

**New Jersey Department of Health and Senior Services
Governor's Council for Medical Research and Treatment of Autism**

Meeting Minutes – August 3, 2009

6:00pm – 8:00pm

**Location: Department of Human Services, Division of Developmental Disability Services
Conference Room 199A**

5 Commerce Way, Hamilton, NJ 08691

Council Members Present

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

Ms. 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

Linda S. Meyer, EdD, MPA, BCBA-D 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

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

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

Celeste Andriot Wood, Assistant Commissioner
Division of Family Health Services

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

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

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

Public Attendees

Jean Hewens, Hunterdon Regional Autism Center

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

Agnes Cushing Ruby

Keith Christoffers

Kathy Selvaggi Fadden, Child Development Center; Goryeb Children's Hospital

Genevieve Kumapley, Executive Director, My Goal Inc.

Liz Bell

Lisa Huguenin

I. Welcome

Meeting called to order at 6:10pm by Council Chair, Dr. Eggerding. Council members, Department of Health and Senior Services staff and public members in attendance introduced themselves.

A. Introductory Comments by DHSS

Ms. Celeste Andriot Wood, Assistant Commissioner of the Division of Family Health Services, welcomed and thanked the Council for their important work. She stated that she is in attendance at the meeting to answer any questions the Council may have on administrative and/or management issues at the Department level. Ms. Wood further stated that the revenue that supports the Council's work continues to build, and that there have been many opportunities for, and areas of growth over the last few years since the Council's transition from UMDNJ to DHSS.

II. Chair's Report

A. Approval of June 1, 2009 Governor's Council Meeting Minutes

MOTION by Dr. Janvier: to approve June 1, 2009 meeting minutes with correction.
Seconded by Ms. Goldfarb.

Chair Activities:

Dr. Eggerding attended the Autism New Jersey Listening Tour Summit on June 20, 2009. Over 200 people, which included consumers and service providers, participated in the event. The Listening Tour is a strategic planning event and its work continues.

A number of telephone conferences were held with Drs. Gallo and Garg about the Council's strategic plan and conducting a needs assessment.

A meeting with the Council's Autism Clinical Enhancement grantees was held on July 30, 2009 to discuss data issues. A second meeting to discuss goals and challenges for Year 2 of the grant program has been scheduled for September 10, 2009. Dr. Eggerding has been invited to attend and hopes to be able to do so. A report of these meetings is to be generated for the next Council meeting scheduled for October 5, 2009.

Relevant to a needs assessment, its cost, the role of the Council, and its role in DHSS, Dr. Eggerding looked at Legislation PL 2007, c. 168, to understand what it means to be "in" the DHSS. Dr. Eggerding stated that in reading the Legislation it is evident that the Council does

have some role as an advisory council and some role in decision making. However, the question is, where is that line? Dr. Eggerding stated that the language of the Legislation is not clear.

Ms. Celeste Andriot Wood stated the Governor's Council for Medical Research and Treatment of Autism is "in" the Department of Health and Senior Services and therefore subject to DHSS authority and approval process. As the Legislation is written the Council is not a completely independent body, but in no way states there cannot be independent thought and independent recommendations. However, Ms. Wood noted that the DHSS does have the right to override any decision made by the Council that DHSS is in complete disagreement with by virtue that the Council is "in" the Department. Ms. Wood instructed the Council to look at the Legislation and follow each charge. Regardless if the Council is "in but not of" the Department or "in and of", the Department's role poses no negative impact on the Council and therefore, the Council should move forward with its agenda.

Comments

Dr. Janvier expressed her concern with barriers to screening autism.

Dr. Evans noted there are challenges within the early intervention practice, such as the fact that diagnosing autism is outside the scope of some of their staff.

Dr. Eggerding suggested the relationship/partnership with early intervention and the autism Clinical Enhancement grants could be a discussion point at the next Clinical Enhancement grantees meeting.

