

**New Jersey Department of Health and Senior Services
Governor's Council for Medical Research and Treatment of Autism
Interim Meeting held by conference call
September 15, 2009
1pm – 3pm**

Meeting Minutes

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

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-D Executive Directory of Autism New Jersey (formerly COSAC),
Autism Organization 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

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

Absent

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

NJ Department of Health and Senior Services (DHSS) Attendees

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

I. Welcome

Meeting called to order at 1:12pm by Council Chair, Dr. Caroline Eggerding.

Dr. Gallo stated the focus of today's meeting is to discuss and vote on two issues:

- Proposal by DHSS to develop an RFA to fund a coordinating center for all Council-funded initiatives.
- Granting a 2-year non-competitive grant renewal to each of the six Council Enhancement Centers.

Council members affiliated with one of the six funded Clinical Enhancement Centers will need to recuse themselves when a call for a vote is made on granting a 2-year non-competitive grant renewal to the six Clinical Enhancement Centers.

II. Chair's Report

Housekeeping

- Dr. Eggerding noted that because this is an interim meeting there are no minutes for review.
- Council members were asked to identify themselves before speaking.
- Dr. Eggerding welcomed public members listening in and requested they hold any comments until the Public Comment section of the meeting.

A. Update on the Process of Developing and Conducting a Council Sponsored Needs Assessment

- Dr. Eggerding stated the first step in developing a strategic plan is a needs assessment. Drs. Eggerding, Garg and Gallo held a conference call on September 8, 2009 with Dr. Joel Cantor and Ms. Margaret Koller of the Rutgers University Institute for State Health Policy to discuss the approaches and challenges of conducting a needs assessment.
- Concern was expressed that the needs assessment be done in a timely manner and that current work being done by Autism New Jersey and the Adults with Autism Taskforce not be duplicated.
- The needs assessment is to address the autism clinical and research services in New Jersey.
- The scope of the needs assessment is related to the response of the Council as it relates to Legislation PL 2007, c. 168 and in DHSS.
- Dr. Cantor will be making a presentation at the October 5, 2009 Council meeting and a call for a vote on whether to contract with the Institute to have it conduct the needs assessment will be made following the presentation, and question and answer period.
- Preliminary recommendation from Dr. Cantor includes two phases:
 - Phase 1: environmental scan – identifying existing funding and programs in research and clinical service. Service delivery in New Jersey will be looked at and compared to other states.
 - Phase 2: key informant interviews with stakeholders about the role and funding strategy of the Council and in-depth review of funding strategies in selected states.
- Timeline:
 - Presentation and Council vote at October 5, 2009 Council meeting.

- Receive Phase 1 briefing in May 2010.
- October 2010 receive final report on findings.

Summary

- Council members will receive Dr. Cantor's presentation materials one week before the October 5, 2009 Council meeting.
- The cost of Phase 1 will be presented at the October 5, 2009 meeting.
- No Research RFA will be announced prior to May 2010. Current research funding is anticipated to go out December 2009 or January 2010.
- It is anticipated that the needs assessment results will inform the next Basic Science and Clinical Research RFA.
- Council work will continue while a needs assessment is pursued.

III. Executive Director's Report

A. Discussion of Proposal by DHSS to Develop an RFA for a Coordinating Center for all Council Funded Initiatives

- Dr. Gallo stated that the role of a coordinating center would be to provide support in all Council-funded initiatives. This includes administrative, data reporting, and technical and clinical assistance areas.
- Dr. Rodriguez suggested that a written schematic or outline to include specific goals and objectives of a coordinating center be presented to the Council for approval before an RFA is written by DHSS.
- Council members expressed concern about being rushed and requested more detailed information about the responsibilities that a coordinating center would fulfill.
- Council requested an outline of DHSS staff responsibilities so that work currently being done is not duplicated by a coordinating center.
- Other options discussed included in-house hiring and contracting with a consultant.
- Ms. Goldfarb tabled the vote.
- Dr. Bier suggested Council members present their ideas/other types of what a coordinating center would look like.
- Dr. Rodriguez clarified that due to a statewide hiring freeze the hiring of additional DHSS staff is not possible at this time. The only DHSS staff person whose time is totally dedicated to the Council is the Executive Director, Dr. Gallo. Other DHSS staff have multiple job responsibilities.
- Consultants can be hired, however, depending upon the cost it does go to a competitive process. Dr. Rodriguez will write a brief synopsis on the guidelines for an RFP (Request for Proposal).
- Dr. Eggerding stated that at the next Council meeting a consultant model and coordinating centers will be looked at. Council members are to submit their ideas of what a coordinating center will look like to Dr. Gallo so ideas can be reviewed before the next Council meeting.
- Setting dollar amount is premature at this time.

