



**NJ Department of Health
Governor's Council for Medical Research and Treatment of Autism
Council Meeting Minutes (ratified)
September 17, 2018**

Council Members Present

Michael Aquino, MD, F.A.C.G., Senate President Appointee; Partner, Shore Gastroenterology Associates; Co-founder, Pathology Solutions (present via phone)

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

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

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 (present via phone)

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)

Absent

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

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

Michele Sorvino, RDMS, Speaker of the General Assembly Appointee; Executive Director, Golden Door International Film Festival of Jersey City

*Denotes Council Chairperson

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

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

Public Attendees

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

Eric Eberman, M.S.Ed., Director, Public Policy, Autism NJ

Walter Zahorodny, Ph.D., Rutgers University

Note: Motions are numbered.

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.

III. Approval of the June 4, 2018 Council Meeting Minutes-Dr. Eggerding called for a motion to approve the minutes. MOTION by Dr. Wang to approve the minutes was seconded by Mr. Weitzen.

1. MOTION to approve the minutes was passed with six members in favor. One member arrived later (did not vote).

IV. Approval of the 2019 Council Meeting Calendar- Dr. Eggerding called for a motion to approve the calendar. MOTION by Dr. Wang to approve the calendar was seconded by Mr. Weitzen.

2. MOTION to approve the calendar was passed with all members in favor. One member arrived later (did not vote).

V. Presentation by Walter Zahorodny, Ph.D.-Final Research Report – CAUT13APL014

Dr. Zahorodny presented his research project entitled *Perinatal Risk Factors and their Influence on ASD Prevalence*.

The objective of this study is to profile two birth cohorts (children born in 1998 and 2002), from Essex, Union, Hudson and Ocean Counties in New Jersey, to identify possible demographic, maternal, obstetric and neonatal risk factors associated with ASD. A second objective of this study is assessment of the changes in ASD prevalence related to perinatal risk factors, over a recent 4-year period and application of a mathematical model developed by CDC-ADDM Network investigators to assess the contribution of each of these factors to the change in the prevalence of ASD observed, over this time period.

The study findings will inform future investigations of ASD risk factors based on combining case-specific data from multiple cohorts. The investigators have identified and characterized 1985 ASD cases, spanning 10 years. This pilot study is an important step toward a larger project to evaluate the change in ASD risk factors longitudinally using similar, population-based cohorts from around the U.S., for the 2000 to 2010 period. Future studies will also investigate phenotypic differences and assess risks related to environmental factors, including concentration of hazardous air pollutants and other defined ecological variables. If significant ASD risk factors are identified, this knowledge may lead to the development of strategies which may address preventable risks and reduce the prevalence of ASD.

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

VI. Presentation by Jill Harris, Ph.D.-Final Research Reports - CAUT15APL020 and CAUT16MED003

Dr. Harris presented two medical homes projects, the first entitled *Children's Specialized Hospital Pediatric Primary Care ASD Medical Home* and the second entitled *The Autism Medical Home Transition Collaborative: Partnering Pediatric and Adult Care*.

In recognition of the unique needs of patients with ASD, the first project focused on implementing an enhanced care bundle for families with children with ASD. The care bundle included various care coordination elements and staff/family trainings designed to improve patient/family quality of care and access to care. The enhanced care coordination project provided ASD resources and services to families in a structured and organized fashion with the goal of maintaining a strong family-centered approach. By leveraging the existing practice excellence and medical home guidelines, CSH Primary Care Practice expanded services for children with ASD through the implementation of the care bundle. By the end of the two-year project, the Practice included 331 patients, an increase from the original 298, representing a 12% growth of the ASD patient population in the Practice.

While building upon the first grant, CSH's second grant focused on improving the care for adolescents ages 14-21 years old. The Autism Medical Home Transition Collaborative improved the care delivered to adolescents and young adults with ASD through the cooperative creation, implementation, and dissemination of a practical, evidence-based transition care tool focused on improving the evolution of care for individuals with ASD in New Jersey. The ASD transition tool was implemented into CSH's primary care practice reaching 211 individuals with ASD ages 14-21+. Additionally, the new ASD transition tool will be utilized as a support for education delivery to the CSH community focused on the topic of transition care for adolescents and young adults with ASD and made publicly available for use by healthcare providers who care for adolescents with ASD in New Jersey by sharing the tool and resources at applicable conferences and professionally-oriented newsletters.

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

VII. Strategic Planning – Follow-up (Goal Setting)

Council members identified goals and priorities during small group discussions at the Council's 2016 Strategic Planning Meeting. The meeting facilitator noted it is important for members to discuss and refine the goals, especially to ensure that they are clearly articulated with expected impacts and outcomes, implemented over time and evaluated.

