



**New Jersey Department of Health  
Governor's Council for Medical Research and Treatment of Autism  
Meeting Minutes – June 30, 2014 (ratified)**

**Council Members Present**

Caroline Eggerding, M.D., Division Head, Department of Pediatric Neurology and Development Cooper Children's Regional Hospital and Chairperson of the Governor's Council for Medical Research and Treatment of Autism, Healthcare Organization Representative

Susan P. Evans, Ed.D. Education Program Specialist for Early Intervention Program, NJ Department of Health, Commissioner of Health Appointee

B. Madeleine Goldfarb, MA, Founder/Director of the Noah's Ark Children's Association, Autism Organization Representative

Gary Weitzen, BA, Executive Director, Parents of Autistic Children (POAC) Autism Services, Organization Representative

**Absent**

Elizabeth K. Bell, BS, volunteer and independent contractor with Autism Speaks, Autism Organization Representative

Ketan Kansagra, M.D., FAAP, Neonatologist, Children's Hospital of New Jersey at Newark Beth Israel Medical Center, Academic Institution Representative

**NJ Department of Health (DOH) Attendees**

Martin T. Zanna M.D., MPH  
Acting Executive Director  
Governor's Council for Medical Research and Treatment of Autism

Linda N. Boclair, M.Ed., MBA  
Executive Assistant  
Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 2  
Governor's Council for Medical Research and Treatment of Autism  
Commission on Brain Injury Research  
Commission on Spinal Cord Research

Daphne Robinson, Ph.D., Consultant  
Scientific Planning Consulting

**Public Attendees**

Audrey Mars, M.D., Hunterdon Medical Center, Regional Autism Center

Gerard Costa, Ph.D., Center for Autism and Early Childhood Mental Health at Montclair State University and Principal Investigator, NJ ACE Coordinating Center

Karen Hood-Kasim MPH, Project Coordinator, NJ ACE Coordinating Center

Kathleen Freeman Ph.D., RNC-NIC

**I. Welcome** - Council Chairperson, Dr. Caroline Eggerding called the meeting to order at 6:10 PM and welcomed everyone.

**II. Public Meetings Act Announcement**- Dr. Eggerding read the Public Meetings Act, followed by roll call.

**III. Approval of the May 19, 2014 and June 2, 2014 Council Meeting Minutes**

Dr. Eggerding called for a motion to approve the May 19, 2014 minutes. MOTION by Dr. Evans to approve the minutes was seconded by Ms. Goldfarb. No discussion.

**MOTION to approve the May 19, 2014 meeting minutes was passed with three in favor and one abstention.**

Dr. Eggerding called for a motion to approve the June 2, 2014 minutes. MOTION by Dr. Evans to approve the minutes was seconded by Ms. Goldfarb. No discussion.

**MOTION to approve the June 2, 2014 meeting minutes was passed with three in favor and one abstention.**

**IV. Continuation Funding for FY12 and FY13 Grantees**

Dr. Gerald Costa, Principal Investigator for the NJ ACE Coordinating Center grant, presented summaries of each of the FY12 and FY13 grantees' progress through mid-June 2014. The Council discussed the reports and voted for continuation funding.

**CAUT12APS006 - Rutgers University**  
**“Elucidating Genetic Components of Autism and Related Disorders”**

Dr. Eggerding called for a motion for approval of continuation funding for CAUT12APS006.

MOTION by Ms. Goldfarb to approve grant # CAUT13APS006, “Elucidating Genetic Components of Autism and Related Disorders”, for year three continuation funding was seconded by Mr. Weitzen.

**Discussion:** Dr. Costa explained that this research project is using clinical data and DNA samples from New Jersey families to search for specific genetic changes that increase risk for autism spectrum disorders. They have identified four locations where these genes are contributing to risk.

The research team is making steady progress based on their narrative report. They have some delays with uploading their data to the National Database for Autism Research (NDAR) due to transitional problems from a prior format to a new format. They continue to work on identifying strategies to enhance recruitment with the help of the Coordinating Center at Montclair State University (CC-MSU). It was recommended to the CC-MSU that Autism New Jersey be contacted for a recruitment service available through their website at a modest cost.

