



**NJ Department of Health
Governor's Council for Medical Research and Treatment of Autism
Council Meeting Minutes (ratified)
June 5, 2017**

Council Members Present

Michael Aquino, MD, F.A.C.G., Senate President Appointee; Partner, Shore Gastroenterology Associates; Co-founder, VP of Operations, Pathology Solutions

***Caroline Eggerding, MD**, Healthcare Organization Representative; Division Head, Department of Pediatric Neurology and Development, Cooper Children's Regional Hospital

B. Madeleine Goldfarb, MA, Autism Organization Representative; Founder/Director of the Noah's Ark Institute (present via teleconference)

Ketan Kansagra, MD, FAAP, Academic Institution Representative; Neonatologist, 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

Samuel Sheng-Hung Wang, Ph.D., Academic Institution Representative; Professor, Department of Molecular Biology and Princeton Neuroscience Institute, Princeton University (present via teleconference)

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

*Denotes Council Chairperson

Absent

Dana E. Spett, MSW, Autism Organization Representative; Founder/Executive Director, Pony Power Therapies

Cheryl F. Dreyfus, Ph.D., Academic Institution Representative; Professor and Chair, Department of Neuroscience and Cell Biology, Rutgers University, Robert Wood Johnson Medical School

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

Wilma Judith Friedman, Ph.D., Academic Institution Representative; Professor, Department of Biological Sciences, Rutgers University

NJ Department of Health (DOH) Attendees

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

Linda N. Bocclair, 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 and Commission on Spinal Cord Research

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

Public Attendees

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

Eileen McKeating, Ph.D., Research Associate, NJ ACE Coordinating Center

Anna Dulencin, Ph.D., Biomedical Research Consultant, NJ ACE Coordinating Center

Charles Matteis, Ph.D., Strategic Planning Consultant, NJ ACE Coordinating Center

Mark Mintz, M.D., President and CEO, The Center for Neurological and Neurodevelopmental Health (CNNH)

Pnina Mintz, Ph.D., Grant Administrator, The Center for Neurological and Neurodevelopmental Health (CNNH)

Cecelia Feeley, Ph.D., Rutgers University

Note: Motions are numbered.

I. Welcome - Council Chairperson, Dr. Caroline Eggerding called the meeting to order at 6:05 PM and welcomed everyone.

II. Public Meetings Act Announcement - Dr. Eggerding read the Public Meetings Act.

III. Presentation by Mark Mintz, MD-Final Research Report - CAUT14APL014

Dr. Mintz presented his research project entitled *Mitochondrial and Channelopathy Disorders and Dysfunction in Autism Spectrum Disorders: Genotypic and Phenotypic Correlations*. The goal of the study was to determine and elucidate genotype-phenotype correlations of mitochondrial disease/dysfunction and/or channelopathies in a well-defined cohort of moderate to severe individuals with ASD.

Each of the 26 subjects was clinically assessed for neurological, neuropsychological, functional analytical behavioral and medical co morbidities (epilepsy, gastrointestinal, inflammatory/immunologic/infections, elemental deficiencies, hormonal and autonomic nervous system, sleep and behavioral dysfunction). The enzymological and genetic results of the study suggested the utility of further diagnostic testing, and/or have implicated changes in clinical management. The researchers discussed study results with participating families. For those subjects not under the care of the Principal Investigator (Dr. Mark Mintz), the patients' physicians were informed of the results with suggestions for additional clinical testing or treatment interventions.

This study generated an array of clinical treatment implications. The researchers plan ongoing analyses of the extensive dataset and are talking with other labs for additional analyses of their biobanked DNA and other clinical information. They will be searching for additional sources of funding to continue their research.

The presentation was followed by a Q&A session. Dr. Eggerding, on behalf of the Council, thanked Dr. Mintz for his most informative presentation.

IV. NJ ACE Coordinating Center Update – Gerard Costa, Ph.D.

Dr. Costa (1) presented a summary of the Coordinating Center's activities and services noting the Coordinating Center staff is currently overseeing a total of 27 grants and anticipates adding the 2016 Hackensack University Medical Homes grant in the near future; (2) reviewed the summary report of the 2017 Summit (Part I) and described plans for Part II of the Summit scheduled for October 6, 2017; (3) stated his staff is codifying the Coordinating Center's systems and processes with a plan for transitioning of the Center if Montclair is not awarded the SFY18 grant for funding a NJ Autism Center of Excellence (NJACE) and; (4) continues his site visits to each of the Principal Investigators to elicit feedback on services provided by the Coordinating Center.

V. Acting Executive Director Report- Martin T. Zanna, MD, MPH

- Dr. Zanna thanked Dr. Mintz for his presentation and Dr. Costa for his report.
- **State Ethics Commission** - We are pleased to report the State Ethics Commission (SEC) approved our request to “apply the multi-component rule used by the NIH as a method for dealing with applications from Rutgers University where there are independent components that do not interact with each other”. The decision of the SEC will have a significant impact on the work of the Council, giving Drs. Dreyfus and Friedman and possibly other members in the future the right to participate in the review and approval of research grant applications from Rutgers and review progress once the grants are funded.
- **SFY’18 RFA** - The RFA was reviewed by five Council members with recommended changes incorporated into the document. The RFA is currently being reviewed by the DOH. We anticipate it will be posted on June 15, 2017 with letters of intent due August 16, 2017 and grant applications due September 14, 2017. Council will be asked to vote at the December 4, 2017 meeting. The anticipated start date of the grant is April 2, 2018. Dr. Costa submitted a request for a no cost extension for the Coordinating Center through June 30, 2018 to continue work with the grantees and provide a three-month transition period in the event Montclair is not awarded the new grant.

