement to qualify for SSI with his diagnosis. Further, David's school had inexplicably switched his disability classification from mental retardation in grades 3-10 to learningdisabled in 11th-grade, implying he'd somehow improved his abilities, which wasn't the case.

I reached out to Dr. Shafali Spurling Jeste and Dr. Amanda Gulsrud at UCLA CART for referrals to L.A. area doctors who might perform an adult IQ evaluation at no cost to this low-income client. They promptly connected me with the CAN Clinic, which performs multidisciplinary assessments for children and adults and provides scholarships to indigent families. The CAN Clinic was able to assess David on short notice, and their evaluation placed David's IQ unequivocally in the mental retardation range, a finding that was pivotal to the court's decision to fully reinstate David's SSI benefits. David's case illustrates a common but little-known challenge of the developmentally disabled: navigating the government benefits system to obtain and retain benefits available to them by virtue of their disability. The SSA conducts "Continuing Disability Reviews (CDRs)" to determine whether SSI recipients remain disabled and eligible for benefits, and even slight changes in medical or school records can lead to benefit reductions or terminations. Because the disabled and their caregivers are often challenged in properly explaining the nature of changed circumstances, comprehending and complying with complicated written notices requiring time-sensitive responses, and

navigating the appeals process, they fall out of the system, and find themselves in the same place as David.

The CAN Clinic's collaboration in David's SSI appeal demonstrate the interdisciplinary approach necessary to serve the needs of people with disabilities. Understanding the nature of their disability is as essential to representing them as fluency in the law. The fact that David had gone all those vears with no IQ score to corroborate his mental retardation diagnosis would have been very damaging to his appeal, which makes the CAN Clinic's assistance even more significant. Not only did the CAN Clinic help secure a win in David's immediate case, it also supplied him with a strong piece of evidence to use in future CDRs he'll encounter as a disabled adult on benefits, and we and his family couldn't be more grateful.

No two SSI cases are the same, and legal claims are fought and won with evidence. Families with disabled SSI recipients can protect themselves and prepare for CDR actions by 1) Immediately seeking attorney assistance for SSA notices you don't understand; and 2) Keeping meticulous files of SSA notices received and their mailed envelopes, and the SSI recipient's lifelong medical and school records.

*Names changed throughout, to protect client privacy.

CART Awards Two Pilot Grants

UCLA CART's goal for the Pilot Research program is to attract investigators to study autism and to fund innovative projects so as to broaden the scope of autism research at UCLA. Major funding for the CART pilot grants includes NIH Center grants to CART under the STAART (2003-2008) and ACE (2008-2012; renewed to 2017) programs, as well as UCLA Clinical and Translational Institute (2012-2017). CART has successfully attracted some very innovative and excellent research proposals and has funded 28 pilot projects to date, including human studies as well as innovative neurobiological studies using molecular and animal models. Of note, most of these CART pilot grant investigators already have published their findings and/or secured additional major funding for their work. CART plans to continue funding one or more new pilot grants every year, depending upon funding resources.

This year's recipients are Weizhe Hong, Ph.D. for his project titled: "Investigating The Role of Amygdala Circuitry in ASD-Related Behavior" and Michael Gandal, M.D., Ph.D. (PI), Edythe London, Ph.D. (co-PI), and Jim McCracken, M.D. (co-Investigator) for their project titled: "Targeting Microglial Activation for Treatment of Autism Spectrum Disorder (ASD): A Proof-of-Concept, Targetengagement Study."

Here is more about the this year's Pilot Grant projects:

"Investigating The Role of Amygdala Circuitry in ASD-Related Behavior" Weizhe Hong, Ph.D.

Autism spectrum disorder (ASD) represents a heterogeneous group of neurodevelopmental conditions that share behavioral deficits in the domains of socialcommunication functioning as well as repetitive behaviors and restricted interests. Existing evidence indicates that disruption of neural circuit development and function likely make a critical contribution to the behavioral symptoms in ASD. However, our understanding of the neural circuit mechanisms underlying this disorder is still rudimentary, hindering the development of targeted treatments. The amygdala is involved in the regulation of fear, anxiety, and social behaviors and has been hypothesized to play an important role in ASD. Through functional manipulations using optogenetic and chemogenetic tools, we recently demonstrated that two distinct neuronal subpopulations in the medial amygdala function antagonistically to regulate the dichotomy between social versus repetitive self-grooming behaviors. In this study, we will examine whether and how the MeA regulates ASD-related social and repetitive behaviors. This study can significantly advance our understanding of the function of the amygdala in regulating social and repetitive behaviors, and provide important mechanistic insights on the neural circuit basis of ASD.

