

**New Jersey Department of Health and Senior Services (DHSS)
Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – April 6, 2009
6:00pm – 8:00pm
Location: Department of Human Services, Division of Disability Services
Conference Room 199A
5 Commerce Way, Hamilton, NJ 08691**

Council Members Present

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

Caroline Eggerding, MD, Vice President Clinical Services, Bancroft NeuroHealth,
Assembly Speaker Appointee.
Chair of Governor's Council for Medical Research and Treatment of Autism.

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

Yvette Janvier, MD, FAAP, Medical Director for the Children's Specialized Hospital in Toms River,
Healthcare Organization Representative.

Leslie Long, Director, Public Policy and Systems Advocacy Department, Autism New Jersey,
non-voting representative for Linda S. Meyer, EdD, MPA, BCBA

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

Kendell R. Sprott, MD, JD, Acting Director of Pediatrics, University of Medicine and Dentistry New
Jersey Medical School, Academic Institution Representative.

Barbie Zimmerman-Bier, MD, University of Medicine and Dentistry-NJ Medical School,
Academic Institution Representative.

Absent

Jessica C. Guberman, PhD, Executive Director for Community Options, Inc., Autism Organization
Representative.

Linda S. Meyer, EdD, MPA, BCBA, Executive Directory of Autism New Jersey (formerly COSAC),
Autism Organization Representative.

Mr. Judah Zeigler, Associate Vice President of Sharp's Retail and Consumer Marketing, Senate
President Appointee.

NJ Department of Health and Senior Services (DHSS) Attendees

Michael A. Gallo, Jr., PhD, Executive Director, Governor's Council for Medical Research and
Treatment of Autism

Gloria M. Rodriguez, DSW, Director, Special Child Health and Early Intervention Services

Sandra Howell, PhD, Research Scientist 1, Autism Registry

Diane DiGiovacchino, Administrative Assistant 3, Special Child Health and Early Intervention Services

General Public Attendees

Julie Caliwan, Department of Human Services, Division of Developmental Disabilities

Keith Christoffers, The Autism Center, UMDNJ-NJMS

Audrey Mars, Hunterdon Medical Center

Rosemarie Dubrowsky, National Autism Association

I. Welcome

Meeting called to order at 6:17pm by Dr. Gallo. Council Members, Department of Health and Senior Services staff, and public members in attendance introduced themselves.

A. Introductory Comments by Gloria M. Rodriguez, DSW

Dr. Rodriguez welcomed and thanked the Council members for their commitment, time and work thus far. The Council's progression of work, which includes the announcement of a new Basic Science and Clinical Research Request for Applications (RFA) and the important information generated from these grants, along with the Clinical Enhancement grants, are highly anticipated.

II. Chair's Report

A. Approval of February 2, 2009 Governor's Council's Meeting Minutes

- No revisions or corrections.

MOTION by Dr. Eggerding: approve February 2, 2009 meeting minutes.

Moved by Dr. Sprott and seconded by Ms. Goldfarb.

B. Status of Council Subcommittees

Dr. Eggerding noted that although subcommittee members are not ready for a full Council presentation with discussion and voting, members were reminded to review their charge and begin the process.

1. Subcommittee Addressing Role of Scientific Advisory Committee and Development of Strategic Plan for Council.

- Subcommittee members: Dr. Eggerding, Dr. Bier and Ms. Goldfarb.
- The Scientific Advisory Committee is part of legislation PL 2007, Ch168 and the Council's Rules of Order. Its members and specific function are not addressed in these documents.
- Per subcommittee discussion the intent of the Advisory Committee is to focus on research in New Jersey.
- Tasks to assign Advisory Committee: RFA process (ex., extensions, guidelines for review, bridge process), research direction, education focus, direction for year end research conference.

Questions for the subcommittee to address:

- Identifying members from New Jersey creates conflict of interest. Can an Advisory Committee member be a representative of New Jersey and apply for grants?