Dr. Costa was pleased to announce that the grantee published their first linkage paper continuing their collaboration with two Council grantees on stem cell projects. The Principal Investigator (PI) of this project has been very active in the grantees' meetings and discussed at a recent meeting a possible collaboration with a PI of a pilot project. This grant has been meeting its stated objectives.

**Conclusions:** Mr. Weitzen offered the free services of Parents of Autistic Children (POAC) for recruiting their members (11,000 families). Mr. Weitzen suggested attendance at a POAC event may be more effective than emails. CC-MSU staff will follow-up with Mr. Weitzen. Ms. Goldfarb suggested asking speech and language professionals about their clients and autism. A member suggested that out of state subjects could be referred to a New Jersey site for participation in a research study. The CC-MSU will send a link to the published paper to the Council staff for posting on the Council's website.

**MOTION to approve grant # CAUT13APS006, “Elucidating Genetic Components of Autism and Related Disorders”, year three continuation funding was passed with all in favor.**

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**CAUT14APL018 - Rutgers University**

## **“Autism Spectrum Disorder-Inflammatory Subtype: Molecular Characterization”**

Dr. Eggerding called for a motion to approve continuation funding for CAUT14APL018.

MOTION by Dr. Evans to approve grant # CAUT13APL018, “Autism Spectrum Disorder-Inflammatory Subtype: Molecular Characterization” for year two continuation funding was seconded by Ms. Goldfarb.

**Discussion:** Dr. Costa explained that this study focuses on identifying biomarkers for the inflammatory subtype (IS) of ASD (ASD-IS) children (less than 6 years) in comparison with normal ASD/normal controls. ASD-IS children have a non-IgE mediated food allergy (NFA) whose symptoms are not controlled by a restricted diet. Typically ASD children who have GI issues respond well to a restricted diet, but ASD-IS children do not.

This project and the PI are in the process of moving from Rutgers University to Saint Peter’s University Hospital as a result of reorganization at Rutgers and elimination of the PIs specialty clinic. The New Jersey Department of Health (NJDOH) received a letter of commitment from Saint Peter’s University. Once approved the PI will need time to set up the laboratory and submit for IRB approval.

Progress toward meeting the grant objectives has been quite substantial in all categories, as indicated in their reports.

**Conclusion: MOTION to approve grant # CAUT13APS018, “Autism Spectrum Disorder-Inflammatory Subtype: Molecular Characterization” for year two continuation funding was passed with all in favor.**

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## **CAUT13APL015 - Rowan University**

**“Efficacy of Relationship Development Intervention and Parent Implemented Applied Behavior Analysis/ Verbal Behavior on Joint Attention and Communication of Preschool Children with Autism”.**

Dr. Eggerding called for a motion to approve continuation funding for CAUT13APL015.

MOTION by Mr. Weitzen to approve grant # CAUT13APL015, “Efficacy of Relationship Development Intervention and Parent Implemented Applied Behavior Analysis/ Verbal Behavior on Joint Attention and Communication of Preschool Children with Autism” for year two continuation funding was seconded by Ms. Goldfarb.

**Discussion:** Dr. Costa stated that one hypothesis of this research project is that children of parents receiving RDI (Relationship Development Intervention) or ABA/VB (Applied behavior Analysis/Verbal Behavior) will demonstrate more joint attention (JA) and more language during parent-child interactions compared to children or parents receiving TAU (Treatment As Usual) only after 3 months of treatment as well as at 3 month follow-up. TAU is assessed through

parental weekly reports of the type and length of services provided during TAU. The second hypothesis is that children in the ABA/ VB will demonstrate better expressive language skills than children in the RDI group, and children in the RDI group will demonstrate better JA than children in the ABA/VB group at the end of 3-month treatment.

