



NEW JERSEY
AUTISM CENTER
OF EXCELLENCE

AUTISM
SUMMIT
2017

MEETING
OF THE MINDS
AND HONORING
DIVERSITY
IN RESEARCH:
CONTINUING THE
CONVERSATION

PART II



October 6, 2017

Dear Summit Participants,

Welcome to our NJ ACE **Autism Summit 2017 Part II, Meeting of the Minds and Honoring Diversity in Research: Continuing the Conversation!** Today, you will hear about the proceedings of the April 19 – 20, 2017 Summit Part I. During this Summit, the NJ ACE research community and invited stakeholders met with each other and national/international experts in autism research to explore five domains: 1. Etiology of ASD, 2. Cross and Multi-disciplinary Inquiries into ASD, 3. Life Span Interventions and Support for ASD, 4. Diagnostics and Classification Systems for ASD and 5. Neurodiversity and Social Views of ASD.

I will provide a brief overview of the highlights from the Summit in April, in each of the five domains. Then, one of our own New Jersey Autism Center of Excellence researchers will offer a brief talk on their research, representing the work being done in New Jersey related to each domain. After each presentation, there will be time for open discussion among the presenter, other NJ ACE researchers, and all members of the assembly.

In hosting this Part II Summit, our goal is to engage the larger community in discourse about the presentations and discussions and explore the “knotty questions” that can guide future research into ASD. Participants consist of about 200 guests, representing five identified stakeholder groups: families and individuals with ASD, educators, researchers, providers and policymakers.

The national data are quite clear. The prevalence of autism in all forms has increased dramatically in the United States. Nearly 2% of all children have autism, with higher prevalence in boys. With that being said, our Summit looks to bring together the best and the brightest researchers in New Jersey with the varied stakeholders present here today. Our goal is to build on our state’s remarkable record of research, funded largely by the Department of Health, Governor’s Council for Medical Research and Treatment of Autism.

The New Jersey Autism Center of Excellence Coordinating Center at Montclair State University serves as the “Voice of Autism Research” in New Jersey. In that role, we support, coordinate and promote collaboration among 31 NJ Autism Center of Excellence clinical research and medical home projects. These projects are funded by the Governor’s Council. As conveners of this Summit, our goal is to engage in interdisciplinary discourse towards an integrated understanding of the nature of ASD through biological, psychological and social perspectives.

Thank you for joining us and please speak with me or any of our NJ ACE team about questions and ideas.

My very best,

Gerard Costa, PhD, Director, CAECMH
Professor, ECELE, CEHS, MSU
PI, NJ ACE CC-MSU



AUTISM SUMMIT 2017 PART II

MEETING OF THE MINDS AND HONORING DIVERSITY IN RESEARCH: CONTINUING THE CONVERSATION

FRIDAY, OCTOBER 6, 2017

- 9:00 AM WELCOME AND OVERVIEW
Tamara Lucas, PhD, Dean, College of Education and Human Services, Montclair State University
Gerry Costa, PhD, Principal Investigator, NJ ACE CC-MSU
Welcome message from **Anthony Welch, MBA**, Director of Policy and Strategic Planning,
NJ Department of Health
- 9:30 AM ETIOLOGY (CAUSES) OF ASD
Introduction
Linda Brzustowicz, MD, Rutgers University
Facilitated Discussion
- 10:20 AM CROSS AND MULTIDISCIPLINARY INQUIRIES INTO ASD
Introduction
Jill Harris, PhD, Children's Specialized Hospital
Facilitated Discussion
- 11:10 AM BREAK
- 11:30 AM LIFE SPAN INTERVENTIONS AND SUPPORTS FOR ASD
Introduction
Cecilia Feeley, PhD, Rutgers University
Facilitated Discussion
- 12:20 PM LUNCH
- 1:20 PM DIAGNOSTICS AND CLASSIFICATION SYSTEMS FOR ASD
Introduction
Walter Zahorodny, PhD, Rutgers University
Facilitated Discussion
- 2:10 PM NEURODIVERSITY AND SOCIAL VIEWS OF ASD
Introduction
Anna Dulencin, PhD, NJ ACE CC-MSU
Facilitated Discussion
- 3:00 PM FORMAL WRAP-UP
- 3:15 PM MEET THE NJ ACE RESEARCHERS
- 3:30 PM CLOSE



BACKGROUND: SETTING THE STAGE

The state of New Jersey supports talented researchers, working to understand the nature of autism spectrum disorder (ASD). The complexity of ASD calls for a comprehensive and integrated research agenda that seeks to better understand and support persons on the spectrum and their families.