- Representation wanted from New Jersey, but recognize non-New Jersey individuals may be needed. Issue has not yet been resolved.
 - Should Committee members be reimbursed? If so, structure must be determined.
 - **Call for members of the Scientific Advisory Committee**
The composition of the Advisory Committee is to be made up of 3 basic researchers and 2 clinicians. Dr. Gallo developed a list of recommendations and a call for Council members to forward recommendations was made.
2. Integration of the Council's goals with goals of the Interagency Autism Coordinating Committee (IACC) and other federal organizations
 - Dr. Eggerding will contact subcommittee members.
 - Important for the next RFA announced.
 3. Subcommittee Formulating Council's Policies and Procedures for Supporting other Autism Organizations
 - Subcommittee members: Dr. Evans, Dr. Guberman, Dr. Meyer and Mr. Ziegler
 - Drs. Evans and Meyer reviewed Council legislation, PL 2007, Ch. 168 which was found to be vague in this area.
 - Amount of financial support available from the Council and percentage of total money dedicated to outreach/advocacy needs to be determined.
 - Types of requests to be considered.
 - Subcommittee will regroup to discuss further with all subcommittee members.
 - Dr. Eggerding suggested that because there is no policy in place and legislation is vague as written, that the subcommittee develop a recommendation.

Discussion of Historical Perspective

- Dr. Evans commented that the Council is seen as an opportunity for funding or for many diverse autism organizations when this may, or may not be, within the scope of the Council.
- Dr. Spratt noted that historically COSAC (new name Autism New Jersey) has been the only organization funded by the Council, and that this funding was awarded to satisfy the Council's need to provide educational outreach. However, Dr. Spratt mentioned that no formal discussions took place on what organizations to support or on organizations that were specifically looking for Council funding. At this time there is no policy in place, and it first must be determined if it is within the Council's scope, and if so, what categories will support fall under, i.e., education, outreach, lecture series. The subcommittee on the Council's Policies and Procedures for Supporting other Autism Organizations will need to determine amount of funding and parameters.

Clarification: in past, outreach activities were funded on an ad hoc basis in absent of Council policy.
- Dr. Spratt inquired about the history with other State Councils and their support of organizations.
- Dr. Rodriguez responded by saying it depended upon how the Council was instituted, i.e. some State of New Jersey Councils are "in, but not of" a state department. However, Dr. Rodriguez stated that The Governor's Council for Medical Research and Treatment of Autism is "in and of" the Department of Health and Senior Services. Further, Dr. Rodriguez mentioned that once the Council determines its policy for supporting organizations, it's important to keep in mind that the Council's recommendation must be

in accordance with the Department's fiscal mechanisms that are used to support outside organizations. Therefore, all grants, consulting and professional services must be administered within existing state policy.

C. Autism New Jersey Conference Panel on Autism Research in NJ, October 2009

- Dr. Eggerding accepted Dr. Meyers' invitation to be on the Autism New Jersey's panel during its upcoming Issues in Autism Conference, and to represent the Autism Council at this conference.

D. Autism New Jersey Listening Tour (Autism New Jersey)

- Leslie Long of Autism New Jersey stated that the Autism New Jersey Listening Tour is currently underway. A core group of volunteers are conducting interviews of stakeholders within New Jersey.
 - Data received from the Listening Tour will help form the basis of a collaborative and constructive dialogue at a two-day summit scheduled for June 5th and 6th.
 - A Blueprint for Lifespan Services for Families and Persons with Autism will be developed.
 - Goal is that the Blueprint will serve as a planning and advocacy platform to improve the lives of families and individuals with autism throughout New Jersey.

E. Format for Council Review of Current Funded Projects

- Current format:
 - The 2009 Clinical Enhancement grants submit quarterly expenditure and progress reports to the DHSS. A narrative on initiatives and operational issues is also submitted quarterly.
 - The 2009 Basic Science and Clinical Research grants submit year end reports and end of grant reports.
- As representatives of the state Council, many members are questioned about grant happenings, so Council members stated that consistent grant reporting to the Council would be very helpful and informative.

