

New Jersey Department of Health Governor's Council for Medical Research and Treatment of Autism **Meeting Minutes – March 28, 2016 (ratified)**

Council Members Present

Elizabeth K. Bell, BS, Public Member - Individual or Family Member with Autism Representative; Volunteer and Independent Contractor with Autism Speaks

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

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

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

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

Samuel Sheng-Hung Wang, Ph.D., 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)

*Denotes Council Chairperson

Absent

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

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

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

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. 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

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

Cecilia Feeley, Ph.D. Rutgers CAIT

Jill Harris, Ph.D., Children's Specialized Hospital

Richard Dreyfus, Short Hills, NJ

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

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

III. Approval of the December 7, 2015 Council Meeting Minutes

Dr. Eggerding called for a motion to approve the minutes. MOTION by Dr. Friedman to approve the minutes was seconded by Ms. Spett. No discussion.

MOTION to approve the minutes was passed with seven in favor and one abstention.

IV. Schedule a meeting to discuss continuation funding

The Council will meet on Thursday, May 26, 2016 to consider continuation funding for a total of 15 grants funded in 2012 (five year grants) and 2015 (two year grants). The May 26, 2016 meeting is an additional meeting for the Council given the originally scheduled June 6, 2016 meeting is reserved for planning for SFY'18 funding initiatives.

Members with the exception of Dr. Dreyfus, Mr. Weitzen and possibly Ms. Bell will attend the May 26, 2016 meeting. Ms. Spett will call into the meeting. All members will attend the June 6, 2016 planning meeting. Drs. Evans and Wang suggested locations for the June 6, 2016 meeting. Council staff will follow-up with Drs. Evans and Wang.

V. NJ ACE Coordinating Center Report-Dr. Costa

Dr. Costa reported on (1) collaborating with grantees to address subject recruitment; (2) sponsorship of a Parents of Autistic Children (POAC) training program on January 8, 2016; (3) 10 events his staff will attend through December 2016 to represent the NJACE; (4) meeting with the 2017 Summit Planning Committee to identify potential speakers, discuss the 'knotty questions' to be addressed at the Summit and work on the information required by the DOH for approval of the Summit (will be submitted to the DOH in May 2016); (5) the work of strategic planning consultant Charles Matteis in strengthening the role of the NJACE Coordinating Center; (6) grantee Dr. Cecelia Feeley's role in introducing bills to the Senate and Assembly for a task force to address the needs of adults with autism and (7) the addition of consultants Dr. Lisa Shulman and Dr. Anna Dulencin as well as two graduate assistants to the NJACE Coordinating Center staff.

VI. NJ ACE Grant Applications-discussion and voting

Twenty-two grant applications were submitted for consideration for funding by the Council. Dr. Eggerding asked the Council staff to comment on the process that lead up to tonight's meeting. Dr. Zanna explained that with the number of applications and the diversity of topics a significant amount of work was involved in processing the applications. He credited Dr. Daphne

Robinson for playing a major role in selecting reviewers thus ensuring their areas of expertise were well matched with the topical areas of each application.

As a result of the diversity of applications three review panels were needed with one meeting on February 9, 2016, the second on February 11, 2016 and the third on February 17, 2016. The last step leading up to the Council meeting was to convene the Scientific Advisory Committee (SAC). The SAC made specific recommendations on three applications.

Dr. Eggerding referred to the Conflict of Interest declaration and asked members to complete the forms and return them to Mary Ray. Members who declare conflict of interest will abstain from discussions and voting.

A member commented on the importance of recruiting applicants for Council's RFAs possibly through visiting research institutions. Another member commented on the need to increase awareness of the Council's work including the availability of funding, perhaps through press releases and other media. Council staff described efforts to advertise RFAs and welcomes ideas from Council members.

The next order of business was voting on the SFY'16 grant applications.

CAUT16APL010

Dr. Eggerding called for a motion.

Dr. Dreyfus moved and seconded by Mr. Weitzen to accept the recommendation to fund CAUT16APL010.

<u>Discussion:</u> A member questioned comments by the Scientific Advisory Committee (SAC). The applicant will be advised to strongly consider comments made by the SAC.

MOTION to approve the recommendation to fund CAUT16APL010 advising the applicant to strongly consider comments by the Scientific Advisory Committee (SAC) was passed with six in favor and two abstentions.

CAUT16APL012

Dr. Eggerding called for a motion.

Mr. Weitzen moved and seconded by Dr. Evans to accept the recommendation to not fund CAUT16APL012.

MOTION to approve the recommendation to not fund CAUT16APL012 was passed with six in favor and two abstentions.

CAUT16APL004

Dr. Eggerding called for a motion.

Dr. Evans moved and seconded by Ms. Bell to accept the recommendation to not fund CAUT16APL004.

MOTION to approve the recommendation to not fund CAUT16APL004 with six in favor and two abstentions.