WHAT IS AUTISM?

Autism represents a difference in the structure, function and processing of the human brain that often leads to particular patterns of behavior. ASD is typically a group of developmental disorders, described by significant social, communication and behavioral challenges. The range of individual differences and the likely “causes” are varied. This leads the field to use the phrase, “spectrum disorder”. ASD impacts each person differently. Problems in the social, communicative and behavioral/emotional areas can be mild to severe.

HOW COMMON IS ASD?

ASD occurs in all groups of people, regardless of their race, ethnicity or income level. It is present in children and adults of all ages. The frequency of ASD has increased dramatically, partly due to increased awareness and diagnosis. Based on data published in 2016, the prevalence of autism in the U.S. was 1 in 68 children (1.5% of all 8 year olds)¹. This represented a 30% increase since the 2012 report. Of the 11 states examined, New Jersey was the highest with 1 in 41 children diagnosed with autism by age 8. ASD diagnosis is 4.5 times more likely in boys than girls. There are lower rates of ASD evaluation and identification for black and hispanic children.

WHAT CAUSES ASD?

As a “spectrum” of disorders, ASD does not have one cause. It is likely related to genetics, neurological, and environmental factors. Researchers have identified a number of associated genes. Studies of people with ASD have also found differences in several regions of the brain. Twin and family studies strongly suggest that some people may be more susceptible to autism. Identical twin studies show that if one twin is affected, there is up to a 90% chance the other twin will be affected. In families with one child with ASD, the risk of having a second child with the disorder is approximately 5%, or one in 20. ASD is not caused by poor parental care.

HOW IS ASD TREATED?

There are a number of programs to treat ASD. The most frequently used are structured, skill-oriented training programs based on principles of applied behavioral analysis (ABA). These programs focus on behavioral/symptom change. Other programs are rooted in developmental perspectives. They emphasize “engagement” and understanding a child’s unique “bio-psycho-social” profile, including neurosensory systems. There are a growing number of medications that are helpful in addressing certain emotional and behavioral symptoms. Most critical is determining a child’s “individual differences” and creating a program to support development and growth. Educational programs that promote inclusion are critically important. All programs must be supported by thorough research. The nature of the program must involve parental, familial, educational and community support. It is also important to include programs across many disciplines. In 2013, the NIMH called for an approach to diagnosis and treatment of ASD that does not rely solely on “symptoms” but recognizes that in “brain disorders, symptoms are generally a late manifestation of a years-long process.” (<http://www.nimh.nih.gov/about/director/2013/ten-best-of-2013.shtml>).

HOW CAN I LEARN MORE OR PARTICIPATE IN A RESEARCH STUDY?

If you are interested in participating in any of the research studies, please visit the NJ ACE CC-MSU website at: <http://NJACE-cc.montclair.edu> You can click on the PARTICIPATE button in the upper right hand corner of the page or click on the “Research Sites” tab and pull down the menu to choose the study you’d like to investigate.

¹Centers for Disease Control and Prevention (2016).



TWO STATEWIDE AUTISM SUMMITS

The New Jersey Autism Center of Excellence Coordinating Center at MSU sponsored *Autism Summit 2017 Part I, Meeting Of The Minds And Honoring Diversity In Research* on April 19 and 20, 2017 at the Princeton Marriott at Forrestal in Princeton, NJ. The goal was to engage in an interdisciplinary discourse towards an integrated understanding of the nature of ASD through biological, psychological and social perspectives.