F. Communication from Grantees Regarding Bridge Funding

- Dr. Eggerding received two letters from Research grantees whose funding ended March 2009. Copies of these letters were distributed to Council members.
- The first letter was from Gleb Shumyatsky, PhD, Rutgers-Human Genetics Institute, (which was also addressed to the Council members), and the second letter was from Walter Zahorodny, PhD, Director, New Jersey Autism Study. Both researchers have completed their projects for the Council.
- Drs. Shumyatsky and Zahorodny expressed concern regarding the lapse between the 2007 Basic Science and Clinical Research grant initiative and the upcoming grant program. Both researchers stated that without continued funding during this lapse of funding they would need to dismantle their lab and personnel.
- Dr. Eggerding stated that it was at the February 2, 2009 meeting that the Council decided not to fund bridge grants, as doing so implied continuous funding. Dr. Eggerding also stated that in issuing the new RFA there is no guarantee the current research grantees (including Drs. Shumyatsky and Zahorodny), would be funded again, and that at the

February 2, 2009 meeting the Council agreed that the best course of action would be to move forward and focus resources to funding the new RFA initiative.

- Dr. Eggerding conveyed to the Council that this message was communicated to Drs. Shumyatsky and Zahorodny and that both were thanked for their input and that they stated that they understood why the Council was moving forward.

III. Executive Director's Report

A. Financial Status Report

Uncommitted for grant funding: \$15.8 million

Committed for coming year: \$7.5 million for the following projects:

- \$2.5 million for the Basic Science and Clinical Research grants (year 1)
- \$3 million for second year of Clinical Enhancement grants (year 2)
- \$1 million for database project
- \$500,000 for conference in Spring 2010
- \$500,000 Post-doctoral Fellowship program

B. Submittal of Council's Annual Report to the Governor and Legislature

- Submitting an Annual Report is stipulated in PL 2007, Chapter 168. Dr. Gallo stated that the 2008 Report was submitted on March 1, 2008.
- Dr. Gallo announced to the Council members that he had brought along a copy of the Annual Report if any Council member would like to review it.

C. The Governor's Council's Official Website (www.nj.gov/health/autism)

- The Governor's Council website when housed at UMDNJ is still active and is the most common site found on the internet causing confusion for the public and constituents.
- The Council set a deadline of mid-May 2009 to have a link installed that will guide viewers from the old Council website to the DHSS official website, or to dismantle the old Council website. Dr. Gallo will work with Judah Zeigler to resolve this problem.

D. Request from DHSS to have the Council fund a collaborative research database structure through a National Institute for Mental Health (NIMH) grant

- Dr. Gallo outlined the scope of the DHSS project and of its request to the Council. It was stated that if the Council funds the DHSS for this database development project, funding will be matched by the federal Recovery and Reinvestment Act of 2009.
- The grant period for the project being presented to the Council would be September 30, 2009 – September 29, 2011, and the DHSS is asking the Council for a funding level of \$1 million. Dr. Gallo stated that it was necessary for the DHSS to make its request of the Council at the April 6, 2009 meeting because the federal Recovery and Reinvestment Act of 2009 grant is due to NIMH by April 27, 2009.
- Dr. Sandy Howell, Research Scientist 1 and Director of the Autism Registry with the DHSS stated that the NIMH funding will support the continuing progress on maintenance and enhancement of a statewide surveillance and tracking system for children screened and diagnosed with Autism Spectrum Disorders.
- In addition, an expanded Autism Data System (linkage to other registries and the National Database for Autism Research) will be developed.
- Therefore, the NIMH project would leverage the development of the Council-funded research database to create a statewide, integrated database for autism research.
- DHSS is asking the Council to fund the database development project (at a funding level of \$1 million over 2 years) contingent upon the DHSS' being awarded the NIMH grant.