B. Update on the Process of Developing and Conducting a Council-sponsored Needs Assessment – Open to Council Questions and Discussion

- Dr. Eggerding stated the Council has been funding and supporting Basic Science and Clinical Research and Clinical Enhancement grant programs. However, with the recent Basic Science and Clinical Research RFA now announced and closed an opportunity presents itself for the Council to think about defining its role in the larger context of providing and delivering autism services. Dr. Eggerding has had numerous conversations with Drs. Garg and Gallo over the last two months regarding the fact that there is no overall state plan for autism in New Jersey. Rather, as Dr. Eggerding stated, there are many agencies, state government entities, and a network of influential advocacy groups in existence and the Council also has a role. The Council has the ability to fund a comprehensive look at the delivery of autism services in New Jersey. Legislation, PL2007, c. 168 includes language about creating a Center of Excellence; however, what does this mean in New Jersey and how is the Council going to work towards that designation? A strategic plan begins with an analysis of needs. A Council sponsored needs assessment is an opportunity for the Council to take a comprehensive look at the current systems and define gaps.
- Two telephone calls have been held with Dr. Joel Cantor and Ms. Margaret Koller of the Rutgers University Institute for State Health Policy about conducting a needs assessment on autism clinical and research services in New Jersey as it relates to the Council's work, and the creation of a Center of Excellence in New Jersey.
- Dr. Gallo noted this is also an opportunity to open the scope wider and look at different services throughout New Jersey. Dr. Gallo also stated that such a needs assessment would then be a statewide resource for other groups, ex. clinics, hospitals, researchers. He also noted that if the Council were to expand the scope of the needs assessment, the timelines would change.

Council Discussion

- The process of a needs assessment would take one year to 18 months and cost up to \$200,000. However, depending upon the size of the scope requested by the Council the cost would increase. The process would begin with a literature review and review of other state models. Focus groups, advocacy groups and government would also be looked at.
- Dr. Evans expressed concern over widening the scope and duplicating the efforts of Autism New Jersey, the Adults with Autism Taskforce, and what the Council already knows in terms of the medical and research base in New Jersey. She asked how is the process of a needs assessment, which could take 18 months, different from the information that may already be available to the Council? She also stated that the Council's scope and boundaries are established in Legislation PL 2007, c. 168.
- Dr. Eggerding responded by saying information and policies already available would be used. There are more elements to look at in terms of what the public health response is to issues such as the barriers to screening for autism.
- Dr. Janvier would like to see needs in the area of autism identified and have the Council spend money in those areas.
- Dr. Meyer suggested that all points of view regarding the potential of doing a needs assessment be looked at carefully and thoughtfully as a great deal of money would be spent. Dr. Meyer asked is the Council exhausting its own talents, resources, thoughts, and energy first before beginning a needs assessment. She also questions the value of the needs assessment.
- Ms. Wood suggested the Council take into consideration what it wants to happen. A strategic plan does exist by virtue of Legislation PL 2007, c. 168; however, the details of what was discovered in the Autism New Jersey Listening Tour and the Adults with Autism Taskforce need to be examined. The Council needs to remain within the context of the Legislation and the charges that the Legislation set forth. A needs assessment, whatever the size, will be valuable regardless of the Council's existing talents and knowledge as it will be difficult to document those things without a third party being involved.
- Dr. Evans expressed concern with the lack of communication between various entities and how to foster that type of communication.
- Dr. Meyer asked Ms. Wood to give examples of facts the Council would learn from a needs assessment.
- Ms Wood stated that a needs assessment is based on fact. The Council needs to focus on its charge as specified in the Legislation, then look at those areas in the needs assessment, or choose to go beyond it. It is the Council's decision. Ms. Wood stated that one of the questions that can be asked is, is research being focused in the right area?
- Ms. Wood stated some of the information that would be obtained from a needs assessment would help to identify necessary training for practitioners to be able to make appropriate referrals. Ms. Wood also stated that the needs assessment could address questions such as, what key components are necessary to have across each Clinical Enhancement Center? What is considered state of the art in regards to the approach taken in diagnostic treatment centers? On the national level what centers have that type of state of the art reputation and what are they doing? Are national centers doing something different or are we doing everything they are doing?
- Dr. Bier asked if the needs assessment could look at funding agencies outside of the Council, ex. housing and transportation, and how these issues impact health issues.
- Dr. Gallo indicated that having the needs assessment look at funding agencies outside of the Council depends upon the size of the scope requested. He also said Dr. Cantor is open to targeted questions and reiterated that a recording of what services and information currently exist is paramount, but will be difficult for the Council to do on its own.

