

**New Jersey Department of Health and Senior Services  
Governor's Council for Medical Research and Treatment of Autism  
Meeting Minutes – August 2, 2010 (ratified)**

**6:00pm – 8:00pm**

**Location: Department of Human Services/Division of Developmental Disabilities  
Conference Room 199A, Hamilton, NJ**

**Council Members Present**

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

Caroline Eggerding, MD, Vice President Clinical Services, Bancroft NeuroHealth,  
Assembly Speaker Appointee, and Chair of 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

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

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

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

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, Appointment at Rutgers University, clinician at St. Peter's University, Academic  
Institution Representative

**Absent**

Michele Adubato, MSW, MA, Deputy Executive Director, The North Ward Center, Inc., Public Member

Jessica C. Guberman, PhD, Executive Director for Community Options, Inc., 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**

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

Lori Garg, MD, MPH, Senior Public Health Physician  
Special Child Health and Early Intervention Services

John Crosbie, Executive Director  
Governor's Council for Medical Research and Treatment of Autism  
Commission on Brain Injury Research  
Commission on Spinal Cord Research

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

**General Public Attendees**

Kathleen Freeman, PhD, RNC

Ms. Josephine Shenouda

Ms. Susan Freedman, Hunterdon Regional Autism Center and Special Child Health Services Case Management

Audrey Mars, MD, Medical Director, Regional Autism Center at Hunterdon Medical Center

Pnina Mintz, PhD, Executive Vice President, Center for Neurological and Neurodevelopmental Health

**I. Welcome and Introductory Comments from DHSS**

Meeting was called to order at 6:04 pm by Dr. Eggerding, Council Chair. Dr. Rodriguez thanked everyone for attending this evening's meeting.

**II. Review and Approval of the June 7, 2010 and July 12, 2010 Meeting Minutes**

MOTION by Dr. Sprott: to approve the June 7, 2010 Council meeting Minutes with no corrections. Seconded by Ms. Goldfarb. Motion carries.

MOTION by Dr. Sprott: to approve the July 12, 2010 Council meeting Minutes with no corrections. Seconded by Dr. Meyer. Motion carries.

**III. Announcement of Executive Director**

Dr. Eggerding introduced Mr. John Crosbie the new Executive Director of the Governor's Council for Medical Research and Treatment of Autism, Commission on Brain Injury Research, and Commission on Spinal Cord Research. Mr. Crosbie said he looks forward to working with everyone and is in the process of developing a time line for the Council and two Commissions.

The Council members in attendance introduced themselves.

**IV. Rules of Order Change Relating to Attendance and Provision for Chairman Absence**

Dr. Eggerding noted at the Council's June 7, 2010 meeting discussions regarding the Rules of Order relating to the attendance of Council members and the provision for the Chair's absence took place.

**Council Members' Attendance**

Dr. Eggerding said there have been challenges with respect to achieving a quorum on a regular basis and the review of the grounds for recommending removal was discussed at the last Council meeting. As the current approved Rules of Order are written, page 7, Section 4, "It is grounds for recommending the removal of a member from the Council if that member: 3. is absent from more than half of the Council meetings that the member is eligible to attend during a calendar year without providing notification to the

Council prior to such absence;...”

Dr. Eggerding said this wording allows a member to be absent an entire year as prior notification of a member’s absence is only required. This makes it very difficult to consistently have a quorum and comprehensive discussions. Last month the Council discussed eliminating “without providing notification to the Council prior to such absences,...”. The revised Rules of Order will say “...a member can be recommended for removal if a member is absent from more than half of the meetings that a Council member is eligible to attend during a calendar year.”

MOTION by Dr. Sprott: move to accept recommended changes. Seconded by Dr. Meyer.

Vote

All in favor: 10

Oppose: 0

Motion passes.

**Provision for Absence of Chairman**

Dr. Eggerding noted as the Council has been set-up and with respect to the legislation, PL 2007, c 168, (Legislation) only calls for a Chairman. There is no provision as to what happens when the Chair is unable to attend a Council meeting. Dr. Eggerding said the options discussed at the last meeting included electing a Vice Chair and electing a parliamentarian. Dr. Eggerding’s recommendation is to change the Rules of Order to include a statement noting it is the Chair’s responsibility to name a Council member to Chair the meeting.

MOTION by Dr. Sprott: move to have changes made. Seconded by Dr. Meyer.

