

**New Jersey Department of Health and Senior Services  
Governor's Council for Medical Research and Treatment of Autism  
Meeting Minutes – December 7, 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

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

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

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

**Absent**

Ms. B. Madeleine Goldfarb, MA, 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**

Gloria M. Rodriguez, DSW, 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

**Public Attendees**

Audrey Mars, MD, Medical Director, Regional Autism Center at Hunterdon Medical Center  
Kathy Patrick, Easter Seals  
Elizabeth Bell, Autism Speaks  
Susan Freedman, Hunterdon Regional Autism Center and Special Child Health Services  
Case Management

**I. Welcome**

Meeting called to order at 6:08pm by Council Chair, Dr. Eggerding.

**A. Introductory Comments by DHSS**

Dr. Gloria Rodriguez welcomed and thanked everyone for attending. Council members, DHSS staff and public attendees introduced themselves.

**II. Chair's Report**

**A. Approval of the October 5, 2009 Council Meeting Minutes**

MOTION by Dr. Janvier: to approve the October 5, 2009 Council meeting minutes with no changes.

Seconded by Dr. Evans.

Dr. Eggerding reported she wrote a letter to Governor Corzine encouraging him to fill the vacant Council seats. If Dr. Eggerding does not receive a response before Governor Corzine leaves office she will forward another letter to the new Governor.

**B. Update on the Council Sponsored Needs Assessment**

Dr. Eggerding noted at the October 5, 2009 meeting that Council meeting members voted and agreed to have Rutgers University Center for State Health Policy conduct a needs assessment on the autism research and services in the State of New Jersey. A Memorandum of Agreement (MOA) in draft form was developed by Dr. Garg and sent to the Center for State Health Policy for their input. Once the Center for State Health Policy has completed its review the Council will have the opportunity to comment and add or subtract from the MOA. This is expected to happen at the next Council meeting. The needs assessment will be completed in two phases. Dr. Eggerding outlined each phase:

Phase One: includes a review of literature on needs assessment and strategic plans developed by other states and other agencies, of the Autism New Jersey Listening Tour and New Jersey Adults with Autism Taskforce reports, of autism research funding in New Jersey, of autism research proposals and research funding in keys states and of published literature in autism research.

Phase Two: includes key interviews with stakeholders addressing where services are being delivered in New Jersey, what is happening to outreach as it relates to autism education, and focusing on the role of Council as it relates to funding opportunities.

Dr. Eggerding reported she had conversations with other agencies that had contracted with the Center for State Health Policy to complete needs assessments. Dr. Eggerding stated that the Brain Injury Council was the one most similar in structure and purpose to the Autism Council, and that the Brain Injury Council was positive about the work conducted by the Center for State Health Policy.

Completing the needs assessment in two phases was proposed by the Center for State Health Policy. The MOA submitted as a draft to the Center for State Health Policy is to serve as a first step in developing the completed MOA. Once the draft MOA is returned to DHSS from Dorothy Gaboda of the Center for State Health Policy it will be distributed Council members.

### **C. Set Date for Council One-day Meeting**

Dr. Eggerding reported that at a previous meeting the Council discussed and agreed to spend more time together to plan and discuss significant issues regarding moving forward with the work of the Council. In particular, the Council needs to put work into defining an Autism Center of Excellence for New Jersey so that this definition can inform the next round of Clinical Enhancement grants.

Dr. Eggerding spoke with Dr. Garg about dates in February 2010 and about recruiting a facilitator for the one-day meeting.

Dr. Garg has also been in contact with Dr. Daniel Coury, Medical Director of the Autism Treatment Network (ATN), a national network of hospitals and physicians dedicated to developing a model of comprehensive medical care for children and adolescents with autism. Dr. Garg has arranged to have Dr. Coury speak to the Autism Clinical Enhancement Centers on the evening of Monday, February 8, 2010. It was suggested that Council members also attend this session and then have the full one-day, retreat meeting on Tuesday, February 9, 2010. Some Council members who travel a long distance raised concerns with driving to and from Hamilton on two consecutive days.

It was noted by Dr. Bier the ATN does not model what New Jersey currently has in place. Dr. Eggerding said New Jersey is not joining ATN or using their model. Dr. Eggerding stated that it would be helpful for the Council to hear about what an existing treatment center structure looks like and whether there are elements that we may want to have as part of our Center of Excellence in New Jersey. An honorarium will be paid to Dr. Coury.