- Council members expressed a great deal of concern over the short turn around time in having to vote on this funding request after having only a week to review the written proposal, and expressed the need for more information on specifically how the Council funds are to be spent and what the operation of the database entails.
- After much discussion, Dr. Eggerding asked if a Council member wanted to make a motion to vote on approving the DHSS request.

MOTION by Dr. Bier: Approve the expenditure of \$1 million of Council funding in Fiscal Years 2010 and 2011 (\$500,000/year for 2 years), for the development of the proposed relational database contingent upon the DHSS being awarded the NIMH Challenge Grant. If the DHSS is not awarded the Challenge Grant the Council will not be obligated to fund the development of the relational database. Motion seconded by Dr. Janvier.

Vote

All in favor: 6

Opposed: 1

Motion passes.

E. DHSS Commissioner's Event for National Autism Awareness Month

- Dr. Gallo stated that April is National Autism Awareness month, and that the Commissioner of Health and Senior Services, Heather Howard and Governor Corzine are going to mark the event by visiting one of the Council's Clinical Enhancement.
- Public event to take place April 30, 2009 at the Center for Neurological and Neurodevelopmental Health in Voorhees, NJ
- The topics that will be discussed include: the work of the Council, the Clinical Enhancement Centers and the Autism Guidelines.

F. Update on 2009 Basic Science and Clinical Research RFA (Request for Applications)

- Dr. Gallo emailed the RFA to the Clinical Enhancement Centers and past Council-funded grantees and the Adults with Autism Task Force.
- The RFA will also be emailed to grant managers of New Jersey colleges, universities and government agencies.
- The RFA is expected to be posted on the Council's website shortly.
- The grant application forms are currently available on the Council's website.
- Letters of Intent are due April 27, 2009. Recruitment of grant reviewers will be based on topic areas received.

Update on recruitment of grant reviewers

- Recruitment to begin when Dr. Gallo returns from vacation on April 20th.

Update on recruitment of Study Section Chair

- Dr. Gallo included recommendations in meeting packets distributed to Council members.
- Chair will oversee scoring and ranking of grants.
- Dr. Gallo will compile Basic Science and Clinical Research grant information and present to scoring committee.
- Council members asked to send Study Section Chair recommendations to Dr. Gallo.
- Selection of Chair will be put to vote by Council members.

IV. Comments by Public Attendees

Rosemarie Dubrowsky

- Inquired about a repository of information, such as published studies and work beyond what the Council does, for parents to access and include information on a clinical perspective for professionals.

Note: Council-funded research will be available on the website or will include a link to access information. At a later date, a Council subcommittee will be formed to address the issue of which links will be posted on the Council's website.

Leslie Long (Autism NJ)

- After reading the letters received from Drs. Shumyatsky and Zahorodny, Ms. Long expressed interest on the impact of losing good information from the research grants due to not receiving bridge funding to continue research. Leslie also asked if such an impact statement would be relayed to the public.

Note: Both Research projects have been completed and the Council is not letting significant research drop. This was addressed with both Drs. Shumyatsky and Zahorodny whose major concern was with dismantling their lab and personnel.

V. Identify Action Items for April-May 2009

- Dr. Eggerding will be in contact with subcommittee members addressing the role of the Scientific Advisory Committee before the next Council meeting to work on a consensus for recommendations to the Advisory Committee with the expectation of a Council vote. If a consensus is not met, it will be open to a full Council discussion.
- Dr. Gallo will contact other existing state council constituents and inquire about their policy of organizational support.
- Dr. Gallo will compile a summary of the progress of the Basic Science and Clinical Research grants and a summary of the second quarterly progress reports from the Clinical Enhancement grantees.
- Dr. Gallo and Mr. Ziegler will work together to either link the UMDNJ Council website to the current DHSS website or de-commission the UMDNJ site by mid-May 2009.

VI. Next meeting scheduled for June 1, 2009 at the Division of Developmental Disabilities, Conference Room 199A, 5 Commerce Way, Hamilton, NJ

MOTION by Dr. Evans: adjourn meeting, seconded by Dr. Eggerding.

Meeting adjourned at 8:17pm.