Five national and international autism research experts led plenary sessions and participated in round table discussions with over 80 New Jersey researchers, their teams and other invited experts. Investigators from within New Jersey were joined by experts from over 25 organizations and universities including Albert Einstein College of Medicine, George Washington University, Harvard University, the Autism Science Foundation, Children's Hospital of Philadelphia, the University of California, San Diego and King's College London.

Participants engaged in discourse about the many perspectives in ASD research, identified new directions and "knotty questions" that can guide future research. The content focused on five focus areas:

- Etiology of ASD
- Cross and Multidisciplinary Inquiries into ASD
- Lifespan Interventions and Supports for ASD
- Diagnostics and Classification Systems for ASD
- Neurodiversity and Social Views of ASD

Today, we join together for *Autism Summit 2017 Part II, Meeting Of The Minds And Honoring Diversity In Research: Continuing The Conversation*. This event is planned to share the outcomes from *Part I* with researchers, educators, multidisciplinary providers, policy-makers, self-advocates and families. The broader community of stakeholders will have the opportunity to share their perspectives on future directions for autism research in our state.

The proposed goal for *Summit 2017 Part II* is to disseminate findings from *Part I* to a larger audience and to gain perspectives from a larger ASD community about what you perceive are research questions that need to be answered.

OBJECTIVE 1: Conduct a forum to engage ASD researchers, families, educators, providers and policy makers within the state of NJ.

OBJECTIVE 2: To share the findings from Part I and engage Part II participants in discussions through guided sessions that will identify what participants perceive are ASD research questions that need to be answered.

To achieve these objectives, the following questions will be posted to guide the discussion and encourage audience/stakeholder participation:

- What questions do you have about what you just heard? What is unclear?
- What reactions do you have? What does this mean to you?
- What do you still want to know? What still feels like it's missing for you?

SPEAKERS



Etiology of ASD

Linda Brzustowicz, MD is a renowned geneticist and researcher and currently, a distinguished Professor and Chair of the Department of Genetics at Rutgers University. Dr. Brzustowicz's NJ Autism Center of Excellence funded research is aimed at understanding the underlying molecular neurobiology of autism and specific language impairment. The two and five-year studies aim to identify genetic mutations or susceptibilities that are common to study participants with autism and their family members with specific language impairment.



Cross and Multidisciplinary Inquiries into ASD

Jill Harris, PhD is the Director of Program Development for the Autism Program at Children's Specialized Hospital (CSH). Dr. Harris is currently involved in several NJ ACE projects, including studies to expand screening and to explore the experience of families of newly diagnosed Latino children. Dr. Harris was also a Co-Investigator on an Autism Medical Home at CSH, aimed at providing coordinated, high quality care across disciplines to individuals with ASD. The goal of the current Autism Medical Home is to support teens as they transition into adulthood.



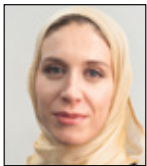
Lifespan Interventions and Supports for ASD

Cecilia Feeley, PhD has been with the Center for Advanced Infrastructure and Transportation at Rutgers since 2010 as a transportation autism project manager. Her NJ ACE studies address transportation and mobility issues for individuals on the autism spectrum. As a result of Dr. Feeley's research and advocacy, the New Jersey Senate and House of Representatives have established a task force to make recommendations concerning mobility and support services needs of New Jersey adults with ASD so they can be active, contributing members of society throughout their lives.



Diagnostics and Classification Systems for ASD

Walter Zahorodny, PhD has been the recipient of six NJ ACE grant awards to date. Dr. Zahorodny is a psychologist, providing comprehensive developmental, psychological and neuropsychological assessments of children and adolescents, as well as individual psychotherapy. He is the Director of the New Jersey Autism Study, a public health ASD surveillance system conducted in concert with the CDC since 2002. Dr. Zahorodny brings his expertise and experience on early identification, public health monitoring and on the diagnosis of ASD.