### **D. Council Subcommittee Reports**

- **Composition and Role of Scientific Advisory Board**
  - Subcommittee members: Drs. Eggerding, Bier and Ms. Goldfarb.
  - Dr. Eggerding reported the Subcommittee has not met.
  - A list of recommendations was presented to the Council two meetings ago.
  - The development of the Scientific Advisory Board is stipulated by PL. 2007, c. 168.
  - Unresolved issues, such as whether Board members will be compensated and what role the Council wants the Advisory Board to serve need to be discussed and resolved.
  - Full Council input will be required on some issues.

- **Linkage of Research Efforts to IACC (Interagency Autism Coordinating Committee) and Autism New Jersey Listening Tour**

- Subcommittee members: Drs. Janvier, Spratt and Ms. Reilly.
- Subcommittee has not met.
- Dr. Janvier noted no one is in-charge of Subcommittee.
- Dr. Janvier commented as a member of IACC, many of the premises of the federal work done by IACC should be followed.

- **Policies to Support Autism Organizations**

- Subcommittee members: Dr. Evans, Dr. Guberman, Dr. Meyer and Mr. Ziegler.
- Dr. Gallo reported he spoke with Dr. Guberman before this evening's meeting.
- Dr. Guberman wrote a draft on the policy for unsolicited requests that focused on having the Council fund community outreach opportunities.
- Dr. Gallo noted since the Council's move to DHSS, as stipulated by P.L. 2007, c. 168 the type of education and outreach to be sponsored by the Council became more specific. As stated in the legislation, the role of the Council is to inform the Executive Director for outreach and education programs that provide information on the advancement of autism treatment and research in New Jersey.
- Dr. Guberman will rewrite the policy to focus more on education and outreach that is treatment and science based.
- Dr. Evans noted the Council had good intentions a year ago, however, with the amount of work the Council already needs to address she questioned if the Council was ready to take on unsolicited requests. Depending upon this answer, the Council may be able to table the issue.
- Dr. Janvier suggested staggering Requests for Applications.
- Dr. Evans said these types of requests can be done as a mini-grant.

Dr. Eggerding noted because the Council's time is limited, the subcommittee structure was used during the past year to get work done outside of Council time. Attempting to complete Council work in this manner has its challenges, and she suggested that the Council think about whether or not it wants to continue to use this model. This is a topic that can be discussed at the one-day meeting. Dr. Eggerding stated other ways to get work accomplished is to meet more frequently or for longer periods of time. If the Council decides to continue to use the subcommittee structure, to ensure productivity she suggested Dr. Gallo be a part of each subcommittee to bring to those subcommittees the DHSS perspective. Dr. Janvier suggested this person does not have to be Dr. Gallo, but someone who can help move the process forward.

### **III. Executive Director's Report**

#### **A. Basic Science and Clinical Research Grant Initiative**

- **Overview of the Review Process**

- The Council received 39 grant applications in response to its Basic Science and Clinical Research Request for Applications (RFA). However, one grant application pulled out due to receiving NIH (National Institutes of Health) funding.
- Members of the autism research and clinical communities were recruited to evaluate grant applications that were within their specific area of expertise. Ninety (90) individuals were asked to participate and 13 national and international autism researchers and clinicians agreed to evaluate and score the 38 grant applications.
- The grant applications were reviewed and ranked using the NIH Criteria for the Evaluation of All Research Applications.

