



**New Jersey Department of Health and Senior Services  
Governor's Council for Medical Research and Treatment of Autism  
Meeting Minutes – March 5, 2012, 6pm – 9pm (ratified)**

**Council Members Present**

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

Matthew Cortland, BA, Instructor, Teach for America, Public Member

Caroline Eggerding, MD, Vice President Clinical Services, Bancroft NeuroHealth,  
Healthcare Organization Representative and Chair of the Governor's Council for Medical  
Research and Treatment of Autism

Susan P. Evans, EdD, Education Program Specialist for Early Intervention Program,  
Commissioner of Health and Senior Services Appointee

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

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

Linda S. Meyer, EdD, MPA, BCBA-D Executive Director of Autism New Jersey, Autism  
Organization Representative

Barbara Morvay, MA, Trustee, Richard Stockton College of New Jersey, Academic Institution  
Representative

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

**Absent**

Grace M. Reilly, RN, MSN, APN-C, Adult Nurse Practitioner for Riverview Medical Center,  
Individual with Autism or Family Member Representative

Judah Zeigler, Senate President Appointee

## **NJ Department of Health and Senior Services (DHSS) Attendees**

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

Cynthia Kirchner, MPH  
Director, Quality Improvement  
Ethics Liaison for the DHSS

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

## **General Public Attendees**

Harsim Patel, Ph.D.  
UMDNJ

Tricia Wagner  
Center for Neurological and Neurodevelopmental Health (CNNH)

**I. Welcome** - Council Chair, 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. Comments by Ms. Cynthia Kirchner, Director of Quality Improvement and Ethics Liaison.**

Ms. Kirchner noted that the election of the Chairperson will be held at the end of the meeting to enable Council to first conduct its business. If a new Chairperson is elected at the end of the meeting he/she will have time to prepare for the May 21 and subsequent meetings.

Ms. Kirchner noted that everyone on Council and the members of the public attend the meetings for the betterment of the children and adults with autism and their families. Council is on a good course in moving forward with their mission. It has been brought to Ms. Kirchner's attention that occasionally statements are made that are not in keeping with the intent and mission of Council. As professionals we must be aware of and sensitive to any public statements made during the

Council meetings. Ms. Kirchner's appreciates the cooperation of Council and welcomes feedback if there are any concerns.

#### **IV. Approval of the December 12, 2011 Council Meeting Minutes**

Dr. Eggerding called for a motion to approve the minutes. MOTION by Ms. Goldfarb to approve the minutes was seconded by Ms. Bell.

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

#### **V. Report of the Acting Executive Director, Martin T. Zanna, MD, MPH**

##### **Administrative Issues and Website**

The Ethics Commission requests that all Special State Officers and State employees update their training on an annual basis. The Commission requests that training be completed March 30, 2012. Council should have received the request to update their ethics training on-line. Please send your certificate of completion to Ms. Bocclair by March 30.

Council also received notice of the State Policy Prohibiting Discrimination in the Workplace. Members of Boards, Councils and Commissions that operate within the Department of Health and Senior Services are expected to adhere to the State Policy. Copies of the forms are included in your packets and have been sent to you electronically. Please sign the Acknowledgment of Receipt Forms and return them to Ms. Bocclair by April 9.

Website postings since the last Council meeting include Frequently Asked Questions (FAQs) for NJ ACE grant program. The answers to the questions were refined and posted to ensure consistency in responding to questions from applicants. With the flurry of activities during the grant application period (December 5, 2011 – March 19, 2012) the FAQs illustrates the level of development in this process.

Also, the Council's meeting calendar and membership list have been updated. And we are considering posting the names and affiliations of the Scientific Advisory Committee (SAC) members, once they approve the posting.

##### **Scientific Advisory Committee (SAC)**

The first meeting (teleconference) of the Scientific Advisory Committee (SAC) was held on February 15, 2012 with four of the five members in attendance. They included Drs. Catharine Rice, Ted Abel, Stewart Mostofsky and Susan Hyman. Dr. Joseph Buxbaum was not able to participate due to his travel schedule. His secretary provided a bio that Dr. Zanna read as part of the introductions.