Neurodiversity and Social Views of ASD

Anna Dulencin, PhD is the Biomedical Research Consultant for the NJ ACE CC-MSU. Dr. Dulencin not only has expertise in environmental, epigenetic and genetic causes, diagnoses, therapies and pharmacological treatments of ASD but is adept at translating these concepts to various audiences. The intersection of research, biomedical ethics and family centeredness has lead Dr. Dulencin to pursuing her goal of establishing a culture of partnership between scientists, agencies and parents, to transform education and inform policy.

CURRENT CLINICAL RESEARCH GRANTEES



Linda Brzustowicz, MD

Rutgers University

Elucidating Genetic Components of Autism and Related Disorders

2012



Xin Di, PhD

New Jersey
Institute of
Technology

Multimodal Neuroimaging Study of Sex Differences in Preschool Children with Autism Spectrum Disorder

2016



Emanuel DiCicco-Bloom, MD

Rutgers University


Metabolomic Analysis of Neural Precursor Cells Derived from Autism iPSCs and Their Response to Environmental Stressors

2014








Neurobiology of Idiopathic Autism: Cellular and Molecular Phenotypes of Common Copy Number Variant (CNV), 16p11.2

2015

CURRENT CLINICAL RESEARCH GRANTEES

	Cecilia Feeley, PhD	Rutgers University	<i>Analysis, Validation and Dissemination of A Paratransit Travel and Mobility Assessment</i>	2014
			<i>Autism and the Built Environment: Evaluating the Physiological and Biomedical Effects of Pedestrian Infrastructure Design and Road Crossing Behavior of Adults on the Autism Spectrum.</i>	2016
	Yvette Janvier, MD	Children's Specialized Hospital	<i>Development of a New Autism Screening Tool for Traditionally Underserved Families</i>	2013
	William G. Johnson, MD	Rutgers University	<i>Sulforaphane in Autism. A Treatment Trial to Confirm Phenotypic Improvement with Sulforaphane Treatment in a NJ Population of Individuals with Autism.</i>	2015
	Harumi Jyonouchi, MD	Saint Peter's University Hospital	<i>Autism Spectrum Disorder-Inflammatory Subtype: Biomarker Analysis</i>	2016
	MaryLouise Kerwin, PhD	Rowan University	<i>Using SMART Treatment Design to Evaluate Applied Behavior Analysis Interventions on Communication in Preschool Children with Autism</i>	2015
	Elizabeth Kim, PhD	Children's Hospital of Philadelphia	<i>Establishing Statistical Measures of Motor Development in Children With and Without Autism Spectrum Disorders</i>	2016
	Amy E. Learmonth, PhD	William Paterson University	<i>Can Video Speak the Language of Autism?</i>	2014
	Steven Levison, PhD	Rutgers University	<i>Immune Regulation of Neural Stem/Progenitors</i>	2017
	Michael Lewis, PhD	Rutgers University	<i>Development of Early Markers of Autism Spectrum Disorder (ASD)</i>	2015
	James Millonig, PhD	Rutgers University	<i>The Generation and Characterization of Autism iPSC's</i>	2012
	Zhiping Pang, PhD	Rutgers University	<i>Regulation of MeCP2 by Micro RNA's and Implications in the Pathophysiology of Autism</i>	2016