- Dr. Sprott noted that whether the needs assessment's focus is limited or broad, having concrete information would be helpful in letting the Council know where it is, decide where it wants to go, and which initiatives to fund that have the greatest merit. Dr. Sprott stated that the Council needs to discuss exactly what information it wants.
- Ms. Reilly accessed the IACC's (Interagency Autism Coordinating Committee) strategic plan via the internet. She thinks it's a good plan and suggested the Council do something in line with this national plan.
- Dr. Meyer was concerned that once the Council had a plan, how receptive would the state be to that plan. She asked, who is going to pay attention? She also didn't think other state agencies would be interested.
- With the end in mind, Dr. Meyer asked Council members to think about what direction the Council will take once a needs assessment is received.
- Ms. Goldfarb stated the Council would use the information to define what it would fund.
- Dr. Evans wants a strategic plan in place as soon as possible. Therefore, she is in favor of a limited scope needs assessment because it would offer the shortest turnaround time. She pointed out that Council members are only appointed for three-year terms and that the body of the Council could change before a strategic plan is in place.
- Dr. Eggerding suggested that if the Council is in agreement, Dr. Cantor would be invited to the next Council meeting. She understands the Council's concerns that a needs assessment be completed in a timely fashion. Dr. Eggerding stated that the Council will have the opportunity to vote on funding a needs assessment and asked Council members to email their thoughts on this issue to Drs. Garg or Gallo.
- Dr. Meyer asked about getting two bids on the cost of a needs assessment. Dr. Gallo then explained that the most expedient process would be implementing a Memorandum of Agreement with a State institution.

C. Status of Council Subcommittees

- Subcommittee Addressing the Role of the Scientific Advisory Committee and the Development of a Strategic Plan for the Council. Subcommittee members: Drs. Eggerding, Bier and Ms. Goldfarb.
 - Dr. Eggerding stated the list of recommended researchers and clinicians compiled by Dr. Gallo was expanded upon due to additional recommendations from Dr. Bier and Ms. Goldfarb.
 - The expanded list of recommendations to the Scientific Advisory Committee was distributed to members of the Council. This list includes New Jersey and non-New Jersey residents.
 - The subcommittee will compile discussion points relative to how the Advisory Committee will function and be funded.
- Subcommittee Addressing the Integration of the Council's Goals with Goals of the IACC and other Federal Organizations. Subcommittee members: Drs. Janvier, Sprott and Ms. Reilly.
 - No report from subcommittee.
 - Dr. Janvier, a member of IACC, suggested a recommendation or model could be used from the IACC. They are charged with developing a strategic plan for Autism Spectrum Disorders research per the Combating Autism Act and to also update this plan annually.
 - An IACC Scientific Workshop is scheduled for September 30-October 1, 2009 in Washington, DC to update the current strategic plan and is open to the public.
 - Dr. Eggerding suggested the subcommittee members think about models that currently exist and the advantages of using some of those models to move the Council forward to link to a national agenda.

- Subcommittee Formulating Council’s Policies and Procedures for Supporting Other Autism Organizations. Subcommittee members: Drs. Evans, Guberman, Meyer and Mr. Ziegler.
 - Dr. Evans reported that based upon the Council’s discussion at its June 1, 2009 meeting, a draft recommendation was written which was distributed to Council members.
 - The recommendation establishes two application procedures for entertaining requests for funding from agencies for education and outreach activities: Council Issued Request for Proposals and Ad-hoc Grants.
 - It was determined that a maximum amount of funding per organization would be set.
 - Dr. Spratt expressed concern with the following language used in one of the criteria in which the Council will not consider nor fund: “Activities that do not take place in New Jersey or do not include or benefit a majority of New Jersey residents.”