The CC-MSU staff has been consulting regularly with the PI. The project has made steady progress throughout the year. This project relates to a research project in Canada with the Canadian PI sharing information with this PI. The grantee is meeting their study objectives with nothing unfavorable to report.

**Conclusions:** Dr. Costa will follow-up on Mr. Weitzen's question regarding the rationale for the selection of the protocol/instrument for measuring speech.

**MOTION to approve grant # CAUT13APS015, "Efficacy of Relationship Development Intervention and Parent Implemented Applied Behavior Analysis/ Verbal Behavior on Joint Attention and Communication of Preschool Children with Autism" for year two continuation funding was passed with all in favor.**

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**CAUT13APL003 – Rutgers University**

**"An Assessment of the Transportation and Mobility Needs and Barriers of Adults on the Autism Spectrum Disorder in NJ".**

Dr. Eggerding called for a motion to approve continuation funding for CAUT13APL003.

MOTION by Dr. Evans to approve grant # CAUT13APL003, "An Assessment of the Transportation and Mobility Needs and Barriers of Adults on the Autism Spectrum Disorder in NJ" for year two continuation funding was seconded by Mr. Weitzen.

**Discussion:** Dr. Costa stated that research project focuses on the transportation barriers and mobility needs of adults with ASD. The PI and the team are progressing steadily in meeting the stated objectives. There are no challenges at this point.

**Conclusion: MOTION to approve grant # CAUT13APL003, "An Assessment of the Transportation and Mobility Needs and Barriers of Adults on the Autism Spectrum Disorder in NJ" for year two continuation funding was passed with all in favor.**

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**CAUT13APL 014 - Rutgers**

**"Perinatal Risk Factors and Their Influence on ASD Prevalence: Study of Two Birth Cohorts in NJ"**

Dr. Eggerding called for a motion to approve continuation funding for CAUT13APL014.

MOTION by Dr. Evans to approve grant # CAUT13APL014, “Perinatal Risk Factors and Their Influence on ASD Prevalence: Study of Two Birth Cohorts in NJ” for year two continuation funding was seconded by Ms. Goldfarb.

**Discussion:** Dr. Costa stated that the study objective is to compare children in two birth cohorts (born in 1994 and 1998) with or without ASD, from four counties in New Jersey. This study will profile the demographic and perinatal characteristics of ASD children (N=1,000-2,000 cases) in the region and compare them to unaffected children (N=~30,000).

This project had delays in obtaining Institutional Review Board (IRB) approval from the NJDOH. They received IRB approval from Rutgers University and recently from the NJDOH. This project is meeting its goals and was able to proceed with their objectives while waiting IRB approval from the NJDOH. The delay with IRB was due to the backlog of requests resulting from Hurricane Sandy.

**Conclusion: MOTION to approve grant # CAUT13APL014, “Perinatal Risk Factors and Their Influence on ASD Prevalence: Study of Two Birth Cohorts in NJ” for year two continuation funding was passed with all in favor.**

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**CAUT13APL016 - Rowan University, School of Osteopathic Medicine  
“Glucuronidation and Autism”**

Dr. Eggerding called for a motion to approve continuation funding for CAUT13APL016.

MOTION by Mr. Weitzen to approve grant # CAUT13APL016, “Glucuronidation and Autism” for year two continuation funding was seconded by Dr. Evans.

**Discussion:** Dr. Costa stated that this research project tests the hypothesis that exposure to environmental pollutants is associated with ASD in genetically susceptible children who have impaired ability to detoxify these compounds (BPA and DEHP). The project compares the ability of 100 autistic and 100 control children and their mothers to detoxify BPA and DEHP (common environmental pollutants).

Progress has been steady in recruitment of subjects and collection and analysis of samples. They are progressing nicely with no challenges identified. They have submitted a paper to *Autism Research* for consideration.