B. Discussion of Granting a 2-Year Non-Competitive Renewal to Each of the Six Clinical Enhancement Centers

- Dr. Gallo asked Council members affiliated with any of the Clinical Enhancement Centers to leave the conference call. This included: Ms. Goldfarb, Dr. Janvier and Dr. Sprott.
- Council members remaining on conference call: Dr. Bier, Dr. Eggerding, Dr. Evans, Dr. Guberman, Dr. Meyer and Mr. Ziegler.

- The current Clinical Enhancement grants end June 30, 2010.
- Dr. Gallo contacted each Center for the following information which was forwarded to all Council members:
 - Overview of programs.
 - Goals - achievements and challenges.
 - Brief overview of each grantees direction for Year 2.
 - Schedule A's of grant applications. Information includes position titles and percentage each position is dedicated to grant activities.
- It was noted because the funding of the 2009 Clinical Enhancements Grant program was funded by a competitive RFA, the current six funded Centers are looked at as a unit if a non-competitive renewal is granted. Grants can be amended with the approval of DHSS as long as changes fall within the general cope of the original RFA.

MOTION By Dr. Eggerding: Grant a 2-year non-competitive renewal to the currently funded Clinical Enhancement Centers.

Second: none.

Mr. Ziegler amends motion to discuss.

- It was reiterated that as stipulated by PL 2007, c. 168, the Council is “in” DHSS. Therefore, DHSS does have the right to override decisions made by the Council if they are not in agreement. There is no process of appeal in the Legislation.
- Council members have questions and need more specific information. A request was made to invite the six Principal Investigators to the next Council meeting. However, it was determined that due to time constraints this was not feasible.
- Dr. Meyer suggested a one page summary signed by the Principal Investigator and immediate supervisor be requested from each of the Centers and submitted to Council members for their review.
- It was noted by Dr. Rodriguez that DHSS does have a grantee monitoring process in place and that Council members should feel comfortable that tax payer money is being well spent. While some grantees have been more successful than others, all have had challenges in moving forward. However, Dr. Rodriguez stated that the grantees should be held to the goals that they set for their Centers. Data from each grantee should be looked at to support if goals have been met, and if not, why not? The DHSS will work with each grant to determine a plan of correction if a grantee is not meeting its goals. Dr. Rodriguez stated that the main objective is that each grantee succeeds.
- Council members requested data and quarterly reports from the grantees.
- It was also noted by Dr. Rodriguez that if the Council decides not to grant a 2-year non-competitive renewal to the Clinical Enhancement Centers, but decides to announce funding via the competitive process, a six month extension must be given to the grantees to allow for the development, processing and announcement of an RFA.
- Discussion by the Council addressed the fact that more specific information is needed before members can make a decision.
- As suggested by Dr Meyer, it was agreed that a one page written summary be requested from each grantee and signed by the Principal Investigator and immediate supervisor would be acceptable and helpful to Council members. Because members have different questions a standard one page summary is to be written based on questions developed by Dr. Guberman.

- In looking ahead to the October 5, 2009 meeting, Dr. Eggerding asked Council members to consider whether to extend funding to the Clinical Enhancement Centers or to terminate the programs.
- Mr. Ziegler suggested that DHSS determine if a conflict of interest exists for Dr. Bier, as UMDNJ was her most recent former employer.

IV. Public Comments

Ms. Heidi Rogers

- Ms. Rogers, a member of the group of parents who wrote Legislation PL 2007, c. 168 and former Council member thanked everyone for their efforts and asked if the status of the Clinical Enhancement grants are public information.

Note: information is available under OPRA (Open Public Records Act). Requests can be made in writing and there is a minimal charge. With Dr. Eggerding's approval, Mr. Ziegler will forward report to Ms. Rogers.

- Ms. Rogers also expressed concern about expenses on administration. She would like to see more money spent on grants and less on administration. She also suggested another organization that uses a coordinating center be looked at.

V. Action Items

Needs Assessment

- Council members to receive materials relevant to a needs assessment one week before the October 5, 2009 Council meeting.

Proposal by DHSS to Develop an RFA for a Coordinating Center for all Council Funded Initiatives

- As requested by Council, an outline of DHSS staff responsibilities is to be developed.
- Council members are to forward their ideas of what a coordinating center would look like to Dr. Gallo. Ideas to be reviewed before October 5, 2009 Council meeting.
- Dr. Rodriguez is to develop synopsis of an RFP as it relates to hiring a consultant.

Granting a 2-Year Non-Competitive Renewal to Each of the Six Clinical Enhancement Centers

- A one page written summary to be developed based on Dr. Guberman's questions. Summary to be completed by each grantee, signed by Principal Investigator and immediate supervisor.
- As requested by Council members, quarterly reports from the grantees are to be provided by the DHSS.

VI. Next Council Meeting

- October 5, 2009 from 6pm – 8pm at the Division of Developmental Disabilities, 5 Commerce Way, Conference Room 199A, Hamilton, NJ.

MOTION by Mr. Ziegler: adjourn meeting.

Meeting adjourned at 3:20pm.