

Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – June 1, 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,
Assembly Speaker Appointee.
Chair of Governor's Council for Medical Research and Treatment of Autism.

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 Directory of Autism New Jersey (formerly COSAC),
Autism Organization Representative.

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

Barbie Zimmerman-Bier, MD, Appointment at Rutgers University, clinician at St. Peter's University,
Academic Institution Representative.

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

Absent

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

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

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

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

General Public Attendees

Audrey Mars, Hunterdon Medical Center
Lisa Huguenin
Agnes Cushing-Ruby

I. Welcome

Meeting called to order at 6:19pm by Council Chair, Dr. Eggerding. Council members, Department of Health and Senior Services staff and public members in attendance introduced themselves

Note: Lorraine Freed Garg, MD, MPH was introduced. Effective Monday, June 8, 2009, Dr. Garg will be employed as a Senior Public Health Physician with the Department of Health and Senior Services, Special Child Health and Early Intervention Services.

II. Chair's Report

A. Approval of April 6, 2009 Council Meeting Minutes.

- Correction to page 3: Drs. Evans and Myers reviewed legislation PL 2007, Ch 168. Remove Dr. Guberman's name.
- Clarification to Discussion of Historical Perspective, page 3: outreach activities were funded on an ad hoc basis, absent of a policy by the Council.

MOTION: approve April 6, 2009 meeting minutes with additions/corrections.
Seconded by Dr. Evans and approved by Dr. Bier.

B. Status of Council Subcommittees

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

- Subcommittee members, Dr. Eggerding, Dr. Bier and Ms. Goldfarb held two telephone conferences regarding the composition and purpose of the Scientific Advisory Committee. PL 2007, Ch. 168, page 6, which defines the Scientific Advisory Committee and Subcommittee recommendations and ideas relative to the Advisory Committee were distributed to meeting attendees.
- PL 2007, Ch 168 reads as follows:
 - Committee members serve at the pleasure of the Council
 - Committee to include three biomedical researchers and two medical clinicians
 - Committee to identify and make recommendation to the council regarding grants for the most promising pilot studies for biomedical research, diagnosis and treatment for autism and autism spectrum disorders
- Recommendations by the Subcommittee (Open to full Council discussion):
 - Role of Advisory Committee
 - Inform Requests for Applications (RFA) Process – provide guidelines to areas of potential dispute including adherence to the RFA process, grant extensions and regular review of grant recipients (interim progress reports).

- Inform Council regarding trends in autism research and demographics worthy of Council focus
- Guide Council regarding development of comprehensive program that builds on prior and current research projects as well as New Jersey resources
- Provide direction for yearly conference on Council-funded research
- Provide scientific leadership at planning groups (i.e. think tanks), to address designated issues of importance to New Jersey

Summary of Council Discussion: the Advisory Committee will be a 3rd party determination or audit in the RFA process; therefore, the Council makes programmatic decisions based on the Advisory Committee's recommendations.

- Advisory Committee Composition. Statute requires five members: three basic researchers and two clinicians.
 - Subcommittee recommends two representatives from New Jersey who will know the State's resources, and three out-of-state representatives.
 - Requests full Council discussion of the potential conflict of interest created when a New Jersey scientist or clinician is appointed to the Committee.
 - Possibilities: no representation from New Jersey, ask retired Scientists, and/or, as a condition of appointment a New Jersey representative on the Advisory Committee is ineligible to receive funding from the Council, or create a liaison position.
 - Recommends terms be established that mirror the terms of individuals who serve on the Council and that terms be staggered for continuity.
 - Recommends Committee members be compensated for their service to the Council.

Summary of Council Discussion: the five member Scientific Advisory Committee cannot adequately review and recommend grant applications for funding because autism is a multidisciplinary field and therefore requires that grant reviewers possess the topic matter expertise reflected in the grant applications to the Council. Thus, the Scientific Advisory Committee is a strategic body as opposed to a body of grant reviewers. So, establishing this distinction will not create a situation where a New Jersey representative to the Advisory Committee will have a conflict of interest.

Mr. Ziegler expressed concern about the recommendation to establishing terms for the Advisory Committee members as it is in conflict with the statute which states "...members shall serve at the pleasure of the council."