IV. Executive Director’s Report

A. Financial Report

- Council currently has a balance of \$20,059,755.
- Council will use \$2.85 million to fund the year 2 Clinical Enhancement grants.
 - Five grants receiving \$500,000
 - One grant receiving \$350,000
- Council will use \$5 million to fund the 2-year Basic Science and Clinical Research Grant Program.
 - Council will fund up to ten grants at \$250,000 each for a total of \$2.5 million for Year 1.
- Council will have a balance of \$14,709,755 in uncommitted monies after funding Year 1 of the Basic Science and Clinical Research grants.

B. Update on the 2009 Basic Science and Clinical Research RFA

- All Basic Science and Clinical Research grant applications were due to DHSS July 23, 2009. Out of the 42 Letters of Intent received, 39 grant applications were received. This is the largest response the Council has received to one of its RFAs.
- Twenty-six applications were basic science projects and 13 were clinical research projects.
- The Consultant Request to hire the 14 out of state grant reviewers to evaluate the grant applications has been submitted to Treasury through channels for approval.
- Timeline for grant evaluation
 - Grant applications assigned to reviewers.
 - Grant applications will be electronically sent to the reviewers along with criteria for review. Grant review is NIH (National Institute for Health) based.
 - Reviewers have four weeks to evaluate assigned applications for scoring committee.
 - Dr. Gallo will write a synopsis of each grant review for the scoring committee.
 - Scoring committee will meet via a telephone conference call moderated by Dr. Gallo.
 - Once grants are ranked the Council will vote on which applications are to be funded. A November Council meeting or structured conference call will need to be scheduled.
 - Funding anticipated to start either December 1, 2009 or January 1, 2010.

C. Year 2 Grant Renewals for the Six Autism Clinical Enhancement Centers

- The 2010 (year 2, July 1, 2009 – June 30, 2010) multi-year grant renewals are currently being processed at the Department’s Financial Services office and Letters of Intent are expected to be mailed shortly.
- A meeting of the Clinical Enhancement Centers grantees was held July 30, 2009 to discuss data issues.
- A second meeting is scheduled for September 10, 2009 to review Year 1 and look at Year 2.

D. Update on Future Council and DHSS Initiatives

- Update on the Department's NIMH (National Institute for Mental Health) Database Grant Proposal.
 - The Council approved 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. The agreement between the Council and the DHSS was that if the DHSS was not awarded the Challenge Grant the Council would not be obligated to fund the development of the relational database.
 - Dr. Gallo stated to the Council that the NIMH database grant proposal was not funded. However, Dr. Gallo reported that the proposal did receive a favorable review.
- Dr. Gallo presented to the Council for their consideration Family Health Services request of \$1 million from the Council for an autism database development project.
 - The budget for this one-time development project would be \$1 million, and developing such a database that would collect patient-level evaluation, phenotype and demographic data on autistic patients throughout the State would allow the Division to link this database to other statewide databases such as the Medicaid and Electronic Birth Certificate databases, and to national data repositories such as the National Database for Autism Research (NDAR), (the database that is administered by NIH). The ultimate goal in developing a network of databases is to provide researchers and clinicians with sufficient population size to have the statistical power to answer the pressing questions in the field of autism.
 - Dr. Gallo recommended the Council ask for a scope of work and detailed budget for an autism database development project. A database is in line with the growth of the Clinical Enhancement Program.
 - The Council agreed to Dr. Gallo's recommendation.
- **The Second Cycle of Clinical Enhancement Grants – Open to Council Discussion**
 - Dr. Gallo presented two options to the Council for consideration. An interim Council meeting via a conference call will be scheduled to allow a Council vote.
 - Option 1: Fund a non-competitive renewal of existing grants.
A non-competitive renewal of existing grants allows Drs. Garg and Gallo to review what has been accomplished by these agencies, and if necessary, provide guidance and monitoring to agencies that require attention. Establishing a timeframe of 1, 2 or 3 years of additional funding would also need to be determined.
 - Option 2: Fund a coordinating center. Proposed by Dr. Gloria Rodriguez, Service Director, Special Child Health and Early Intervention Services, DHSS.
Coordinating centers are used in federal government for their administrative expertise. An RFA would need to be created with funding of \$500,000 per year. A coordinating center would provide technical, logistical and clinical support to agencies.