**Conclusions:** Links to published papers will be posted on the Council’s website.

**MOTION to approve grant # CAUT13APL016, “Glucuronidation and Autism”**

**for year two continuation funding was passed with all in favor.**

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**CAUT13APL010 - Saint Peter's University Hospital  
"Piloting Very Early and Early Markers for Risk of Autism Spectrum Disorder in  
Premature and Low Birth Weight Infants"**

Dr. Eggerding called for a motion to approve continuation funding for CAUT13APL010.

MOTION by Dr. Evans to approve grant # CAUT13APL010, "Piloting Very Early and Early Markers for Risk of Autism Spectrum Disorder in Premature and Low Birth Weight Infants" for year two continuation funding was seconded by Mr. Weitzen.

**Discussion:** Dr. Costa stated that the research project is examining the feasibility of identifying early biomarkers for ASD in pre-term and low birth weight babies. The research is progressing as planned although recruitment of subjects has been a problem in attempting to recruit within 2-3 days of the premature birth. They now approach families 8-9 days after the birth and this appears to be a more reasonable timeframe in their ability to discuss their research with the families.

The CC-MSU will continue to work with the grantee and anticipates that with the change in the timeframe they will be able to meet their target number of subjects.

**Conclusion: MOTION to approve grant # CAUT13APL010, "Piloting Very Early and Early Markers for Risk of Autism Spectrum Disorder in Premature and Low Birth Weight Infants" for year two continuation funding was passed with all in favor.**

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**CAUT13APS025 - Children's Specialized Hospital  
"Development of a New Autism Screening Tool for Traditionally Underserved Families"**

Dr. Eggerding called for a motion for continuation funding for CAUT13APS025.

MOTION by Dr. Evans to approve grant # CAUT13APS025, "Piloting Very Early and Early Markers for Risk of Autism Spectrum Disorder in Premature and Low Birth Weight Infants" for year two continuation funding was seconded by Ms. Goldfarb.

**Discussion:** Dr. Costa stated that this project is developing and validating a screening tool to identify children who may be at risk for developing autism, particularly in traditionally underserved populations. Much of the first year of the project involved developing the screening tool relying on the consultation of two specialists with expertise in the development of screening tools. The grantee has increased the sample size as a result of the addition of items to the

screening tool, resulting in the need to interview additional parents. They anticipate completion of the validation by the end of year two, as was their initial plan. All is going as planned. One Council member questioned the need for another screening tool given that there are other tools currently available. Another member commented that the current tools may not be sensitive enough for the at risk population. However the overall sentiment was positive about continuing development of this new tool.

**Conclusion: MOTION to approve grant # CAUT13APS025, “Piloting Very Early and Early Markers for Risk of Autism Spectrum Disorder in Premature and Low Birth Weight Infants” for year two continuation funding was passed with three in favor and one member voting no.**

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**CAUT12ACC012- Montclair State University  
“The Coordinating Center at Montclair State University (CC-MSU)”**

Dr. Eggerding called for a motion for continuation funding for CAUT12ACC012.

MOTION by Ms. Goldfarb to approve grant # CAUT12ACC012, “The Coordinating Center at Montclair State University (CC-MSU)” for year three continuation funding was seconded by Dr. Evans.

**Discussion:** Dr. Zanna provided an overview of the accomplishments of the CC-MSU and noted their willingness and ability to rapidly expand services resulting from the increase and types of grants funded during the past two years. The NJDOH has increased the CC-MSU’s budget commensurate with the scope of work. Council staff has had a series of meeting with the CC-MSU as they prepare to assume greater responsibilities. The meetings will continue over the next several months and then quarterly starting in 2015. A list of CC-MSU’s staff was distributed to the Council, noting that a new member, Dr.Eileen McKeating will be added to the list. She will begin her position as Research Associate on July 1, 2014. A member commented that she was pleased to see that the CC-MSU activities (meetings, website etc.) are providing the researchers opportunities for collaborating. Another member commented that the feedback from the CC-MSU on the progress of the grantees is invaluable in knowing if the goals and objectives of the projects are truly on track, in identifying the barriers and how they are being addressed. Dr. Zanna recommended year three continuation funding for the CC-MSU.