**Discussion**

It was agreed to use the word “Chair” and remain gender neutral. Dr. Evans inquired as to the advantages of revising the Rules of Order as opposed to electing a Vice Chair. It was noted that revising the Rules of Order allows flexibility and is the most expedient process. Dr. Eggerding added the issue of electing a Vice Chair on a yearly basis is raised and the Legislation does not assume responsibilities to the Vice Chair. In addition to covering for the Chair in his/her absence, responsibilities could be assigned to the Vice Chair, however, this involves a larger change to the Rules of Order.

Vote

All in favor: 10

Oppose: 0

Motion passes.

**V. Center of Excellence Update**

- The Center of Excellence update was presented by Dr. Evans. She noted the Subcommittee is being conscientious of what the Council discussed at its February 2010 retreat and at the same time maintaining the intent of the Legislation. She noted the previous Executive Director of the Council requested public input with approximately 4-5 letters being received. These were reviewed and taken into consideration. Dr. Evans said NJACE (New Jersey Autism Center of Excellence) is one program and noted at the Council Retreat members spoke of a Coordinating Center with multiple program sites reporting to the Coordinating Center. Dr. Evans made a request to the Council on behalf of the Subcommittee for input from any members who will not be responding to the Coordinating Center RFA and the program sites RFA. She also noted the amount of funding for the program needs to be

determined in order for the Subcommittee to move forward. Dr. Evans presented the following options for NJACE asking the Council members to consider where it sees the Basic Science Research Program and the Fellowship Program.

#### Option 1

Model includes a Coordinating Center in which the multiple program sites of the Center of Excellence, the Basic Science Research Program and the Fellowship Program are coordinated through the central Coordinating Center.

#### Option 2

Model includes a Coordinating Center in which the multiple program sites of the Center of Excellence are coordinated through the central Coordinating Center. The Basic Science Research Program and the Fellowship Program report to the Council and DHSS.

Dr. Bier arrives.

- Both options include a central Coordinating Center that also encompasses a Steering Committee, the Scientific Advisory Committee, and data monitoring with the multiple program sites reporting to the Coordinating Center. Dr. Evans noted Option 2 corresponds with what members discussed at the Council retreat. The essential difference between the options presented are where the Basic Science Research Program and the Fellowship Program are placed. Dr. Eggerding asked what the other functional differences between the two options are. Dr. Evans noted depending upon where the Basic Science Research Program and the Fellowship Program are placed it will change the scope of responsibilities and there is the philosophical stand point of what option best reflects the intent of the Legislation. She added there could be a third option in which everything the Council does is via the Center of Excellence and there is no separate Basic Science Program as it currently exists. Dr. Evans stated the RFA Subcommittee views one of the roles of the Coordinating Center will be to develop education and outreach curricula.
- Dr. Eggerding asked about the Steering Committee and it was noted that this follows the national model of a Coordinating Center. Dr. Rodriguez said it would be made up of representatives from the Council, DHSS and from each individual program site to coordinate activities.
- Noting that NJACE includes a Coordinating Center and a Steering Committee Dr. Sprott questioned the function and role of the Council. Mr. Crosbie suggested moving responsibilities to the Coordinating Center in a sequential manner. Dr. Evans said it is an option and something that can be discussed. Dr. Eggerding noted that identifying the essential functions of the Council would help the Subcommittee complete its work on the RFA. In referring to the Legislation the Council's role is to vote on grant award dollars and define the scope of programs undertaken.
- Dr. Janvier questioned the role of the Coordinating Center noting the activities the previous Executive Director coordinated. Dr. Rodriguez clarified DHSS role by saying DHSS is responsible for issuing the RFA, coordinating the review of the RFA, and issuing the grant awards. It is DHSS responsibility to monitor all awarded health service grants both fiscally and programmatically. This role will be the responsibility of Mr. Crosbie and his staff. It is not the role of the Coordinating Center. Mr. Crosbie added he is in the process of hiring an executive assistant who will be assigned almost exclusively to the Council. He said the Council is a priority and gave his commitment that time will be devoted to the Council. It was also noted by Dr. Rodriguez that an RFA is written for the Coordinating Center that addresses its role. Dr. Rodriguez said this information can not be shared with the Council as some of its members will be responding to the RFA. The integrity of the process needs to be protected so that everyone has an equal chance to respond at the same time and with the same information to avoid anyone from potentially being disqualified.
- Dr. Sprott asked about the relationship of the Scientific Advisory Committee relative to DHSS and their

role. Dr. Rodriguez said the role of the Scientific Advisory Committee is to advise the Council members on research areas, opportunities, and pockets of interest on national and state levels. She added the Scientific Advisory Committee in Options 1 and 2 are located within the Coordinating Center because the Coordinating Center will facilitate and coordinate the administrative work of the Scientific Advisory Committee meetings and with bringing its members before the Council.