CURRENT CLINICAL RESEARCH GRANTEES

	Vijayalakshmi Santhakumar, PhD	Rutgers University	<i>Developmental dysregulation of inhibitory neuron migration as an experimental model to analyze mechanisms of Pediatric autism-epilepsy syndromes</i>	2017
	Deborah Spitalnik, PhD	Rutgers University	<i>Exploring the Experiences of Diverse Families of Children Newly Diagnosed with ASD in New Jersey</i>	2015
	T. Peter Stein, PhD	Rowan University	<i>Metabolic Perturbations with autism induced by plasticizers</i>	2015
	Elizabeth B Torres, PhD	Rutgers University	<i>New Objective Autism Inventory to Quantify Peripheral Plasticity During Standardized ADOS-2 Social Exchange</i>	2014
			<i>Bridging Behavior and Genetics Through Sensory-motor Electrophysiology</i>	2015
	Tracy Tran, PhD	Rutgers University	<i>The role for Semaphorin functions in cortico-basal ganglia development, repetitive behavior, and autism spectrum disorder</i>	2017
	Walter Zahorodny, PhD	Rutgers University	<i>Characterizing the Trajectory of Autism Spectrum Disorder (ASD) in Adolescents</i>	2017
	Barbie Zimmerman Bier, MD	Rutgers University	<i>Piloting Very Early and Early Biomarkers for Risk of ASD and Related Disorders in Premature and Low Birth Weight Infants</i>	2015
			<i>Piloting Very Early Electrophysiologic Markers for Risk of ASD and Related Disorders In Preterm and Low Birth Weight Infants</i>	2015
			<i>Cerebral Dysfunction: A Biomarker for Early Signs of Autism and Related Disorders</i>	2016
			<i>A Pilot/Feasibility Study of the Use of High Dose Propranolol to Treat Severe and Chronic Challenging Behaviors in Adolescents and Adults with Autism Spectrum Disorders.</i>	2017

CURRENT AUTISM HEALTH NEEDS MEDICAL HOME GRANTEES

	Denise Aloisio, MD	Hackensack Meridian Health	<i>Autism Care Coordination Program (ACCYP)</i>	2017
	Randy Huron, MD	Hackensack Meridian Health	<i>Enhancement of Service and Technology Coordination to Establish a Medical Home for Autism at the Institute for Child Development, Hackensack University Medical Center</i>	2015
			<i>Comprehensive Service Provision and Care Coordination for Adolescents and Young Adults with Autism Spectrum Disorders.</i>	2016
	Matthew McDonald, MD	Children's Specialized Hospital	<i>Children's Specialized Hospital Pediatric Primary Care ASD Medical Home</i>	2015
			<i>The Autism Medical Home Transition Collaborative: Partnering Pediatric and Adult Care</i>	2016



NJ GOVERNOR'S COUNCIL FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM: A BRIEF HISTORY

THE GOVERNOR'S COUNCIL FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM (COUNCIL)

was created by State appropriation in 1999 and has been issuing research, clinical and educational enhancement grants since 2000. The Mission of the Council is to advance and disseminate the understanding, treatment, and management of ASD by means of a coordinated program of biomedical research, clinical innovation and professional training in New Jersey.

As detailed in P.L. 2007, c.168, the Council is to establish an Autism Center of Excellence in the State. First Lady Mary Pat Christie and Health Commissioner Mary E. O'Dowd, M.P.H., joined the Council on June 28, 2012 to announce the creation of the New Jersey Autism Center of Excellence (NJ ACE) Coordinating Center at the Center for Autism and Early Childhood Mental Health, Montclair State University, marking a new, coordinated approach to autism research in New Jersey. A total of thirty six clinical research grants have been funded between 2012 and 2017. In addition, three Autism Health Needs Medical Homes were funded in 2015, two in 2016 and one in 2017. The NJ ACE initiative represents the Council and State's commitment to advancing the current knowledge pool through clinical and health services research, leading to improvements in interventions that address the physical and behavioral health needs of children, adolescents and adults with ASD. As per P.L. 2007, c.174, monies from \$1 surcharges on fines and penalties from traffic violations are deposited by the State Treasurer into the Autism Medical Research and Treatment Fund to sponsor the Council to fund autism research and treatment in the State of New Jersey.

Please refer to the Council's website at www.nj.gov/health/autism for additional information about the Council. In addition to supporting research and treatment, the Department of Health works to connect families affected by autism to programs and services. For information about these services, please visit <http://nj.gov/health/fhs/eis/index.shtml>.