- Process
 - A list of names for consideration was presented to the Council by its Executive Director, Dr. Gallo, and at the April 6, 2009 meeting Council members were asked to suggest additional names. A call for recommendations to the Advisory Committee was made again so that a final list of names can be presented at the August 3, 2009 meeting.
 - Recommends that Advisory Committee candidates be sent a letter asking about their interest in serving on the Advisory Committee, and explaining

the amount of time that will required of them to serve on the Committee, and the amount of compensation that they will receive for their service.

- Upon reviewing candidates' resumes the Subcommittee recommends that the Council conduct a vote to determine the membership of the Advisory Committee.

2. Integration of the Council's Goals with Goals of the IACC and other Federal Organizations

- Subcommittee members: Drs. Janvier, Sprott and Ms. Grace Reilly.
- No report.
- Subcommittee to meet before next Council meeting.

3. Formulating Council's Policies and Procedures for Supporting Other Autism Organizations

- Subcommittee members, Drs. Evans, Guberman, Meyer and Mr. Zeigler are to develop policies and procedures regarding the Council's support of autism organizations.
- No previous guidelines or policies exist; a policy recommendation can be made by this Subcommittee.
- PL 2007, Ch 168 was previously reviewed. Goal of legislation is for research into cause and treatment of autism. Outreach and education are also part of the legislation which may be accomplished, in part, through providing support for autism organizations.
- One telephone conference held by Drs. Meyers, Evans and Mr. Ziegler.
- RFPs (Request for Proposals) for autism organization activities and workshops considered.
 - The Council to consider proposals/requests from autism organizations that are primarily based in New Jersey, may be local chapters of national organizations, and non-profits.
 - The Council may issue RFPs around specific outreach/education needs.
 - The Council will accept proposals for review that meet certain criteria.
- Details:
 - Recommend up to 30% (\$750,000) of total Council yearly funding allocated to support autism organizations and their outreach efforts.
 - Maximum grant for each proposal and length of activity not determined.
 - Acknowledgement of Council and its funding is to be used on all materials produced by the recipient of funds.
 - One application per organization per calendar year.
 - Council can implement restrictions on certain costs/activities that will not be awarded.

Summary of Council Discussion: All the autism clinical enhancement centers have an outreach component and there was concern about the overlap of services. Are the goals of the outreach activities being met through what is currently funded? The coordination of activities could be a part of Council funding. The RFP process may not be the tool needed for unsolicited requests; however, a consistent and appropriate response is needed. A strategic plan should be developed that includes how much money is to be allocated to support outreach/education and what the application process is.

Dr. Rodriguez suggested that the Council can commission a strategic plan and with the help of the Department of Health and Senior Services the Council can contract with a state entity to provide an analysis of what is being accomplished through the clinical enhancement grants and determine where overlaps and gaps occur. This can be accomplished through a Letter of Agreement. Duties of entity could be a presentation for the next Council meeting scheduled for August 3, 2009.

At this time a percentage of money to allocate to support organizations and their outreach efforts is premature.

III. Executive Director's Report

A. Overview of the National Autism Awareness Month Event Held on April 30, 2009

- The National Autism Awareness event was held at the Center for Neurological and Neurodevelopmental Health in Voorhees, New Jersey and attended by the Council's Chair, Dr. Eggerding.
- Governor Corzine and Health and Senior Services Commissioner Howard singled out the efforts of the Council and the leadership within the Division of Family Health Services of the Department of Health and Senior Services.
- There was a question and answer session following the event which focused on adult services.
- Dr. Gallo stated that although the Department of Treasury has inquired about unexpended Council funds, he is optimistic that those funds will remain dedicated funds for use by the Council because both Governor Corzine and Commissioner Howard singled out the efforts and accomplishments of the Council in recent appearances.

B. The Governor's Council's official website is (www.nj.gov/health/autism)

- The URL address that was established when the Council was housed at UMDNJ is no longer active.

C. Processing Year 2 Funding for the Clinical Enhancement Centers

- Year 2 grant funding for the six Clinical Enhancement Centers begins July 1, 2009 and ends June 30, 2010.
- The DHSS has mailed funding letters and Year 2 applications to the Council-sponsored agencies, and the applications are due to the DHSS by June 19, 2009.
- Once received, applications will be reviewed and assembled for processing through appropriate channels.
- The data and clinical functions of the Enhancement grants will need to be reviewed as more focus will be placed on reporting and data in a second 2-year cycle of this grant program. Dr. Gallo stated that additional funding to support these grant services will be needed. Input from the Council and Department staff will be called for.