- Dr. Bier expressed her opinion by saying Option 1 fits best with the Legislation. When applying for federal grant money it is helpful to have a Center of Excellence with clinical components as well as research components. By coordinating these efforts it is anticipated that the Coordinating Center would help with prioritizing, relevance, and avoidance of duplication in areas of funding.
- Dr. Bier noted the Legislation does not address the Executive Director monitoring grants. She added DHSS has a structure for the monitoring of clinical programs which include individual program staff who monitor health service grants. She asked if DHSS will be monitoring the Clinical Enhancement Centers as opposed to the Executive Director and the Coordinating Center be responsible for other work. Dr. Rodriguez said any grant issued by Family Health Services (FHS) has the responsibility of monitoring the grant both programmatically and fiscally. FHS' Fiscal Unit monitors the health service grants' budgets. Mr. Crosbie reports directly to the Assistant Commissioner and he will have staff who will be responsible for monitoring the grants awarded by the Council. Dr. Rodriguez noted she will continue to be responsible for the Autism Registry as it is part of the Birth Defects Registry and those grants that fall under the Registry for Case Management.
- It was noted there is the philosophical stand point in that which NJACE option reflects the Legislation and how Council members view the concept of NJACE. Dr. Eggerding said does the Autism Center of New Jersey completely meet the requirements of the Legislation and does the Council really function as the strategic planning board and the over site board for the NJACE.
- Dr. Eggerding asked Council members to provide feedback to the Subcommittee about structure. Dr. Meyer stated she needed additional information about the function of all parts of NJACE before feedback on structure can be provided. She also requested information about the function of DHSS as it relates to the Council and function of staff involved with the Council. Mr. Crosbie said he would develop a presentation for Council members addressing the function of DHSS and staff.
- Dr. Eggerding noted placing the Basic Science Research Program and the Fellowship Program outside or inside the Coordinating Center, the responsibility of Council is to apportion money, including budgetary priorities, define the scope of programs undertaken, and operating strategic planning equipped with expertise of Scientific Advisory Committee.
- Dr. Janvier expressed her concern with Council members who receive grant funding or potential grant funding and how to balance that with the function of the Council. She suggested addressing the issue in the Council's Rules of Order. This is an area of future discussion.
- Given her concerns with structure Dr. Sprott asked Dr. Meyer to help the RFA Subcommittee. Dr. Meyer agreed, as long as she is not putting her agency at risk of being ineligible to respond to the RFA. It was noted how the structure of DHSS has changed or potentially will change in the future. Dr. Rodriguez clarified that the structure of DHSS has not dramatically changed. One internal reporting change that has occurred is that the Executive Director will report to Ms. Celeste Andriot Wood the Assistant Commissioner of FHS and not Dr. Garg. She stated the function of the Executive Director remains the same.
- It was noted, based on the upcoming budget projections to be presented, the amount of funding for the NJACE program needs to be determined by the Council for the Subcommittee.
- Council did not reach a consensus on the NJACE options.

#### **VI. Budget: Current Status and Projection/Discussion: Strategic Plan for Budget**

- Dr. Rodriguez presented the Council's budget for State Fiscal Year (SFY) 2010 and the projected Council budgets for SFY 2011 and 2012. A SFY runs from July 1 – June 30 of any given year. Dr. Rodriguez also presented the estimated Council's operating expense budgets for SFY 2011 and

2012 and the estimated Autism Registry's operating expense budget for SFY 2011 saying up to \$500,000 can be allocated for each. She added the State Budget for Fiscal Year 2010-2011 includes language authorizing DHSS to use money from the Council's Treatment fund, PL 2007, ch 174, to support the operating expenses. Previously, special line items were included in the State Budget to support the operating expenses.

