

Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – February 2, 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.

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

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

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

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

Barbie Zimmerman-Bier, MD, University of Medicine and Dentistry of New Jersey, New Jersey Medical School (UMDNJ-NJMS), Academic Institution Representative.

Absent

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

Marilyn Gorney-Daley, DO, MPH, Medical Director, Special Child Health and Early Intervention Services.

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

Other Attendees

Liz Bell, member of the general public.

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

I. Welcome

Meeting called to order at 6:15pm by Dr. Gallo.

A. Introductions

Introduction of Council member Dr. Jessica Guberman of Community Options, Inc. was made by Dr. Gallo. Remaining Council Members, Department of Health and Senior Services staff, and other attendees introduced themselves.

B. Introductory Comments by Dr. Gorney-Daley.

Dr. Gorney-Daley welcomed and thanked the Council members for their expertise and a productive first meeting on December 8, 2008. An update on the autism-related activities supported by the Department of Health and Senior Services was given:

Autism Registry - comment period on the Rules has closed and about 17 technical comments were received. One substantial comment directed toward autism was that the Autism Registry should be separate from the Birth Defects Registry; however, the technical comments should not cause the resubmission of the Rules. At this time it is not known when the Rules will be approved.

Autism Guidelines – first draft developed by Dr. Susan Evans and should be available soon. The goal is to have the Guidelines available this April to coincide with Autism Awareness Month.

First Responders Training – draft developed by Emergency Medical Services within the Department of Health and Senior Services. How the training will be presented has not yet been determined.

II. Chair's Report

A. Approval of December 8, 2008 Council Meeting Minutes.

- Revision requested by Dr. Linda Meyer to incorporate COSAC's name change: Autism New Jersey.
- Draft of December 8, 2008 Meeting Minutes is currently posted on DHSS website which caused concern by some Council members about the potential for inaccuracies in the minutes.

MOTION by Dr. Sprott: only approved Meeting Minutes will be posted on DHSS website to ensure transparency and accuracy, seconded by Ms. Goldfarb, and approved by the Council.

B. Assessment of Council's Charge

Dr. Eggerding proposed the creation of subcommittees to better define the Council's mission, strategies and decision making in the following areas:

- Composition and role of the Scientific Advisory Board stipulated in PL2007, Ch 168.
- Aligning the Council with the federal Interagency Autism Coordinating Committee (IACC) to have Council-sponsored projects mirror federal research initiatives.

- Creating Council policies to guide the Council in assisting other agencies and organizations that focus on autism.

Discussion

- Dr. Sprott expressed concern about the linkages and did not think mirroring the federal research initiatives was a definite direction in which the Council had decided to move.
- Dr. Eggerding stated that this was an idea discussed at our first meeting on December 8, 2008 and not definite. It was agreed upon that mirroring the federal research initiatives will change how Requests for Applications (RFA) are called for.
- Dr. Janvier who sits on the Interagency Autism Coordinating Committee (IACCC), under the federal Department of Health and Human Services stated the focus was to identify National Research Goals of Autism (40 research initiatives) and in order to accomplish this, national and international published researchers were recruited. Dr. Janvier suggested the RFA should have a connection to one of these areas and to also take into consideration the need to have partnership with families, the availability of funding, and where New Jersey can be a leader in the areas New Jersey is skilled in.
- Dr. Eggerding noted that there is an IACC Summary in Advances in Autism Spectrum Disorders Research for 2007 available on the intranet which speaks to these research initiatives.
- Ms. Goldfarb expressed the need for the Council to encumber money at this evening's meeting.

A subcommittee sign-up sheet was passed along to all Council members for each to indicate their first and second choices for participation.

C. Ratification of Council's Rules of Order

Dr. Gallo stated that he will incorporate the December 8, 2008 Council minutes revisions that had been mentioned. Dr. Eggerding called to ratify the Council's Rules of Order for discussion. MOTION by Ms. Goldfarb: Call for motion to discuss approval of the Rules of Order. Accepted and seconded.

Comments

Dr. Meyer: Define ethics and include a yearly sign-off sheet. DHSS will look into its Code of Ethics policy.

Dr. Eggerding called for approval: Approval: yes. Opposed: none. Rules of Order will be posted on the Council website.