Dr. Zanna thanked Dr. Caroline Eggerding for welcoming the members and providing opening remarks during the meeting. This was an introductory meeting with members providing

information about themselves and their special interests and expertise. Dr. Zanna presented an update on Council's NJ ACE grant program and the role of the SAC. Also discussed were additional potential SAC related tasks, and the frequency and mode of communicating. Quarterly teleconferences will be scheduled and members and Council staff will communicate via email as needed.

### **March 2012 Scientific Meeting of the Council funded Research Grantees**

The scientific meeting of basic and clinical science researchers funded by the Council will be held on Friday March 23, 2012 from 9 AM to 4 PM at the National Conference Center at the Holiday Inn in East Windsor. Council received an invitation with a request to RSVP by today, March 5, 2012.

The meeting provides a forum for the basic science researchers to showcase their research and how Council played a role in advancing the state of the science of autism research through its funding. A list of participants (researchers) is included in Council's packet. The meeting is open to the public although space is limited to 40. A public notice was sent to the State House on February 23 with a request to distribute to the press.

The morning session will include a presentation by Dr. Dorothy Gaboda, Rutgers Center for State Health Policy. Her presentation is based on the needs assessment, funded by the Council, which identifies relevant autism related biomedical research, clinical services, training and educational needs and gaps in the State. For those of you who were present at the December 12, 2011 meeting, you will recall hearing Dr. Gaboda's phase one report and she's presenting phase two at today's meeting. Following Dr. Gaboda's report Dr. Zanna will provide an update on Council activities.

Because a goal of the meeting is to promote interdisciplinary dialogue as a first step toward possible collaboration, the remaining time will be designed around discussion groups with specific themes. Groups will present their findings in a general plenary session. Program materials will include research profiles from each of the attendees. The information will enable grantees to know what others are doing as well as to memorialize how the Council's efforts have contributed to the documented successes.

### **VI. May 21, 2012 Council Meeting**

Ms. Kirchner reminded Council that the purpose of the May 21, 2012 meeting is to recommend funding for the NJ ACE Coordinating Center and up to three Program Sites. It is critical that Council reach consensus and vote at the May meeting for the \$8M in funding to be awarded by end of FY 12 (June 2012). Eleven Letters of Intent (LOI) have been received for the Program Sites and two for the Coordinating Center. Since LOI are not required additional applications may be submitted by the deadline, March 19, 2012.

Council will have a leaderboard listing the title, institution and principal investigator for each of the grant applications. Each application will also have a score as determined by the Scientific Merit Review Panel. Ms. Ray explained that she will send emails with instructions for logging on to SAGE including each member's password and instructions for navigating the site. Council

will review the grants, the reviewers' critiques and the brief synopsis of the discussions at the April 30, 2012 meeting of the reviewers. All information from reviewers are blinded. Applications are not blinded. If any Council members have conflicts they will be recused from the specific grants. Council's discussions and deliberations are open to the public.

The question was asked about the requirement for IRB approvals since this was a major problem in the past. The Notice of Grant Award (NOGA) will state that funding will be withheld if grantees do not achieve various milestones on a timely basis stated in the NOGAs. In addition, the Grant Guidelines state that grantees must have IRB approval by end of the first year. After one year if criteria are not accomplished Council could vote not to fund second year. If a grantee is not funded for the second year the funds can be applied to future funding initiatives but not to the current funding of the NJ ACE Coordinating Center and Program Sites.

Dr. Eggerding commented that the process is a fundamentally different way in how the Council has input into the grant process. Previously ranked and Council voted blindly on the scores. Council members expressed that they look forward to the May meeting.

## **VII. Ad hoc Committee - FY 13 Research Funding**

Dr. Eggerding noted that Council voted at the December 12, 2011 meeting to fund \$2M in autism research in FY 13 with the understanding that funding would not be limited to basic science research (as has been the case in previous years). Funding can be used to expand to other areas of responsibility in addition to basic/bench research, such as educational and clinical research, translational research and the possibility of funding training programs, possibility fellowships. While there is a potential for collaborating with Coordinating Center, the Center is not charged with oversight of this research funding.

The ad hoc committee will recommend to Council the best use of the \$2M in research funding, defining the direction for the FY 13 cycle. This is in addition to the NJ ACE (Coordinating Center and Program Sites) funding.