CAUT16APL006

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Mr. Weitzen to accept the recommendation to not fund CAUT16APL006.

MOTION to approve the recommendation to not fund CAUT16APL006 with six in favor and two abstentions.

CAUT16APL011

Dr. Eggerding called for a motion.

Mr. Weitzen moved and seconded by Ms.Spett to accept the recommendation to not approve CAUT16APL011.

MOTION to approve the recommendation not to fund CAUT16APL011 was passed with six in favor and two abstentions.

CAUT16APL013

Dr. Eggerding called for a motion.

Mr. Weitzen moved and seconded by Ms. Bell to accept the recommendation to not fund CAUT16APL013.

MOTION to approve the recommendation to not fund CAUT16APL013 was passed with all in favor.

CAUT16APL026

Dr. Eggerding called for a motion.

Ms. Spett moved and seconded by Mr. Weitzen to accept the recommendation to not fund CAUT16APL026.

MOTION to approve the recommendation to not fund CAUT16APL026 was passed with all in favor.

CAUT16APL017

Dr. Eggerding called for a motion.

Mr. Weitzen moved and seconded by Ms. Spett to accept the recommendation to not fund CAUT16APL017.

MOTION to approve the recommendation to not fund CAUT16APL017 was passed with all in favor.

CAUT16APL022

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Ms. Spett to approve the recommendation to not fund CAUT16APL022.

MOTION to approve the recommendation to not fund CAUT16APL022 was passed with all in favor.

CAUT16APL015

Dr. Eggerding called for a motion.

Dr. Evans moved and seconded by Dr. Wang to accept the recommendation not to fund CAUT16APL015.

MOTION to approve the recommendation not to fund CAUT16APL015 was passed with six in favor and two abstentions.

CAUT16APL019

Dr. Eggerding called for a motion.

Mr. Weitzen moved and seconded by Ms. Spett to accept the recommendation to fund CAUT16APL019.

<u>Discussion:</u> Although this is a very significant topic with a research team experienced with fMRI the team has no experience working with toddlers. Reviewers recommend funding based on the condition of switching from 3-5 year olds to 7-11 year olds (before puberty). With the 7-11 year olds it is best if they are not taking medications; however; if they are the research team will need to account for the medications.

MOTION to approve the recommendation to fund CAUT16APL019 with the condition as recommended by the reviewers was passed with all in favor.

CAUT16APL020

Dr. Eggerding called for a motion.

Mr. Weitzen moved and seconded by Ms. Spett to accept the recommendation to fund CAUT16APL020.

MOTION to approve the recommendation to fund CAUT16APL020 was passed with six in favor and two abstentions.

CAUT16APL021

Dr. Eggerding called for a motion.

Dr. Friedman moved and seconded by Dr. Dreyfus to accept the recommendation to fund CAUT16APL021.

MOTION to approve the recommendation to fund CAUT16APL021 was passed with all in favor.

CAUT16APL007

Dr. Eggerding called for a motion.

Dr. Evans moved and seconded by Ms. Spett to accept the recommendation to fund CAUT16APL007.

MOTION to approve the recommendation to fund CAUT16APL007 was passed with all in favor.

CAUT16APL016

Dr. Eggerding called for a motion.

Mr. Weitzen moved and seconded by Dr. Evans to accept the recommendation not to fund CAUT16APL016.

MOTION to approve the recommendation not to fund CAUT16APL016 was passed with six in favor and two abstentions.

CAUT16APL025

Dr. Eggerding called for a motion.

Mr. Weitzen moved and seconded by Dr. Evans to accept the recommendation not to fund CAUT16APL025.

<u>Discussion:</u> Although CAUT16APL025 was recommended not to fund, one member spoke in favor of funding and several members agreed given the significance of the topic and other comments by the review panel. The reviewers considered this to be a good team working in a good research environment.

Dr. Eggerding called for an amended motion.

Mr. Weitzen moved seconded by Ms. Bell to fund CAUT16APL025.

<u>AMENDED MOTION to fund CAUT16APL025 was passed with four yes votes, two no</u> votes and two abstentions.

CAUT16APL018

Dr. Eggerding called for a motion.

Dr. Evans moved and seconded by Dr. Wang to accept the recommendation not to fund CAUT16APL018.

MOTION to approve the recommendation not to fund CAUT16APL018 was passed with six in favor and two abstentions.

CAUT16APL009

Dr. Eggerding called for a motion.

Dr. Wang moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT16APL009.

MOTION to approve the recommendation not to fund CAUT16APL009 was passed with six in favor and two abstentions.

CAUT16APL005

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Ms. Spett to accept the recommendation not to fund CAUT16APL005.

MOTION to approve the recommendation not to fund CAUT16APL005 was passed with all in favor.

CAUT16MED003

Dr. Eggerding called for a motion.

Mr. Weitzen moved and seconded by Dr. Evans to accept the recommendation to fund CAUT16MED003.