"Targeting Microglial Activation for Treatment of Autism Spectrum Disorder (ASD): A Proof-of-Concept, Targetengagement Study." Michael Gandal, M.D., Ph.D. (PI), Edythe London, Ph.D. (co-PI), and James McCracken, M.D. (co-Investigator)

Recent work has suggested that brain inflammation may contribute to the biological underpinnings of autism spectrum disorders (ASD). In particular, it has been shown that microglia, the resident immune cells of the brain, may be hyperactive in individuals with ASD. However, it remains unknown whether this inflammation directly relates to core features of ASD or represents a biomarker that can be used to guide treatment. This pilot study will use positron emission tomography (PET) imaging to directly measure brain inflammation and its relationship to cognitive and behavioral symptoms of ASD. Young adults with ASD and healthy control subjects will undergo comprehensive cognitive and behavioral assessment, followed by PET imaging. The ASD participants will be then be treated for 12 weeks with minocycline, an antibiotic thought to reduce brain inflammation. A follow-up PET scan and clinical evaluation will investigate whether changes occurred with minocycline treatment. This study will help to better understand the relationship between brain inflammation and symptoms of ASD. Additionally, these results may identify biological targets to guide new treatments for ASD.

PEERS[®] Update

Social skills training is a common method of treatment for individuals on the autism spectrum. However, research suggests that these programs don't tend to be very effective. Developed at UCLA, the Program for the Education and Enrichment of Relational Skills (PEERS®) is one of the only evidence-based social skills interventions for people with ASD in the world.

CART scientist and PEERS® program developer, Dr. Elizabeth Laugeson, founded the UCLA PEERS® Clinic in 2007 in response to a direct need from families seeking empirically supported social skills treatment. With its unique focus on helping youth learn to make and keep friends, the UCLA PEERS® Clinic, housed within the UCLA Semel Institute for Neuroscience and Human Behavior, provides treatment to over 150 families each year through parentassisted, group-based instruction spanning preschool to adulthood.

With PEERS® used in over 25 countries and translated into over a dozen languages, the UCLA PEERS® team is dedicated to the dissemination of evidence-based social skills training through the certified trainings at UCLA and across the globe. Crosscultural validation of this intervention is equally important, with multiple randomized controlled trials underway in places like Korea, Hong Kong, China, Japan, Israel, and Holland, just to name a few.

Since certified training is not an option for all mental health professionals and educators,



The UCLA PEERS® Team

three treatment manuals for adolescents with ASD have been published, highlighting the methods used in the PEERS® intervention. For families who are unable to attend a PEERS® program in their school or community, The Science of Making Friends (Laugeson 2013) was written for parents of teens and young adults with social challenges interested in knowing more about the methods used in PEERS®.

In an exciting new development, a fourth treatment manual will be published in November 2016 highlighting the PEERS® for Young Adults program. This evidencebased social skills intervention not only teaches important skills related to making and keeping friends, but also strategies for how to handle peer conflict and rejection, as well as general rules for dating etiquette. With two published randomized controlled trials establishing strong empirical support for this program, PEERS® for Young Adults (Laugeson 2016) will be the first and only available evidence-based social skills training program for adults with ASD, once again highlighting the cutting-edge research being conducted at UCLA CART.

For more information, please contact:

UCLA PEERS® Clinic (310) 26-PEERS peersclinic@ucla.edu www.semel.ucla.edu/peers/ Facebook, Twitter, and Instagram: UCLAPEERS

Research at CART

Are you interested in participating in a research study?

Research studies advance our knowledge of autism spectrum disorder (ASD), leading to earlier diagnosis and better treatment. Research at UCLA CART focuses on a variety of topics surrounding ASD, including early identification of brain and behavioral signs underlying autism and effective treatments and intervention practices for people with ASD.

Participation in research studies is free. When you participate, you will be assisting our researchers develop a better understanding and determine better treatments for ASD. To learn more about our research projects, including how to enroll, please visit the CART website: www.autism.ucla.edu, contact the study coordinator directly, or call our general information line at (310) 825-9041.