STATE OF NEW JERSEY



Governor Chris Christie

Lt. Governor Kim Guadagno

Cathleen Bennett

Commissioner, New Jersey Department of Health

Anthony Welch

Director of Policy and Strategic Planning, New Jersey Department of Health

GOVERNOR'S COUNCIL FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM

Caroline Eggerding, MD

Council Chair and Healthcare Organization Representative; Division Head, Department of Pediatric Neurology and Development, Cooper Children's Regional Hospital

Michael Aquino, MD, FACC

Senate President Appointee; Partner, Shore Gastroenterology Associates, Cofounder, VP of Operations, Pathology Solutions

Cheryl F. Dreyfus, PhD

Academic Institution Representative; Professor and Chair, Department of Neuroscience and Cell Biology, Rutgers University, Robert Wood Johnson Medical School

Susan P. Evans, EdD

Commissioner of Health Appointee; Education Program Specialist for Early Intervention Program, NJ Department of Health

Wilma Judith Friedman, PhD

Academic Institution Representative; Professor, Department of Biological Sciences, Rutgers University

B. Madeleine Goldfarb, MA

Autism Organization Representative; Founder/Director of the Noah's Ark Children's Association

Ketan Kansagra, MD, FAAP

Academic Institution Representative; Division of Neonatal Medicine, Children's Hospital of New Jersey at Newark Beth Israel Medical Center

Thomas V. Macchiaverna, MA

Public Member representative; Special Education Teacher

Michele Sorvino

Speaker of the General Assembly Appointee; Executive Director, Golden Door International Film Festival of Jersey City; Sonographer, Morristown Memorial Hospital

Dana E. Spett, MSW

Autism Organization Representative; Founder/Executive Director, Pony Power Therapies

Samuel Sheng-Hung Wang, PhD

Academic Institution Representative; Professor, Department of Molecular Biology and Princeton Neuroscience Institute, Princeton University

Gary Weitzen, BA

Autism Organization Representative; Executive Director of POAC (Parents of Autistic Children)

COUNCIL STAFF

Martin T. Zanna, MD, MPH

Acting Executive Director, Governor's Council for Medical Research and Treatment of Autism

Linda N. Bocclair, MEd, MBA

Executive Assistant, Governor's Council for Medical Research and Treatment of Autism

Mary Ray

Contract Administrator II, Governor's Council for Medical Research and Treatment of Autism



NEW JERSEY AUTISM CENTER OF EXCELLENCE COORDINATING CENTER AT MONTCLAIR STATE UNIVERSITY

In June 2012, The Governor's Council for Medical Research and Treatment of Autism of the New Jersey Department of Health, awarded a five year grant and, subsequently a one year extension to Montclair State University to serve as New Jersey Autism Center of Excellence (NJ ACE) Coordinating Center. The role of the NJ ACE Coordinating Center at Montclair State University (NJ ACE CC-MSU) is to support and advance the mission of the funded NJ ACE clinical research sites. The NJ ACE CC-MSU provides common management and support functions to unify the NJ ACE sites by serving as the voice of the NJ ACE and promoting the sharing of lessons learned and best practices in the conduct of clinical research.

Gerard Costa, PhD, Principal Investigator

Kaitlin Mulcahy, MA, LPC, Fiscal Agent

Karen Hood Kasim, MPH, Program Coordinator

Eileen McKeating, PhD, Research Associate

Charles Matteis, MBA, Organizational Consultant

Anna Dulencin, PhD., Biomedical Research Consultant

Lisa Shulman, MD, Clinical/Behavioral Research Consultant

Katherine Herbert, PhD, I.T. Manager

Eden N. Kyse, PhD, Director, Center for Research & Evaluation on Education and Human Services (CREEHS)

Erin M. Bungler, MPH, Senior Research Associate, CREEHS

Lina Acosta, MPH, Research Associate, CREEHS



Check out our page at [facebook.com/MSUCoordinatingCenterNJACE](https://www.facebook.com/MSUCoordinatingCenterNJACE)
and visit our website at: <http://NJACE-cc.montclair.edu>



NEW JERSEY AUTISM CENTER OF EXCELLENCE COORDINATING CENTER AT
MONTCLAIR STATE
UNIVERSITY

1 Normal Avenue, Montclair, NJ 07043 · 973-655-6685 · <http://NJ ACE-cc.montclair.edu>

This NJ ACE Coordinating Center is funded by the New Jersey Governor's Council for
Medical Research and Treatment of Autism, New Jersey Department of Health.