Six members volunteered to serve on the ad hoc committee. They are Ms. Bell, Ms. Goldfarb Mr. Weitzen and Drs. Eggerding, Kansagra and Meyer.

Council's Rules of Order state that the Council Chair appoints the Chair of the ad hoc committee. The ad hoc committee is appointed on a temporary basis (six months) to address a specific issue that includes a clear charge of duty and an established date of completion. Dr. Eggerding asked members to notify Ms. Bocclair if interested in chairing the ad hoc committee. If there are no volunteers the Council Chairperson will make the appointment. Meetings will be called by the chair with some meetings via teleconference.

The final report of the ad hoc committee is due at the September 10, 2012 meeting with an interim report (progress and unresolved issues that require Council input) at the June 4, 2012 meeting. Council will receive preliminary information before the September meeting so they can think and prepare for active discussion at the September meeting and a week later via teleconference.

Following Council vote, there is a short timeline to ensure funding by the end of FY 13. RFAs will be developed and posted in the NJ Registry, applications and critique forms developed in SAGE, reviewers recruited, applications critiqued and scored, Council vote and funding awarded by June 2013.

**Note:** The following two PowerPoint presentations summarized below will be posted at [www.nj.gov/health/autism](http://www.nj.gov/health/autism) "Reports/News/Meeting Minutes".

### **VIII. Rutgers Center for State Health Policy -Phase 2 Report** **Dr. Dorothy Gaboda, Associate Director for Data Analysis**

Dr. Gaboda discussed Phase 2 of the Needs Assessment Report that had been sent to the Council for review. The purpose of the needs assessment is to inform Council about the status of clinical and basic science research and services for individuals with autism, highlighting the needs and gaps in research and services. The report can be used by Council in guiding their strategic planning. During Phase 1 Dr. Gaboda and her team gathered and reviewed background information including previous New Jersey reports and national priorities for autism-related biomedical research and then cataloged autism-related funded research in New Jersey. Please refer to the December 12, 2011 Council meeting minutes at [www.nj.gov/health/autism](http://www.nj.gov/health/autism) for additional information about the Phase 1 report.

For the Phase 2 report Dr. Gaboda reported on finding from interviews with researchers, clinicians, family members, service providers, advocates and educators. She discussed research strengths in New Jersey, opportunities for future research, autism services in NJ, information and education for families and the public, perceptions of the role of Council and key ideas from autism centers in other states.

Dr. Eggerding, on behalf of the Council, thanked Dr. Gaboda for a very interesting and informative report.

### **IX. Jersey Shore Medical Center Presentation** **Dr. Denise Aliose, Medical Director**

Dr. Aliose provided an overview of accomplishments\* throughout the three years (July 1, 2009-June 30, 2011) of Council's funding for Jersey Shore Medical Center Clinical Enhancement Center. The primary objectives were to increase the primary care screening and early identification of children with signs of ASD; develop and implement an accessible and rapid process for secondary screening of children identified by primary care providers; provide timely comprehensive diagnostic assessment and care management services; expand, enhance and coordinate language, social skills and behavioral therapy for children diagnosed with ASD; and collaborate with community agencies to increase community awareness and increase support services for families and professionals.

Dr. Aliose's presentation was followed by a Q&A session. Her slide set was made available to Council members. Dr. Eggerding, on behalf of the Council, thanked Dr. Aliose for a most informative presentation reflecting Jersey Shore's accomplishments in enhancing services for individuals with autism.

\*Note: Please refer to [www.nj.gov/health/autism](http://www.nj.gov/health/autism) “Current Initiatives” for Summary Reports, including accomplishments, for each of the six Clinical Enhancement Centers.

#### **X. Report of Revenue and Expenditures**

Ms. Ray presented the Revenue and Expenditures Report (July 1, 2011 – June 30, 2012). There were no comments or questions.

#### **XI. Election of the Council Chairperson**

Ms. Kirchner called for nominations. Ms. Goldfarb nominated Dr. Eggerding. Ballots were distributed; members voted and unanimously elected Dr. Eggerding as Chairperson for 2012. Dr. Eggerding thanked the members

#### **XII. Comments by public member attendees**

#### **XIII. Adjournment**

MOTION by Ms. Bell to adjourn the meeting and seconded by Ms. Goldfarb.

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