D. Update on the 2009 Basic Science and Clinical Request for Applications (RFA)

- The RFA was announced April 6, 2009 and included two parts to the application process: Letter of Intent and Grant Application.
- Dr. Gallo stated that given that autism is very multi-disciplinary field, requesting the submittal of Letters of Intent would help him determine the type of content experts needed to effectively review the grant applications that the Council would receive.

- Original grant application deadline was May 29, 2009. This date was pushed back to June 16, 2009.
- A total of 29 Letters of Intent were received, however, one hospital pulled out.
- Fourteen national and international autism experts have been recruited to review applications.
- One individual is challenging the language of the RFA. This individual did not submit a Letter of Intent, but did submit an application. The individual claims the RFA does not say “if you do not submit a Letter of Intent you cannot submit an application”.

Available options to address the situation:

1. Allow the RFA process to continue as currently scheduled and have the individual decide if he will file a formal appeal with the state Grants Appeal Board. Dr. Rodriguez stated that if an appeal is submitted, the RFA process stops until the Board makes a determination. Dr. Gallo stated that if the Board rules in the individual’s favor, this opens the door for other individuals who would have submitted a letter of intent, but adhered to the submission deadline.

2. Reopen the RFA and include language making the submission of a Letter of Intent a requirement for submitting a full grant application. This action would push the process back two months with funding to start December 1, 2009, as opposed to October 1, 2009. If this action is taken, those individuals that have already submitted a Letter of Intent will not need to resubmit a letter of intent.

The Executive Director was asked for his recommendation by Dr. Linda Meyer. Dr. Gallo stated his recommendation is to reopen the RFA.

Motion by Mr. Ziegler: Move to accept the Executive Director’s recommendation to reopen the RFA. Seconded by Drs. Eggerding and Janvier

Vote

All in favor: 6
 Oppose: 2
 Motion passes.

IV. Public Comments

Agnes Cushing-Ruby

- Ms. Cushing-Ruby has a 22 year old with autism. She wants to see research priorities funded and expressed the disappointment of parents of children with autism when research priorities are not funded.

Other Comments:

Dr. Bier

- Expressed the need for the Council to set specific goals and for it to fund meaningful research. Dr. Zimmerman-Bier believes that barriers preventing these actions from occurring need to be examined. She further stated that she believes that the Council members need to receive regular updates on the accomplishments of the six clinical enhancement centers.

Dr. Janvier

- Dr. Catherine Lord of the University of Michigan will be speaking at the Children’s Specialized Hospital Mountainside location at 1:30pm on June 8, 2009.

- Dr. Susan Levy, from the Center for Autism Research in Philadelphia, will be copying and implementing the Children's Specialized Hospital Developmental Screening Program.

Dr. Meyer

- Invited meeting attendees to day one of Autism New Jersey, Inc.'s Listening Tour Summit on June 20, 2009 in Newark's North Ward Center. Governor Corzine will be in attendance.

V. Action Items

- Role of Scientific Advisory Committee and Development of a Strategic Plan for Council Subcommittee - Council members agree with subcommittee recommendations and a formal proposal will be developed and presented to the Council at the August meeting. Mr. Zeigler will assist Dr. Eggerding with the language in this proposal.
- Dr. Gallo will resend Council members the list of recommended names to the Scientific Advisory Committee.
- Council members are to email Dr. Gallo any additional recommendations for the Scientific Advisory Committee.
- A final list of names for the Scientific Advisory Committee to be in place for the next Council meeting, August 3, 2009.
- There have been no recent appointments to the vacant seats on the Council. Dr. Gallo will be drafting correspondence to the Governor's Office.

VI. August 2009 Meeting

Next meeting scheduled for Monday, August 3, 2009, 6pm – 8pm at the Department of Human Services, Division of Disability Services, 5 Commerce Way, Hamilton, New Jersey.

MOTION by Dr. Eggerding: adjourn meeting.

Meeting adjourned at 8:20pm.