New Jersey Department of Health  
Governor’s Council for Medical Research and Treatment of Autism  
Meeting Minutes – September 10, 2012, 6pm – 9pm (ratified)

Council Members Present

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

Caroline Eggerding, M.D., Healthcare Organization Representative and Chairperson of the Governor’s Council for Medical Research and Treatment of Autism

Susan P. Evans, Ed.D., 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

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

Absent

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

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

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

Judah Zeigler, Senate President Appointee

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
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, followed by roll call.

III. Approval of the May 21, 2012 Council Meeting Minutes

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

MOTION to approve the minutes was passed with all in favor.

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

A. Administrative Issues and Website

Dr. Zanna was pleased to inform the Council that four Council funded researchers will present poster displays at the annual Autism NJ Conference in Atlantic City on October 11, 2012. He thanked Dr. Meyer for extending the invitation to Council’s grantees.

Ms. Grace Reilly resigned from Council on June 24, 2012. While she enjoyed the opportunity to work with the Council she feels that she is unable to fulfill her commitment as a member. Ms. Reilly recently started a new job and is unable to attend
the meetings.

Additions to the website since the last Council meeting include a list of the Scientific Advisory Committee (SAC) members, the NJ Autism Center of Excellence (NJ ACE) Program Sites grant guidelines and Frequently Asked Questions (FAQs), the Fund Balance Statement and the press article from the June 28, 2012 grant award event at Montclair State University.

B. Report on NJ ACE Grant Program

Ten Letters of Intent were submitted for the NJ Autism Center of Excellence (NJ ACE) Program Site’s grant program. Given that the Letters were required; this is the maximum number of applicants for the grant program. Funds are available for up to two clinical research program sites. The applications are due on September 28, 2012 and the Scientific Merit Review Panel will meet on November 5, 2012 to discuss and score the applications. The Council can expect to receive access to the New Jersey System for Administering Grants Electronically (SAGE) on November 19, 2012 to review the applications and the reviewers’ critiques in preparation for voting at the December 3, 2012 Council meeting.

In addition to the critiques Dr. Zanna will provide feedback from the Scientific Advisory Committee (SAC). A conference call is scheduled with the SAC for September 27, 2012. The SAC was very helpful during the last grant cycle in reviewing and commenting on the results of the scoring of the applications by the Scientific Merit Review Panel. Dr. Zanna will ask them for input on the Letters of Intent and ask that they review the critiques and provide feedback prior to the December 3, 2012 Council meeting.

C. Report on June 28 Event at Montclair

The grant awards for the NJ ACE Coordinating Center (Montclair State University) and Program Site (Rutgers University) were announced on June 28, 2012 by First Lady Mary Pat Christie, Commissioner of the Department of Health Mary E. O'Dowd and Dr. Caroline Eggerding, Chair of the Council. The event was held at The Center for Autism and Early Childhood Mental Health at Montclair State University and was well received by all in attendance. In addition to Dr. Eggerding, Council members Dr. Susan Evans and Ms. Madeleine Goldfarb attended the event. A copy of the press article is in Council’s packet and is posted on Council’s website.

D. Report on NJ ACE Grantees

Dr. Zanna welcomed Dr. Gerald Costa to the meeting. Dr. Costa is the Director of the Center for Autism and Early Childhood Mental Health at Montclair University and the Principal Investigator for the NJ ACE Coordinating Center grant. Council staff is working with Dr. Costa to redefine a timeline for his grant given the changes needed until the remaining two program sites are funded. Dr. Costa will provide an overview of the Coordinating Center at the December 3, 2012 Council meeting.
A meeting was held on August 15, 2012 at the Department of Health (DOH) with the Principal Investigators and staff from Montclair State University and Rutgers University. This was a "meet and greet" session that included a review of each grantee's scope of work. In addition to the Council staff, Council members Drs. Eggerding and Evans and consultant Dr. Daphne Robinson attended the meeting. Council members commented on the success of the meeting and the start of a very positive collaborative approach, as reflected in Dr. Costa’s introductory comments, to the implementation of the NJ ACE. Members also commented on the outstanding presentation by Dr. Linda Brzustowicz, Principal Investigator for the Clinical Research Program Site grant awarded to Rutgers University.

E. Status of FY 13 Research Funding Ad hoc Committee

As a result of several events that have occurred, meetings of the ad hoc committee are temporarily on hold. While Dr. Ketan Kansagra will continue to serve on the committee, he is unable to devote the time necessary to chairing the committee as a result of his work and personal commitments. We thank him for serving as chair of the committee and recognize that while the committee met only two times during his tenure, significant progress has been made in generating important information, including a “Models of Applied Research” document submitted by Dr. Meyers and Mr. Weitzen, to inform funding decisions. Dr. Eggerding will appoint a member to chair the ad hoc committee when the committee reconvenes in early 2013.

Also, with the re-issuing of the NJ ACE Program Sites request for applications on July 9, 2012 it is anticipated that the funding decisions that Council will make at their December 3, 2012 meeting will inform the work of the ad hoc committee when they reconvene.