III. Executive Director's Report

A. Financial accounting report

Notice of Grant awards for 2010 has been submitted so money will be earmarked for the purpose of allocating funding for the following projects:

- \$5 million for basic science and clinical research grants
- \$3 million for second year of clinical enhancement grants
- \$500,000 for a post doctoral fellowship program

B. Governor's Council's official website

All Council members were informed that the official website for the Governor's Council for Medical Research and Treatment of Autism was published on the Department of Health and Senior

Services, Division of Family Health Services' website on January 16, 2009. Any feedback about the website from Council members is to be sent to Dr. Gallo. The announcement of the new initiatives will be added to the website along with the Basic Science grant status reports from researchers.

C. 2009 Basic Science and Clinical Research Bridge Grant Program

The Council is currently funding the second year of its \$3.3 million, Basic Science and Clinical Research grant program. This initiative, established in 2007 when the Council was housed at UMDNJ, funds eleven grants and this cycle ends on April 30, 2009. Allocating money to bridge grants could allow currently funded grantees to compete for the next round of Basic Science and Clinical Research funding, however, a more feasible option is to offer mini-grants in the amount of \$25,000. After receiving comments from Council members the decision was made not to offer mini-grants to the currently funded agencies.

D. 2010 Basic Science and Clinical Research Grant Program

Council members authorized the announcement of an RFA to include areas of basic science and clinical research. It is expected the RFA will be announced in April 2009. Another RFA to include national standards will be announced during another grant cycle which is undetermined at this time. Any comments/additions to the RFA from Council members are to be sent to Dr. Gallo.

Amount of Grant Awards

The Council intends to fund up to ten grants at a funding level of up to \$500,000 over a 2- year period. Twenty percent of Principal Investigator's salary will be included and no funding of equipment.

E. Recruiting a Researcher to Chair the Basic Science and Clinical Research Review

The number of research institutions in New Jersey is limited, with the institutions doing the most autism research being Rutgers University, UMDNJ and Princeton University. Dr. Gallo met with Ann Marie Hill, the Executive Director of the New Jersey Commission for Cancer Research, and due to state's financial constraints/restrictions it is best to focus on recruiting a grant review chair from Northeast Corridor states. Many of the New Jersey academic institutions receive funding from the Department of Health and Senior Services, and therefore, in order to avoid bias, it is extremely important to have the grant review process be conducted by individuals outside the State of New Jersey.

F. Public Comments

Dr. Gallo asked if any members of the public had comments.

Julie Caliwán passed.

Liz Bell commented on perhaps offering different amounts of funding for the 2010 Basic Science and Clinical Research grants. Ms. Bell also asked if the autism community receives better research with the award of larger grants, and if it is better to fund 20 smaller studies as opposed to 10 larger studies.

Note: It was agreed upon that the result of strong research is the publication of peer-reviewed basic science, and clinical, research articles.

IV. Election of Council Chair

Though Dr. Caroline Eggerding was elected Council Chair at the first meeting held on December 8, 2008, it is stipulated in the Public Law that a Council Chair is to be elected at the first meeting of each calendar year. To comply with PL2007, Chapter 168 the election of a Chair was necessary, and nominations were taken from the Council members in attendance.

MOTION by Dr. Sprott: Elect Dr. Caroline Eggerding as Council Chair, seconded by Dr. Evans.
All in favor: yes. Opposed: none.

Dr. Caroline Eggerding elected as Council Chair.

V. Action Items

- Dr. Eggerding will compose subcommittees via email and contact those Council members absent this evening. A leader is to be chosen for each subcommittee. Dr. Eggerding stated that two months should be enough time to resolve issues with which the subcommittees have been charged to address.
- Meeting Agendas – Drs. Gallo and Eggerding will identify action items for decision making, standing items, and an opportunity for comments from the general public will be included in future agendas.
- Meeting Schedule – Dr. Gallo will create a year long calendar of Council’s scheduled meeting to be emailed to Council Members and posted on website
- Dr. Gallo will email list of recommended researchers for the Scientific Advisory Board to all Council members.
- Dr. Janvier will email her comments about the 2010 Basic Science and Clinical Research RFA to Dr. Gallo.

VI. April 2009 Meeting

Next meeting scheduled for Monday, April 6, 2009, 6pm – 8pm, same location.

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

Meeting adjourned at 8:03pm.