VI. Managing the Autism Medical Research and Treatment Fund

The initial purpose of this discussion was for the Council to strategize on ways to better manage the funds to ensure they are available for the Council’s initiatives. Dr. Aquino noted the source and amount of funds and suggested ways to maximize the funds.

The discussion then turned to the types of projects funded by the Council with Dr. Aquino suggesting the Council consider funding more projects that the community would see as beneficial in meeting the needs of people with autism (less emphasis on basic research) and Dr. Kansagra speaking in support of the current balance of projects developed over the years including clinical research, basic science research and autism medical homes (health services research).

Dr. Eggerding asked Dr. Robinson (consultant to the Council) if she could comment on ways to connect researchers to other funding sources to help expand their studies. Dr. Robinson commented pilot projects and training are ways to do this. Through pilot projects researchers can demonstrate ability to continue a project with additional funding and training programs can bring researchers and clinicians together to address problems recognized by the community as important. The remaining discussion focused on Council’s role in providing public education, specifically informing parents about their options when seeking services, with the need to decide

how to best do this if all agree with the idea. Dr. Eggerding suggested continuing the discussion at Council's September meeting when all members will be present and the SFY18 RFA will be available given it addresses some of the training issues raised by members. Members will consider the initiatives to be funded in the SFY19 RFA. If public education is to be included details will be discussed, including scope and budget.

VII. Approval of the April 3, 2017 Council Meeting Minutes-Dr. Eggerding called for a motion to approve the minutes. MOTION by Dr. Aquino to approve the minutes was seconded by Mr. Macchiaverna.

1. MOTION to approve the minutes was passed with five members in favor and two abstentions.

VIII. Continuation funding for grants

The Council considered requests for continuation funding for one 2013 grant and seven 2016 grants.

Grant # CAUT16APL019

Dr. Eggerding called for a motion to approve Grant # CAUT16APL019, *Multimodal neuroimaging study of sex differences in preschool children with autism spectrum disorder*, for year two continuation funding.

MOTION by Dr. Aquino to approve CAUT16APL019 for year two continuation funding was seconded by Mr. Macchiaverna.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

2. MOTION to approve continuation funding for year two for Grant # CAUT16APL019 was approved with all members in favor.

Grant # CAUT16APL010

Dr. Eggerding called for a motion to approve Grant # CAUT16APL010, *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*, for year two continuation funding.

MOTION by Mr. Weitzen to approve CAUT16APL010 for year two continuation funding was seconded by Dr. Aquino.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

3. MOTION to approve continuation funding for year two for Grant # CAUT16APL010 was approved with all members in favor.

Grant # CAUT13APS025

Dr. Eggerding called for a motion to approve Grant # CAUT13APS025, *Development of a new autism screening tool for traditionally underserved families*, for year five continuation funding.

MOTION by Dr. Kansagra to approve CAUT13APS025 for year five continuation funding was seconded by Dr. Aquino.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

4. MOTION to approve continuation funding for year five for Grant # CAUT13APS025 was approved with all members in favor.

Grant # CAUT16APL007

Dr. Eggerding called for a motion to approve Grant # CAUT16APL007 *Autism Spectrum Disorder-Inflammatory Subtype: Biomarker Analysis* for year two continuation funding.

MOTION by Mr. Macchiaverna to approve CAUT16APL007 for year two continuation funding was seconded by Dr. Kansagra.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

5. MOTION to approve continuation funding for year two for Grant # CAUT16APL007 was approved with all members in favor.

Grant # CAUT16APL021

Dr. Eggerding called for a motion to approve Grant # CAUT16APL021, *Establishing statistical measures of motor development in children with and without autism spectrum disorders*, for year two continuation funding.

MOTION by Dr. Aquino to approve CAUT16APL021 for year two continuation funding was seconded by Mr. Macchiaverna.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

6. MOTION to approve continuation funding for year two for Grant # CAUT16APL021 was approved with all members in favor.

Grant # CAUT16MED003

Dr. Eggerding called for a motion to approve Grant # CAUT16MED003, *The Autism Medical Home Transition Collaborative: Partnering Pediatric and Adult Care*, for year two continuation funding.

MOTION by Dr. Kansagra to approve CAUT16MED003 for year two continuation funding was seconded by Mr. Macchiaverna.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

7. MOTION to approve continuation funding for year two for Grant # CAUT16MED003 was approved with all members in favor.

Grant # CAUT16APL020

Dr. Eggerding called for a motion to approve Grant # CAUT16APL020, *Regulation of MeCP2 by microRNAs and implications in the pathophysiology of autism*, for year two continuation funding.

MOTION by Mr. Macchiaverna to approve CAUT16APL020 for year two continuation funding was seconded by Dr. Aquino.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

8. MOTION to approve continuation funding for Grant # CAUT16APL020 was approved with all members in favor.

Grant # CAUT16APL025

Dr. Eggerding called for a motion to approve Grant # CAUT16APL025, *Is Cerebellar Dysfunction A Biomarker for Early Signs of Autism and Related Disorders?* for year two continuation funding.

MOTION by Dr. Aquino to approve CAUT16APL025 for year two continuation funding was seconded by Mr. Weitzen.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

9. MOTION to approve continuation funding for year two Grant # CAUT16APL025 was approved with all members in favor.

IX. Report of Revenues and Expenditures

The report was included in members' Council packets, for information.

X. Public Comments

No public comments.

XI. Adjournment

Dr. Eggerding called for a motion to adjourn.

10. MOTION to adjourn by Mr. Macchiaverna and seconded by Ms. Goldfarb was approved with all members in favor.

The meeting was adjourned at 8:30 PM.