The list of the eleven goals identified at the Strategic Planning meeting was sent to members with a request to prioritize for discussion at today's meeting (September 17, 2018). Given that four of the seven members who prioritized the goals did so at the meeting the results will be summarized and sent to members for discussion at the December 10, 2018 Council meeting.

In the meantime, members commented on several of the goals, as noted below:

- How can NJ add value to national efforts? Council could use a landscape scan.
- Consider models to increase access (technical support to assist doctors with their patients with ASD, Medical homes, etc.) and secure insurance reimbursement for services.
- Funding for the greater whole – ways to add something special/unique for people in NJ, fellowships to grow talent in NJ, conference ideas that are special for NJ and contributing as a model.
- What is the potential to follow public health-based issues – drive policy?
- Lifespan and behavioral health issues, behavioral health services for adults -- need to know available services for adults at the national level.
- Increase risk tolerance for grants-fund lower cost grants with shorter time frames to test innovative ideas.
- Would a full-time Executive Director have time to devote many of the responsibilities assigned through the legislation?
- Although not necessarily a topic related to research it was noted evaluation of ASD by nurse practitioners is not accepted by schools. Also, schools are not accepting ADOS.

VIII. Report of the Acting Executive Director- Martin T. Zanna, MD, MPH

Ethics Requirements

As Rutgers New Brunswick/Piscataway is now the NJACE grantee, Nancy Kelly-Goodstein, DOH Ethics Officer, reminds Council members to be alert for any conflict of interest requiring a recusal. Any Council member affiliated with the New Brunswick/Piscataway component of Rutgers should complete the Special State Officer Recusal Statement for the Council's Office records and cannot be involved in the subject matter of the recusal. Such involvement includes but is not limited to: discussing the matter with DOH staff or other Council members; attending closed session meetings related to the matter; participating, voting, or commenting in open session meetings related to the matter; and reviewing any documents pertaining to the matter. This same advice applies to any Council member or their agency that affiliates with the NJACE.

As background, in May of 2017, the State Ethics Commission provided the following advice to the Autism Council: "The multi-component rule used by the NIH and adopted by the Commission on Spinal Cord Research pursuant to 2001 Commission advice is a reasonable approach to handling conflicts at the Autism Council. Rutgers New Brunswick/Piscataway, Rutgers Camden, Rutgers Newark, and Rutgers Biomedical and Health Sciences are sufficiently separate and independent entities that would satisfy the NIH multi-component rule." This advice intends to balance any perceived or actual conflict of interest, as defined by the New Jersey Uniform Ethics Code, with the benefit of subject matter experts providing guidance to the Department. Ms. Kelly-Goldstein can be contacted with any questions. Linda will send Ms.

Kelly-Goldstein's contact information along with this statement and the recusal form to members via email.

Transition of the NJACE Coordinating Center at Montclair to the NJACE at Rutgers

Transitioning the NJACE from Montclair to Rutgers occurred during June and July with teams from both institutions meeting on July 24, 2018 to discuss the differences in roles and to transfer documents. The Montclair team continued to work with grantees to evaluate progress reports and assist with closing grants. A total of 21 active grants were transferred to Rutgers, effective August 31, 2018. The success of the transfer was due, to a great extent, to the efforts of the Montclair team in processing grantees' reports before the transfer and providing detailed processes and procedures they used as the NJACE during the previous six years.

SFY19 RFA

The SFY19 RFA for Clinical Research and Fellowships was posted on August 20, 2018 on Council's webpage and on the on-line DOH Grants Directory in addition to mailings to over 400 potential applicants and grant administrators. Letters of Intent are due October 4, 2018 and applications are due by November 19, 2018 with Council voting for funding on March 4, 2019.

Report on NJ ACE Grantees

The Council has funded 44 grants since 2012. Thanks to Drs. Harris and Zahorodny for reporting on their grants, representing sixth, seventh and eighth grants to close. Three additional grants have closed with several others in the process of closing.

Council

Nancy Kelly-Goodstein, DOH Ethics Officer, will work with us to revisit the multi-component rule used by NIH as it applies to members from Rutgers campuses voting for grants. The current application of the rule to Council members representing various Rutgers campuses is overly restrictive.

IX. Report of Revenues and Expenditures

Copies of the Report of Revenues and Expenditures were sent to Council members for their information.

X. Public Comments - There were no public comments.

XI. Adjournment - Dr. Eggerding asked for a motion to adjourn.

3. MOTION to adjourn by Dr. Kansagra seconded by Dr. Wang was approved with all members in favor. The meeting was adjourned at 8:40 PM.