Council Discussion

- Dr. Janvier asked if there is a 100% satisfaction with the current centers that are funded.
- Dr. Gallo responded by saying some agencies need minor guidance while a couple of agencies need to set benchmarks.
- Dr. Evans asked for reports from each of the six Centers so those Council members who are not affiliated with a Clinical Enhancement Center are aware of their achievements and challenges.
- Dr. Eggerding agreed that reports would be very helpful and would allow Council members to see which Centers set benchmarks, what the rationale is for setting certain benchmarks, and also what happens if benchmarks are not met. She also requested reports for the 2007 Basic Science

and Clinical Research grants. This information would be helpful due to the upcoming vote on what applications to fund for the 2010 Basic Science and Clinical Research Grant program. She also asked if the RFA for a coordinating center would be announced in conjunction with the non-competitive grant renewals or would the RFA be announced in Year 3, (which would be at the beginning of the next round of grants).

- It was determined that the RFA for a coordinating center would be announced in Year 3.
- Dr. Janvier asked if a summary or poster were a requirement of the Basic Science grants.
- Dr. Gallo stated that submission of a final report from the current six Clinical Enhancement grants is a contingency for the grant renewal. However, the submission of publications and/or posters can be made as a requirement of the new Basic Science and Clinical Research grantees that receive Council funding.
- Dr. Sprott noted that gathering grant reports for the Council's information is very difficult. Dr. Sprott also suggested that a conference be held so that results of Council-funded research and clinical initiatives can be shared.
- It was asked if there was any interest in the expansion in the number of clinical enhancement centers and Dr. Gallo said yes there is. However, in order to issue an RFA, timelines and workload involved in creating and announcing an RFA need to be considered.
- Ms. Wood stated that the goal is to establish a Center of Excellence. Benchmarks and criteria need to be further defined as to what a Center of Excellence means to New Jersey. If benchmarks were not previously established, they need to be determined. If grantees are not performing to these standards then the grants will be opened via the competitive process. The Council needs to determine what it wants to support, what the criteria for a Center of Excellence are, and look at geographic distribution to ensure statewide access.
- Dr. Eggerding stated the two issues for the upcoming conference call:
 1. a call for non-competitive renewal of grants for a period of 1, 2, or 3 years with established benchmarks for agencies not performing well.
 2. a call for an RFA for a coordinating center beginning in Year 3.
- Council members affiliated with one of the six funded Clinical Enhancement Centers will need to recuse themselves when a vote is called for a non-competitive renewal of current grants.

V. Comments by Public Member Attendees

- None.

VI. Identify Action Items for August – September 2009

- Drs. Gallo and Garg will assemble reports from each of the six funded Clinical Enhancement Centers on their achievements and challenges in Year 1 of the grant program. These reports will be forwarded to Council members two weeks before meeting via conference call.
- Dr. Gallo will contact the Principal Investigators of the funded 2007 Basic Science grants and request status reports.
- Dr. Eggerding asked Council members to review the Subcommittee Formulating Council's Policies and Procedures for Supporting Other Autism Organizations' recommendations and forward comments to its members. Recommendations will be refined and a draft of the recommendations may be ready for Council ratification at the next Council meeting. If a vote is to take place, inform Dr. Gallo at least one week before the October meeting so that the recommendations can be sent to Council members for their review.

VII. Next Meeting

- The next meeting of the Governor's Council for Medical Research and Treatment of Autism is scheduled for October 5, 2009, 6pm – 8pm at the Department of Human Services, Division of Developmental Disability Services, 5 Commerce Way, Hamilton, New Jersey.

MOTION by Dr. Eggerding: adjourn meeting

Seconded by Dr. Sprott.

Meeting adjourned at 8:45pm