**Conclusion: MOTION to approve grant # CAUT12ACC012 “The Coordinating Center at Montclair State University (CC-MSU)” for year three continuation funding was passed with all in favor.**

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**V. FY15 and FY16 Funding initiatives & timelines**

**Discussion:** Options available for funding in FY15 and FY16 were discussed noting that new funding initiatives could be considered for FY16 given the time required (four to five months) to develop applications in SAGE (System for Administering Grants Electronically). It is important to consider the legislation and ensure that funding initiatives for FY16 and beyond align with the requirements of the statute.

**Recommendations:** The FY15 RFA would call for two-year pilot projects and be posted in early November 2014 with applications due in mid-February 2015. Grants would be awarded in June 2015. The projects will address a subset of the Interagency Autism Coordinating Committee (IACC) objectives, giving priority to those proposals with the IACC objective selected from either IACC Question 4 (Which treatments and Interventions will help?) or Question 5 (Where Can I Turn for Services?). While all proposals addressing objectives in the subset of IACC objectives will be considered, those addressing Question 4 or Question 5 may be recommended for funding over those with better scores, providing the Question 4 and/or Question 5 objectives are within the fundable range as determined by the reviewers.

The Council will review the full set of IACC objectives for Questions 4 and 5 and may recommend additional objectives in the RFA. As in the previous review cycle, the behavioral/clinical applications will be reviewed separately from the biomedical applications.

**Note:** Ms. Bell and Dr. Kansagra were unable to attend this meeting and will be consulted regarding the decisions of the Council. If either has questions, concerns or recommendations a call will be scheduled to discuss the FY15 funding initiatives.

Regarding FY 16 funding initiatives, a strategic planning retreat will be held in November or December 2014 to recommend the types of grants for priority funding to be awarded in June 2016. The RFA will be posted in July 2015 and due in December 2015. The Council will ensure that funding initiatives for FY16 and beyond align with the requirements of the statute. The Council will consult with a professional facilitator to plan and facilitate the retreat and provide a written report.

## **VI. Report of the Acting Executive Director, Martin T. Zanna, M.D. MPH**

### **Administration**

The Council's staff has been working with the NJDOH press office to develop a press release announcing the FY14 grant awards.

### **Grantees**

As mentioned in Dr. Costa's report, Dr. Zahorodny's pilot project was approved by the NJDOH IRB and was previously approved by the Rutgers IRB. Also reported was Dr. Jyonouchi's transitioning to another institution to continue with her research.

Letters notifying the seven PIs of the intent to fund their proposals were sent prior to the June 9, 2014 deadline. Once the grantees receive their Notices of Grant Awards (NOGAs) from the NJDOH the grantees will initiate their research activities as specified in the NOGAs.

Dr. Manny DiCicco-Bloom requested an opportunity to present his research at the September 8, 2014 Council meeting. He would be reporting on his 2010 basic science grant that has been extended to 2015 through a no cost extension. Note: Council was receptive to Dr. DiCicco-Bloom's presenting at the September 8, 2014 meeting.

#### Council staff and members

Liz Bell will be granting an interview on autism for *Real Women's* magazine to be published in August 2014. Ms. Bell coordinated the interview with the NJDOH Press Office.

Linda Bocclair and I attended a lecture by Joseph Buxbaum, Ph.D, at Children's Specialized Hospital in New Brunswick on June 26, 2014. Dr. Buxbaum is the Director of the Seaver Autism Center for Research and Treatment and Professor of Psychiatry, Neuroscience, and Genetics and Genomic Sciences, Mount Sinai School of Medicine, New York. The lecture was entitled: "Gene Discovery in Autism and Impact on Improved Patient Care" and was well received by all. Several grantees were present, including current grantees and those recently funded by the Council.

#### **VII. Adjournment**

Dr. Eggerding asked for a motion to adjourn.

**MOTION to adjourn by Dr. Evans and seconded by Mr. Weitzen was approved with all in favor.** The meeting was adjourned at 8:45PM.