Studies currently at CART:

AGE RANGE	STUDY NAME	CONTACT
All Ages	SPARK: Simons Foundation Powering Autism Research and Knowledge	(310) 206-7478
Infants under 6 weeks	Identifying Early Signs of Autism in High-Risk Infants	(310) 825-3478
12 - 21 months	Joint Engagement in Infants at Risk for ASD: Integrating Treatment with Biomarkers	(310) 206-1268
12 - 36 months	Early intervention for infants with Tuberous Sclerosis Complex	(310) 825-8738
30-54 months	Early Communication Intervention for Children with Down Syndrome Study	(310) 206-1268
3 - 21 years	Autism Genetics and Human Diversity Study	(310) 794-4090
4 - 11 years	Autism Biomarkers for Clinical Trials	(310) 825-0180
5 - 8 years	Adaptive Intervention for minimally verbal children with ASD in the Community	(310) 825-0445
5 -11 years	Augmenting Language Interventions for ASD: A Translational Approach	(310) 825-0180
5 - 11 years	EEG biomarkers of language and literacy abilities in minimally verbal children with ASD	(310) 825-8219
5 - 11 years	Treatment with Aripiprazole and Behavior Intervention for Children with Autism who have Low Language Ability	(310) 825-6170
7 - 17 years	Brain Imaging in Children with Autism or Typical Developing Children	(310) 206-4482
8 - 13 years	Treatment Study for Children with Autism and Anxiety	(310) 882-0537
8 - 16 years	Treatment with Risperidone for Repetitive Behaviors in Children with Autism	(310) 825-6170
8 - 17 years	Brain Imaging Study for Verbally Fluent Children with ASD	(310) 825-5326
8 - 17 years	Sensory Over-responsivity in Children with Anxiety, ASD or in Typically Developing Children	(310) 825-5326
15 - 20 years	Brain Wave Study of Autism Spectrum Disorders	(310) 206-9012



"Research gives us a better understanding of how to improve the lives of children with autism."

Marta Wirga Staff Research Associate, Kasari Lab, CART

Treatment Services at CART

Read more about treatment programs at CART on the CART website: www.autism.ucla.edu.

Currently UCLA offers the following treatment programs and services:

All Ages

Child and Adult Neurodevelopmental Clinic (CAN Clinic)

The UCLA Child and Adults Neurodevelopmental Clinic (CAN Clinic) is our outpatient clinic located at UCLA's Westwood Medical Campus. The CAN Clinic provides multidisciplinary assessments and evidence-based treatment for individuals with suspected disorders of social, cognitive, language, and motor development, including ASD.

The services provided at the CAN Clinic include:

- Evaluation
- Treatments
- · Long-term medical and psychiatric care
- · Referrals for genetic testing

Contact: 310-794-4008

Developmental Neurogenetics Clinic (DNG Clinic)

The Developmental Neurogenetics Clinic is a multidisciplinary clinic that evaluates and treats children with neurodevelopmental disorders (including autism, global developmental delay or intellectual disability) and a known genetic syndrome or variant. Directed by Dr. Shafali Spurling Jeste, a pediatric neurologist, the clinic provides comprehensive evaluations and care for children with complex needs, with the team of specialists including neurology, genetics, psychiatry and psychology. Contact: 310-794-4008

Young Children

Early Childhood Partial Hospitalization Program

The ECPHP is a short-term integrated day treatment program for young children who have been diagnosed with, or may have, autism, developmental disabilities, and behavior disorders. ECPHP is a five-day a week, six-hour a day program. All aspects of the program are fully integrated and coordinated to create an individualized, comprehensive, consistent, interdisciplinary, and therapeutic environment. Contact: (310) 206-2695

Elementary School & Early Adolescents

Parenting and Children's Friendship Program

The program offers parent-assisted social skills group programs for children in elementary school (beginning at end of 1st grade) who are having problems making and/or keeping friends. We also offer parent training/behavior modification programs for parents with children (starting at age 2) and early adolescents (age 12½-15½).

Contact: (310) 825.0142

Ages 6 - 12

ABC Partial Program

The Achievement, Behavior, Cognition (ABC) Child Programs in the Neuropsychiatric Hospital at UCLA provides psychiatric services through the Partial Hospitalization Program and the Intensive Outpatient Program. ABC Child Programs are time–limited, integrated programs dedicated to assisting children ages 6-12 and their families to promote positive emotional and behavioral health. Contact: (310) 825-0415

Ages 8- 12

Secret Agent Society (SAS)

The Secret Agent Society (SAS) is evidence based social skills intervention program for children ages 8-12. This 10-week program has been validated as an effective program to teach social skills to children who have a variety of social challenges in a school setting. Contact: (310) 206-2210

Preschool, Teens & Young Adults

Program for the Education and Enrichment of Relationship Skills (PEERS)