- Of the 13 grant reviewers, 5 individuals participated in a Study Section Review to rank the grant applications.
  - Each grant reviewer received \$100 for every application reviewed and those that participated in the Study Section Review received an additional \$500.
  - Dr. Gallo presented the grant ranking in a blind fashion so that the identity of the grant applications were not revealed.
  - Dr. Gallo announced that due to the transition between Governors the Council will be asked to vote to authorize the funding recommendation of the Study Section Review panel with the understanding that the Council's authorization must be approved by the transition team of the Governor Elect before funding can be released.
  - All funding is based upon availability of funds and once grants are approved by the transition team of the Governor Elect a full list of the grants funded will be made available.
- **Outlining the NIH Review Criteria**
    - The 38 Basic Science and Clinical Research grant applications were reviewed by a Primary and Secondary reviewer across the NIH criteria of significance, approach, innovation, investigators and environment. After evaluating a grant across these criteria both the Primary and Secondary Reviewers assigned a given grant an Overall Impact score. An Overall Impact score is given on a scale of 1 to 9 (with 1 being the most favorable score and 9 being the least favorable score).
    - The Overall Impact scores given by the Primary and Secondary Reviewers were then averaged, and the grants were then ranked by this averaged score.
    - The written critiques by the Primary and Secondary Reviewers were then combined by Dr. Gallo in summary documents. A summary document was generated for each of the 38 grants. As part of the process, every grantee will receive a summary statement.
- **Presentation of the Study Section Panel's Funding Recommendation**
    - The five member Study Section Panel consisted of 2 clinicians/researchers and 3 researchers. The Study Section Review consisted of a 3-hour conference call to determine the grant ranking cutoff point (NIH study section teams often review grants in the 1.00 – 3.00 range and this was the recommendation by the Study Section Panel) and then an in-depth discussion of the grants within that cutoff range took place.
    - Fifteen (15) grants received scores. Grants 16-38 are considered unscored as they were not discussed by the study section team.
    - Following the discussion of each grant application within the cutoff range, each of the 5 panelists stated if he/she concurred with the application's averaged Overall Impact score, or if he/she would give the application a more or less favorable score. The Overall Impact scores of the 5 panelists were then averaged with the scores by the Primary and Secondary Reviewers to arrive at a new averaged Impact score. The grants were then ranked by this new Overall Impact score.
    - It is the recommendation of the 5-member panel to fund the top 10 ranked grants. There are two grants with the same average score in the 10<sup>th</sup> position, but given that all of the grant applications did not have a budget of \$500,000, 11 grants can be funded if the funding level of the \$500,000 grants are reduced by approximately 6%.
    - The grant application ranked 2<sup>nd</sup> included 2 aims. After the Study Section Panel discussed aims 1 and 2 of this application, the Panel recommended funding only aim 1 and reducing the proposal's budget by 25%.
    - Dr. Gallo recommended funding the top 11 grants with funding aim 1 of the 2<sup>nd</sup> grant. He presented one proposal on how the Council could accomplish this. Two applications came

in under \$500,000 for 2 years, this plus the cut from grant ranked 2nd allows funding of the top 11 grants at approximately 94%, or \$470,000. This is a technique often used by federal organizations. He continued to say New Jersey has many gifted researchers and clinicians and the grants received include excellent ideas by those that have produced grants for the Council in the past along with many first time applications. The latter being one of the Council's goals. A \$30,000 reduction in funding will not significantly reduce the quality of the proposed projects.

### **Funding Authorization Open to Council Members for Discussion**

Dr. Eggerding asked what Dr. Gallo would do if the Council wanted to fund only 10 grants and not 11 grants. Dr. Gallo responded by saying as the Executive Director he does not recommend this action. New Jersey is looking to fund excellent grants. Grants 10 and 11 have achieved what the Council has asked and in giving grants of this amount, trimming the budget by \$30,000 doesn't cripple other projects. If the Council has the possibility to fund another grant he recommends that the Council do so.

MOTION by Dr. Janvier: Dr. Gallo deserves accolades for the recruitment of these grant applications. One of the Council's goals is to recruit new people to research along with grant areas that are hot in autism and to have high quality grants based on national standards I move to accept Dr. Gallo's recommendation.

Seconded by Mr. Ziegler.

### **Discussion**

Dr. Meyer inquired about rewarding the top grants by funding them at 100% and asked if a grant ranked at 2.0 is significantly better than a grant ranked at 3.0. Dr. Gallo responded by saying yes, this process rewards merit. The Council can reward a grant for being ranked at the top if the Council chooses to do so. The Council briefly discussed funding grant applications at 100%. Dr. Rodriguez noted if the Council decides to approve Dr. Gallo's recommendation, he will need to meet with the grantees to review each budget, to see where there is flexibility, and to also round off numbers.

### **Vote**

Yes – 8

No – 0

## **IV. Set Council Meeting Dates for the 2010 Calendar Year**

- After discussion, Council agreed to:
  - a full day Council retreat on February 9, 2010,
  - meet monthly for the first half of 2010 then reassess this decision,
  - change start time of meetings from 6pm to 5pm due to travel time required of some members,
  - attempt to move meeting locations to a more central location to enhance public participation.

## **V. Update on the Six Clinical Enhancement Centers Grant Program**

A. DHSS Plan for Monitoring Centers - Dr. Gallo presented the monitoring approach in Year 1 of the Program and proposed an approach for Year 2.

- Year 1
  - Quarterly reports obtained from the six Centers.
  - Telephone calls to personnel at the Centers on an as-needed basis.
  - Independent audit of Centers 60 days after the conclusion of Year 1 of the Program.

- Proposed Year 2 Approach
  - Site visits to each of the six Centers (3 times per year).
  - Scheduled phone calls with Principal Investigators of each Center.
  - Quarterly Reports.
  - More frequent and intensive monitoring will occur if a Program is consistently having challenges or difficulties meeting goals.
  - A bi-annual update of the status of the Programs will be provided to the Council.
  - Independent audit of the Centers 60 days after the conclusion of Year 2 of the Program.