MOTION to approve the recommendation to fund CAUT16MED003 was passed with all in favor.

CAUT16MED002

Dr. Eggerding called for a motion.

Dr. Dreyfus moved and seconded by Dr. Friedman to accept the recommendation to fund CAUT16MED002.

<u>Discussion:</u> The reviewers commented that the applicant should contact their IRB to verify that a quality improvement initiative does not need review.

MOTION to approve the recommendation to fund CAUT16MED002 noting the reviewers' comment was passed with five in favor and one abstention.

CAUT16MED006

Dr. Eggerding called for a motion.

Dr. Wang moved and seconded by Dr. Friedman to accept the recommendation not to fund CAUT16MED006.

MOTION to approve the recommendation not to fund CAUT16MED006 was passed with five in favor and one abstention.

CAUT16APL010-correction on motion

Dr. Eggerding called for a motion given a member who was recused had inadvertently made a motion when this application was first approved for funding.

Mr. Weitzen moved and seconded by Dr. Evans to accept the recommendation to fund CAUT16APL010.

<u>Discussion:</u> A member questioned comments by the Scientific Advisory Committee (SAC). The applicant will be advised to strongly consider comments made by the SAC.

MOTION to approve the recommendation to fund CAUT16APL010 advising the applicant to strongly consider comments by the Scientific Advisory Committee (SAC) was passed with six in favor and two abstentions.

VII. Election of the Council Chair

Dr. Zanna called for nominations. Dr. Eggerding was nominated. There were no additional nominations. Ballots were distributed; members voted and unanimously elected Dr. Eggerding as Chairperson for 2016. Dr. Zanna congratulated Dr. Eggerding as she continues to chair the Council. Dr. Eggerding thanked the members.

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

Dr. Zanna thanked members for rearranging their schedules to accommodate the request for this additional meeting. He also thanked Dr. Costa for his report.

By starting the grant cycle earlier this year it is anticipated the eight grantees approved for funding will be notified in early June with start dates of July 1, 2016.

Council's 2015 Annual Report

The 2015 Annual Report is complete and posted on Council's webpage. Thanks to Dr. Eggerding for reviewing the Report, Linda Boclair for writing the draft and Lisa Cummings (on Anthony Welch's staff) for her work with the graphic design staff to format the report.

Planning for SFY'18

The DOH approved the request for a facilitator for Council's SFY'18 planning meeting to be held on Monday, June 6, 2016. We'll have 100% participation by Council. We appreciate the efforts make by members to adjust their schedules to attend this full day meeting. We anticipate planning for the June meeting to begin in early April with reaching out to Council members, grantees and other stakeholders for input to inform the process.

SFY'17 RFA

Those who attended the December Council meeting, will recall the robust discussion related to the structuring of the SFY '17 RFA. Because of the large number of new members, the evolution of previous RFA's and their development were reviewed. Council is interested in stimulating multi-disciplinary collaborations through the RFA (including basic scientists and clinical researchers) and considerable discussion related to attracting researchers outside traditional domains of autism research. Council is also interested in establishing fellowships as the vehicle for fostering inter-disciplinary collaborations, but due to the complexity of establishing them it was decided to defer their inclusion until a future RFA. It was suggested that a planning grant might serve as a vehicle to develop the fellowships. Dr. Eggerding requested 2 committees (one to address the coordinating center and one to address research projects for inclusion in the RFA) meet to make their final recommendations.

The research committee, chaired by Dr. Dreyfus, recommended the RFA include funding for clinical and translational research and the addition of basic science research. They did an outstanding job in revising the last RFA to include basic science research as an option for SFY '17 funding. The revisions were sent to all members who did not participate on the committee for comments. Council staff will now work to revise other sections of the RFA addressing clinical and translational research and medical homes while creating and updating applications in SAGE. We anticipate releasing the SFY '17 RFA in July 2016.

The meeting of the Coordinating Center committee, chaired by Drs. Evans and Aquino, was productive with members considering the current structure of the Coordinating Center an appropriate model for funding. The challenge is to clearly articulate the functions of a coordinating center and the expertise required considering the ongoing growth in numbers and diversity of Council funded projects. Training of healthcare professions and outreach to families were also discussed as possible functions of a coordinating center. Considering Council's intent to convene a planning meeting to discuss SFY'18 funding it was decided to postpone the RFA for a coordinating center in SFY'17 giving Council the ability to not only plan for research initiatives but also to define the roles and responsibilities and qualifications of a coordinating center under which research and possibly other initiatives will be housed. Given Montclair's

grant ends on June 30, 2017 we are considering options for the interim year between July 1, 2017 and June 30, 2018.

IX. Report of Revenues and Expenditures

The report was included in members' Council packet for their information.

X. Adjournment

Dr. Eggerding asked for a motion to adjourn.

MOTION to adjourn by Dr. Friedman and seconded by Dr. Dreyfus was approved with all in favor.

The meeting was adjourned at 9:00 PM.