



**New Jersey Department of Health
Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes –December 1, 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

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

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

Gary Weitzen, BA, Executive Director, Parents of Autistic Children (POAC) Autism Services,
Organization 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. 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
Commission on Spinal Cord Research

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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

I. Welcome - Council Chairperson, Dr. Caroline Eggerding called the meeting to order at 6:00 PM and welcomed everyone.

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

III. Approval of the September 8, 2014 Council Meeting Minutes

Dr. Eggerding called for a motion to approve the September 8, 2014 meeting minutes. MOTION by Ms. Goldfarb to approve the minutes was seconded by Mr. Weitzen. No discussion.

MOTION to approve the September 8, 2014 meeting minutes was passed with three members in favor and two members abstaining.

IV. Approval of 2015 Council meeting calendar

Dr. Eggerding called for a motion to accept changes to the 2015 Council meeting calendar. MOTION by Ms. Goldfarb to approve the calendar was seconded by Ms. Bell.

Discussion: The original calendar had been approved at the September 8, 2014 meeting. This motion is to approve the addition of a May 18, 2015 meeting (voting for funding SFY15 grants) and changing the September meeting date from September 14, 2015 (Rosh Hashanah) to September 21, 2015.

MOTION to approve changes to 2015 Council meeting calendar was passed with five members in favor.

V. Continuation funding for Program Site grant

Dr. Eggerding called for a motion to approve continuation funding for grant number CAUT13APS010. MOTION by Mr. Weitzen to approve continuation funding was seconded by Dr. Evans.

Discussion: Dr. Gerard Costa presented an overview of Dr. James Millonig's grant (*The Generation and Characterization of Autism iPSC's*) indicating that he is on schedule in

accomplishing the three major aims of his research. Dr. Costa recommended approval of continuation funding for the third year of the grant and Dr. Zanna concurred.

MOTION to approve continuation funding for year three of grant number CAUT13APS010 was passed with five members in favor.

VI. CC-MSU Update – Dr. Gerard Costa

Dr. Costa provided the following update on the activities of the Coordinating Center at Montclair State University (CC-MSU): (1) CC-MSU staff strategic planning, (2) defining the balance between monitoring and mentoring grantees, (3) strategies for assisting grantees with subject recruitment including a dynamic resource page on the CC-MSU website and presentations at state conferences such as POAC and Autism NJ, (4) plans for the quarterly meeting of grantees in early January and (5) a description of the series of DSM 5 workshops offered in collaboration with the DOH Autism Registry staff. Dr. Costa provided the following information (1) Dr. Jyonouchi transferred from Rutgers University to Saint Peter's University Hospital where she will continue her research project funded by the Council in June 2013 and (2) the two Saint Peters University Hospital grants are on hold given the Principal Investigator is no longer with the institution.

Discussion: Council members requested access to the CC-MSU website to view the subject recruitment page. Council staff will send the link and individual passwords to Council. A lengthy discussion regarding the grants at Saint Peters University Hospital followed with concern expressed for the interruption in the research and the impact on the research subjects. The Council staff is working with Saint Peters to determine if they will continue or relinquish the grants.

Conclusion: Dr. Caroline Eggerding requested resolution of the status of grants at Saint Peters University Hospital by December 31, 2014.

VII. Report of the Acting Executive Director, Martin T. Zanna M.D., MPH

Dr. Zanna thanked Dr. Costa for his report.

Report on RFA. The available funding for the SFY15 RFA increased from a total of \$4M to \$6M with the addition of the Autism Health Needs Medical Home Pilot project. Letters of Intent are due by January 14, 2015 and applications on February 25, 2015. Council will vote to fund grants at their May 18, 2015 meeting.

The SFY 15 RFA includes both clinical and translational research pilot projects as well as the newly added option to apply for an Autism Health Needs Medical Home service delivery model. New Jersey, as reflected in this RFA, is cognizant that in addition to the importance of clinical and translational research there is also a corresponding need to offer a funding initiative to support development of service delivery models. This is in line with the National Institutes of Health/ National Institute of Mental Health (NIH/NIMH) recent funding announcement in September 2014 of their intent to also study models for ASD service delivery stemming from the

2013 IACC's strategic Plan for Autism Spectrum Disorder Research. The link to this grant awards announcement and listing of projects is as follows:

<http://www.nimh.nih.gov/news/science-news/2014/new-grants-fund-cross-lifespan-services-research-for-autism-spectrum-disorder.shtml>

Website. The new RFA and the 2013 Annual Report have been posted on Council's website. Dr. Zanna thanked Dr. Eggerding for reviewing the Annual Report and providing the cover letter to the Governor. The April 9, 2014 Autism Conference Proceedings will be posted on the website by mid-December.

DOH accreditation. The DOH is seeking voluntary national accreditation* from the [Public Health Accreditation Board \(PHAB\)](#). The Council staff provided the requested documents to the DOH coordinator for consideration for inclusion in the DOH accreditation application. Examples of the documents provided are grant awards and a description of the Scientific Advisory Committee (SAC) and their role in working with the Council.

*Public health department accreditation is defined as the development of a set of standards, a process to measure health department performance against those standards, and reward or recognition for those health departments who meet the standards.

National Autism Awareness Month. Council members were asked to send event information to the Council staff. A list will be compiled and provided to members and sent to the CC-MSU for posting.

Rutgers University Strategic Plan. The Rutgers Biomedical and Health Sciences (RBHS) strategic plan released in mid-October 2014 mentions that the Governor's Council for Medical Research and Treatment of Autism has provided significant grant funds to Rutgers faculty members. This recognition in the context of the strategic plan is indicative of the importance of Council as a funding source in supporting New Jersey's researchers in one of the largest research qualified institutions of higher learning in New Jersey.

National Database for Autism Research (NDAR). Dr. Janvier's research project description is included on the NDAR site as part of the NDAR collection. Grantees submitting data to NDAR are encouraged to also submit descriptions of their projects.

Resource guide. The DOH approved the revised resource guide entitled *Autism: Navigating Through the Maze, A Family Guide to Navigating the New Jersey Service Systems for Individuals with Autism Spectrum Disorders and other Developmental Disabilities*. When the guide is released by the NJDHS, Division of Developmental Disabilities, Office on Autism it will be posted on the Autism Council's website.

VIII. Preliminary discussion of plans for FY16 funding meeting

Dr. Eggerding provided an overview of the funding cycle and explained the need to plan well in advance of RFA release dates if the Council wants to change current funding initiatives.

Questions to be considered are: (1) which legislative mandates has the Council addressed and where are the gaps? (2) what is needed to inform the Council in decision making?

A lengthy discussion ensued with four major themes: medical research, services/best practices, education/training and assessing/understanding the needs.

Conclusion: A follow-up meeting will be held in January 2015 to decide on funding priorities for SFY15.

IX. Report of Revenues and Expenditures

Ms. Ray presented the Revenue and Expenditures Report. There was no discussion.

X. Adjournment

Dr. Eggerding called for a motion to adjourn. MOTION by Ms.bell to adjourn was seconded by Ms. Goldfarb.

MOTION to adjourn was passed with all in favor. The meeting was adjourned at 9:00 PM.