### **Council Discussion**

- Dr. Janvier commented how this is a sudden and intensive change to the monitoring process and noted the 2-year Clinical Enhancement grant program has been underway for one and one-half years. She also asked if the Clinical Enhancement Centers currently funded will be receiving a 3<sup>rd</sup> year continuation and if this has been put in writing.
- Dr. Gallo responded by saying this monitoring process was something DHSS wanted to do from the start of the grant program, however, with getting the Council up and running with a limited staff, this had not been possible. Therefore, with the addition of new staff, the DHSS is working to change this. He added the Council did vote to extend a continuation of funding for a 3<sup>rd</sup> year to the current Clinical Enhancement Centers and a letter will be sent to each Center in the Spring.
- Dr. Guberman asked if there was a monitoring plan in place for the Research grants. Dr. Gallo responded by saying this needs to be developed and that at this point, research grantees are required to send in status reports after the completion of each year of funding.
- Dr. Meyer noted in her effort to help with transparency and accountability she inquired about seeing quarterly reports, and original grant proposals noting that this is something that may or may not be available to the Council and the public. She asked about consumer evaluations and the one page summary she previously requested from each Center with the Principal Investigator's and immediate supervisor's signature. She would like to see these same standards applied to both grant programs.
- Dr. Gallo stated he and Dr. Garg are considering reporting what the Centers are doing in relation to where they were prior to receiving grant funding so the value that has been added can be seen.
- Dr. Bier noted that with this evening's vote the Council may be funding researchers that were funded in the last round of Basic Science grants and inquired about receiving reports about these grants. She also inquired about reviewing changes made to the Clinical Enhancement grants. In particular, changes to Principal Investigators, personnel, and to the focus of a grant. She asked who approves these changes saying the Council needs to see as much information as possible when making decisions to continue funding as was done for a 3<sup>rd</sup> year for the Clinical Enhancement grants. A process needs to be in place to inform the Council.

MOTION by Mr. Ziegler: Request to go into Closed Session to discuss the same concerns that were voiced by Mr. Ziegler two months ago about making allegations at Council meetings about specific centers.

Seconded by Dr. Guberman.

By a show of hands Council approves and motion passes. Public takes leave of meeting.

**Closed session discussion proceeds.**

End of Closed Session. Public members returned to meeting.

## **VI. Public Comments**

Dr. Audrey Mars, Medical Director, Regional Autism Center at Hunterdon Medical Center

Dr. Mars stated that in looking at the monitoring of the Clinical Enhancement Centers, she suggested the possibility of one site looking at another. She is willing to give guidance and support.

Ms. Elizabeth Bell

Ms. Bell is the parent of a 16 year old with autism and asked if there will be regularly scheduled meetings of the six Clinical Enhancement Centers. She noted due to her involvement with ATNs for a number of years, ATNs share information and from the parent community she encourages the sharing of information and suggested these meetings be held at different Centers. She went on to say children with autism are really complicated and no one person will ever know everything. It will take many different viewpoints and expertise. Knowing where to go for answers is something that needs to happen and could develop out of this network.

Council Members Comments

Although not a requirement of DHSS, Dr. Meyer inquired if consumer evaluations were in place at the Clinical Enhancement Centers. She suggested these types of evaluations be a part of the monitoring process.

Dr. Janvier and Dr. Eggerding suggested consumer evaluations and peer reviews be placed on the agenda for the next Clinical Enhancement Centers meeting to determine if this is currently done as part of the monitoring process.

Dr. Eggerding noted there is value in looking at a network. However, whether or not the Council moves treatment to a more medical model or not, there is the issue of how can the Council do a better job at networking and sharing resources. The Clinical Enhancement Centers are doing great work, but they are not seeing most of the children with autism in the State. The challenge for the Council is to determine how do we manage good care, good medical follow-up, good medical homes for all children with autism.

## **VII. Action Items**

- Dr. Eggerding suggested Dr. Gallo meet with the Subcommittee to discuss in more detail the specifics of the Scientific Advisory Board.
- Dr. Gallo to speak with DHSS fiscal staff to get information about DHSS' mini-grant structure and monitoring needs.
- Dr. Gallo to meet with the Policies to Support Autism Organizations Subcommittee before the all day Council meeting to bring DHSS' perspective and help facilitate the rewriting of the Council's policy to support autism organizations.

## **VIII. Next Meeting**

The next meeting of the Governor's Council for Medical Research and Treatment of Autism is scheduled for January 19, 2010, 5pm – 7pm at the Department of Human Services, Division of Developmental Disability Services, 5 Commerce Way, Hamilton, New Jersey.

MOTION by Dr. Eggerding: adjourn meeting.

Meeting adjourned at 8:45pm.