A third event that may impact the work of the ad hoc committee is the discussions at the recent Interagency Autism Coordinating Committee (IACC) meeting. Two newly constituted IACC subcommittees will be working to identify priorities in each of their areas of expertise and report on findings by the end of the year.

F. Membership on Council

There are currently five open seats on the Council; three for academic institution representatives, one for Assembly Speaker Appointee and one for a public member with a family member with autism. Seven persons have applied through the Governor's Office as a result of our actively recruiting potential members. We are working with the liaison to the Governor’s office to identify any additional applicants who may have applied through the Governor's Office.

Discussion: Dr. Eggerding emphasized the importance for all members to attend the quarterly Council meetings given the reduced membership. Members requested clarification regarding the appointment process. The Governor appoints academic institution representatives, autism organization representatives, public members and a healthcare organization representative. In addition, one person is appointed by the President of the Senate, one by the Speaker of the General Assembly and one by the Commissioner of Health. Council staff has notified the Department’s legislative liaison of the vacancies. Also, Council’s Rules of Order state that a member who is absent for more than half of the Council meetings during a calendar year can be
recommended for removal from the Council. Council staff recommends removal of member(s) from when member(s) do not comply with the attendance rule.

A member asked Dr. Zanna if his position as Acting Executive Director is temporary or if Council can depend on him to continue his work with the Council. He commented that he expects to continue serving as Acting Executive Director given that he will spend 25% of his time in the Department of Health. With the reorganization of state departments 75% of his time is with the Department of Human Services, effective July 1, 2012.

V. Approval of the 2013 Meeting Calendar

Dr. Eggerding reminded members that they had previously discussed the best time(s) of the day to schedule meetings. It was decided that the selection of evening meetings, although not ideal for all members, is the best compromise.

Dr. Eggerding called for a motion to approve the 2013 meeting Calendar. MOTION by Mr. Weitzen to approve the calendar was seconded by Ms. Goldfarb.

Discussion: Dr. Eggerding confirmed that Council is required to meet four times each year and has the option to add meetings with notification to the public, as needed.

MOTION to approve the minutes was passed with all in favor.

VI. Hunterdon Medical Center, Regional Autism Center, Presentation by Dr. Audrey Mars, Clinical Director

Dr. Mars provided an overview of accomplishments throughout the three years (July 1, 2009-June 30, 2011) of Council’s funding for the Hunterdon Medical Center’s Clinical Enhancement Center grant. The goal was to improve the quality of life of individuals with ASD and their families in counties served by providing: (1) early detection and diagnosis of infants and toddlers with the objective that these children begin to receive effective treatments; (2) increased access to multidisciplinary assessment and treatment programs that address the broad symptomatology of ASD; (3) outreach to schools and community providers to improve outcomes throughout the lifespan of individuals affected by AS; (4) training for health and educational professionals serving children with AS and; (5) enhance family training opportunities and collect data to support research and advocacy efforts. Dr. Mars described in detail the methods and success in accomplishing each of the objectives.

Dr. Mars’s presentation was followed by a Q&A session. Her slide set was made available to Council members. Mr. Weitzen complimented Dr. Mars on her work and that of the staff and emphasized the outstanding relationships that she has been able to establish with the families and the community in general. Dr. Eggerding, on behalf of the Council, thanked Dr. Mars for a most informative presentation reflecting Hunterdon Medical Center’s accomplishments in enhancing services for individuals with autism.
VII. Hackensack University Medical Center, Institute for Child Development, Presentation by Dr. Randye Huron, Director

Dr. Huron provided an overview of accomplishments throughout the three years (July 1, 2009-June 30, 2011) of Council’s funding for the Hackensack Medical Center’s Clinical Enhancement Center grant. The primary goal was to increase and improve access to diagnostic and intervention services. The plan that was implemented resulted in reorganization of the infrastructure and collaboration with a prominent autism treatment program to ensure appropriate and timelier services, education and support from initial diagnosis to the full treatment plan. Dr. Huron described the implementation of the clinical enhancements including: (1) the responsibilities of the clinical coordinator, pediatrician and social worker; (2) improved intake/scheduling process; (3) parent training and education programs; (4) occupational and physical therapy evaluations and treatment and; (5) audio/speech language evaluations and therapy. Dr. Huron described success in reducing wait time for evaluation of autism; exceeding the program targets/goals and in receiving positive feedback from parents and caregivers. Dr. Eggerding, on behalf of the Council, thanked Dr. Huron for a most informative presentation reflecting Hackensack University Medical Center Center’s accomplishments in enhancing services for individuals with autism.

VIII. 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.

IX. Comments by public member attendees

Dr. Mars and the Council members briefly discussed the use of the ADOS in evaluating ASD; DSM-4 vs. DSM-5 criteria and the issues and challenges of diagnosing adolescents ages 12-14.

X. Adjournment

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

MOTION passed with all in favor. The meeting was adjourned at 8:30 PM.