- Dr. Rodriguez said \$1.6 million in revenue was generated the first six months of last fiscal year and based on this figure \$3.2 million is the projected revenue for SFY 2011 and SFY 2012. It was noted that the money generated by PL 2007, ch 174 is deposited quarterly and the Department of Treasury has an allotment of \$4 million per fiscal year, however, this figure looks to be unrealistic.
- Dr. Rodriguez noted \$9.2 million was carried over from SFY 2010 into SFY 2011. The expenses for SFY 2011 include the Council's operating expenses, the Autism Registry's operating expenses, and the amount of money committed to the Basic Science and the Clinical Enhancement grant programs. At the end of SFY 2011 approximately \$6.1 million should be available depending upon the amount of revenue generated.
- Any unspent money returns to the revenue account.
- Dr. Rodriguez noted in SFY 2012 the NJACE RFA will be awarded. She added based upon the money the Council will have available on a consistent basis, \$3.2 – \$4 million, the Council can consider how much money it anticipates spending.
- Dr. Eggerding noted in planning for the years ahead and if there are no changes, the Council needs to include \$750,000 - \$1 million for operating expenses saying approximately \$2.5 million per year will be available. She asked Council members to begin considering the amounts of money to support clinical services, basic science research, and professional development. She added there may be others areas Council members feel are important from the stand point of funding based on the Legislation.
- Dr. Spratt asked what salaries are being supported. Dr. Rodriguez responded by saying one-half of the Medical Director, one-third of the Executive Director, one-third of the Contract Administrator, and one full-time equivalent of the Executive Assistant. Dr. Bier requested job descriptions.
- In order to move the RFA process forward Dr. Eggerding said a relative proportion as to what the Council wants allocated to NJACE, which includes the RFA for the Coordinating Center and RFA for the program sites, needs to be determined. The Council also needs to reserve funding for the Basic Science Research Program and the Fellowship Program as the Subcommittee is not planning to include a Basic Science RFA in this grant cycle. Noting that the hour is late, Dr. Eggerding presented three options to the Council: continue discussion, schedule a Council meeting relatively soon, or discuss at the Council's October 4, 2010 meeting.
- Ms. Goldfarb said the Legislation includes language in which the Chair is charged with informing the public. When devising what NJACE looks like she hopes there is thought and considerable revenue put forth to that process.
- Dr. Bier said when committing a certain amount of change to a project, it is beneficial to think about it and obtain needed information to make a good decision. She suggested it would be helpful to know where other children are being seen throughout New Jersey, ie, at the Clinical Enhancement Centers (CECs), review these numbers, amounts attached, and compare them to the Council's Clinical Enhancement grants. She asked is there a way to coordinate efforts going forward and thinks it is also a part of this mission's early diagnosis and treatment, as well as research into causes and treatment, and lifelong issues before the Council makes a decision.
- Dr. Eggerding thanked Dr. Rodriguez for her budget presentation saying it gives the Council a vision on how to guide the revenue. She asked the Subcommittee about direction and time frame so that the Council can respond and inform the Subcommittee adequately of what it thinks is appropriate. Dr. Evans said the RFA needs to be submitted for internal DHSS channels to review by October 2010. In order to support this time frame, the Council agreed to cancel the October 4, 2010 meeting and schedule a three hour meeting on September 20, 2010 to include a discussion and determination of the amount of money to be dedicated to infrastructure and to also focus on the guiding principles of the Scientific

Advisory Committee. As the Council considers funding amounts it was noted NJACE is a 5 year project and is to be funded as a program. The Council also needs to reserve money for the Basic Science Research Program and the Fellowship Program. Dr. Eggerding added there may be other activities to fund, which may or may not be incorporated into the RFA.

- Dr. Bier added the Legislation includes pilot studies for research.
- Dr. Sprott noted with a five year time frame the Council needs to be cautious about spending money as there are variables, ie, health care reform and State fiscal issues, which could impact the amount of money available to the Council to spend.

## **VII. Status Update**

- Scientific Advisory Committee – Council members were requested to submit their top 5 researchers and top 5 clinicians in rank order. Dr. Garg reported she contacted the two Council members whose rankings are outstanding.
- Basic Science Research Grants – Dr. Garg reported eight of the 11 grant applications have been processed.
- Year 3 of the Clinical Enhancement Grants – Dr. Garg reported she has reviewed all six grant applications and requested modifications to the applications which are currently in various stages of being received. The grant application process includes additional review channels and the funding start date is July 1, 2010.
- Memorandum of Agreement (MOA) for Needs Assessment – Dr. Garg reported the conflict in language as reported at the June 7, 2010 Council meeting has been resolved by DHSS and Rutgers University Center for State Health Policy. The budget has been revised to reflect SFY 2011. The MOA has been submitted internally through DHSS channels for processing and approval.

## **VIII. Comments by General Public in Attendance**

None.

## **IX. Identify Action Items**

- Dr. Bier requested job descriptions of the positions supported by the Council's operating expenses.

## **X. Adjournment**

The next meeting of the Governor's Council for Medical Research and Treatment of Autism is scheduled for September 20, 2010, 6pm – 9pm. Location to be determined.

Meeting adjourned at 8:36pm.