PEERS is a manualized, social skills training intervention for preschool aged children, adolescents and young adults. It has strong evidence-base for use with preschool aged children, teens, and young adults with autism spectrum disorders, but is also appropriate for teens and young adults with ADHD, anxiety, depression, and other socioemotional problems. Contact: (310) 267-3377

Giving to CART

CART depends greatly on philanthropy to sustain its cutting-edge research, treatment, and education programs now and into the future. The establishment of CART in 2003 marked an exciting advancement, particularly for the new and upcoming generation of autism researchers. Since then, CART has concentrated its efforts on developing strong collaborations across disciplines and making major scientific breakthroughs to clarify the mechanisms underlying autism and related disorders. CART has also led the field in designing evidence-based treatment interventions. Your support will help CART continue as well as expand its research, treatment, and community outreach activities to improve the lives of countless children and young adults and their families affected by autism spectrum disorders.

Please make your donation by check payable to The UCLA Foundation and specify CART Fund #618040 in the memo line. Mail the check to Alan Han, Director of Development for Neuroscience: UCLA Health Sciences Development, 10945 Le Conte Avenue, Suite 3132, Los Angeles, California 90095-1784.



You may also donate to CART online at https://giving.ucla.edu/CART. If you have more questions about making a gift to CART, please contact: Alan Han, Director of Development for Neuroscience at (310) 825-1546.

CART in the Community



CART team at the Autism Speaks Walk in Pasadena

CART regularly attends events in the community. CART attended the Autism Speaks Walk Now for Autism at the Pasadena Rose Bowl on April 2, 2016. We joined hundreds of community organizations and thousands of walkers in this annual autism awareness event. CART also attended the Special Needs Network's Back to School Resource Fair in August 2016.

Come out and visit us! We will be at the following events:

- Autism Conference at the Mexican Consulate on October 27, 2016
- Family Focus Resource Center Special Needs Fair at Cal State University, Northridge on October 29, 2016

Upcoming Events at CART

UCLA CART Distinguished Lecture Series

UCLA CART offers the distinguished scientific lecture series on the first Friday of each month from October through June. This lecture series brings scientific experts from around the country and internationally to present and discuss multidisciplinary topics of autism spectrum disorders (ASD). The lectures are free and open to the public.

Location: UCLA Gonda (Goldschmied) Neuroscience & Genetics Research Center

1st Floor Conference Room 695 Charles E. Young Drive South Los Angeles, CA 90095

October 7, 2016

Speaker: Nathan Call, PhD, BCBA-D Emory University, Atlanta, GA **Title:** Behavioral Interventions for Severe Challenging Behavior in Children with ASD

December 2, 2016

Speaker: Omar Khwaja, PhD

Roche Pharma Research and Early Development, Basil, Switzerland **Title:** *Development of Pharma Cotherapeutics for Neurodevelopmental Disorders*

January 13, 2017

Speaker: Jacqueline Crawley, PhD MIND Institute, UC Davis Medical Center, Sacramento, CA **Title:** *Mouse Models of Autism for the Discovery of Effective Therapeutics*

February 3, 2017

Speaker: Joseph Piven, MD University of North Carolina at Chapel Hill, Chapel Hill, NC Title: TBD

Time: *Coffee Served: 8:30AM *Lecture: 9:00AM-10:00AM *Questions & Discussion: 10:00AM-10:30AM

March 3, 2017

Speaker: Lisa Croen, PhD Kaiser Permanente Division of Resaerch, Oakland, CA **Title:** *Medical and Psychiatric Comorbidities in ASD across the lifespan*

March 3, 2017

Speaker: Evdokia Anagnostou, MD, PhD

Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Canada **Title:** *TBD*

More information: (310) 825-9041

May 5, 2017

Speaker: Matthew State, PhD UCSF School of Medicine, San Francisco, CA **Title:** *Recent Progress in Autism Genetics*

June 2, 2017

Speaker: Charles Nelson, PhD Harvard University, Boston, MA Title: TBD



Guest speaker, Thomas Bourgeron, PhD visiting from the Institut Pasteur during the 2015-2016 Distinguished Lecture Series

SAVE THE DATE

FALL AUTISM FESTIVAL

SPARK for Autism Sign-Up Event

Come out, join the fun, and enroll and complete the SparkforAutism study!*

Both biological parents and individual/child with ASD are encouraged to attend the event. **RSVP required.**

*Families must be able to consent and complete registration in English.

RSVP by November 10th

Provide name of parents and child/individual attending, and contact info. RSVP at (323) 221 -6696 or jbecerra@mednet.ucla.edu

FREE PARKING!



