

**New Jersey Department of Health and Senior Services  
Governor's Council for Medical Research and Treatment of Autism  
Meeting Minutes – September 20, 2010 (ratified)  
6pm – 9pm**

**Location: Department of Human Services/Division of Developmental Disabilities  
5 Commerce Way, 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**

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

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

Mary Ray, Contract Administrator 2  
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**

Frank Costello, MD

Kathleen Freeman, PhD, RNC

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

Walter Zahorodny, PhD

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

Meeting was called to order at 6:15pm by Council Chair, Dr. Eggerding. Mr. Crosbie thanked everyone for attending and introduced Ms. Mary Ray, Contract Administrator 2. The Council's Basic Science and Clinical Research grants will be transferred to Ms. Ray for her responsibility. She currently is responsible for the health service grants associated with the Commission on Spinal Cord Research and Commission on Brain Injury Research. Mr. Crosbie reported he received the resignation, effective immediately, of Ms. Michele Adubato who held the Public Member seat on the Council. He noted this creates a vacancy on the Council and said the Governor's Office has been contacted. Mr. Crosbie also noted due to Ms. Wood's retirement, effective December 1, 2010, this is the last Council meeting she will be attending. Mr. Crosbie noted Ms. Wood has worked for DHSS for 33 years. Mr. Crosbie reported the Memorandum of Agreement (MOA) with Rutgers Center for State Health Policy (Rutgers) has been finalized and signed by DHSS and Rutgers. Rutgers will be conducting a needs assessment of the autism research and services available in New Jersey. Mr. Crosbie gave credit to Dr. Garg for her diligence in getting the MOA processed. Phase 1 of the MOA will be completed within 6 months of the start with an interim report submitted within 7 months of start, Phase 2 is to be completed within 12 months after start, and a final report to be generated by Rutgers within 15 months after start which includes a presentation to the Council.

Following the completion of the project a six month period is included for any questions the Council may have. Mr. Crosbie said SAGE (System for Administering Grants Electronically) is the mechanism put in place by the State for all agencies seeking grant funds. This is new system and workshops have been set-up for researchers. He added those agencies responding to the Center of Excellence RFA (Request for Applications) will need to submit a grant application through SAGE. In regards to the Scientific Advisory Committee, Mr. Crosbie said he has spoken to Council members and colleagues who oversee other Commissions with a Scientific Advisory Committee attached to them. He noted as the Executive Director the appointments fall upon him in consultation with the Council members. He encouraged feedback from the Council members and added if any Council members have questions about an individual he has selected to inform him. He stated his goal is to report to the Council the names of the five individuals selected by the next scheduled Council meeting, December 6, 2010.

The Statewide Parent Advocacy Network (SPAN) will receive Federal funding from HRSA (Health Resources and Services Administration) for the proposal they submitted for the State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder (ASD) and other Developmental Disabilities. One component of the grant is to have family advisors attached to all the clinical centers. As the Chair, Dr. Eggerding did submit a letter of support on behalf of the Council.

## **II. Review and Approval of Minutes – August 2, 2010**

MOTION by Dr. Sprott: to approve the August 2, 2010 Council Minutes with no corrections. Seconded by Ms. Goldfarb. Motion carries.

## **III. Strategic Plan for Budget: RFA and New Jersey Autism Center of Excellence**

Mr. Crosbie noted the Council will have a balance of about \$6 million at the end of State fiscal year 2011. Budget projections are based on information received from the Department of Treasury and currently the Department of Treasury is projecting somewhere around, but no more than \$4 million in revenue. This revenue is generated from the \$1 surcharges on fines and penalties from traffic violations per PL 2007, ch 174. Mr. Crosbie said a bill has been introduced in the legislature that seeks a one-time adjustment by taking the Council's \$4 million projected revenue for State fiscal year 2011 and due to a shortfall direct it to the Early Intervention Program which also provides autism services. He added this raises the issue of Council money being taken in the future. He said though it is not a guarantee, in order to protect Council money, a 5-year budget plan needs to be developed to make clear the Council's plans for the money. By doing this it is less likely funds will be taken.

Dr. Sprott expressed concern with losing the projected \$4 million in revenue and would like to obligate, if possible, all of the Council's money. Ms. Wood said a program needs to be in place in order to obligate money and the Council does not currently have a program in which to obligate money to. This evening's goal is to set in place a plan for the funds and make a budgetary statement to the Department of Treasury, Office of Management and Budget of certain activities even if commitments are not for this fiscal year.

Mr. Crosbie said given the economy and his fiduciary responsibility, a projected revenue of \$3.5 million annually is more realistic, and conservative revenue numbers are in the Council's best

interest. Mr. Crosbie continued to say the Council's programs include the Autism Center of Excellence, Research and Fellowships, and the Autism Registry/Administration Cost. The Autism Center of Excellence is comprised of a Coordinating Center and Program Sites. Two RFA's will be announced. This is a new model that replaces what currently exists and is a much more collaborative process as the Coordinating Center will work with the Program Sites.

Mr. Crosbie reviewed the Council's budget items which include a Coordinating Center, Program Sites, Research and Fellowships, and Autism Registry/Administration Cost.

- Coordinating Center – The RFA for the Coordinating Center is a five year commitment. The goal is to focus on the intent of the enabling Legislation, PL 2007, ch 168, in establishing a Center of Excellence. Dr. Evans spoke about the role of the Coordinating Center, which includes centralizing and standardizing the data to be used to address collective research questions. It is a central repository that will facilitate the Center of Excellence's ability to address issues and concerns raised related to autism, coordinate, synthesize and analyze the data findings from Program Sites, disseminate information to the public, coordinate meetings, provide outreach and education, work to help create and enhance research protocols, and ensure the high standards as a Center of Excellence are met.
- Program Sites – Mr. Crosbie noted the RFA is being finalized. A decision will need to be made on the amount of money dedicated annually for program sites, as this will determine the number of sites funded.
- Research and Fellowships - Mr. Crosbie recommends the establishment of a Council Research Subcommittee to shape the focus and mechanism. He added the definition of fellowships needs to be determined which will also impact cost. This review should occur with a group of Council members.
- Autism Registry/Administration Cost – Mr. Crosbie said the Autism Registry's operating budget is \$500,000 and noted 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 Autism Registry. Mr. Crosbie said his goal is to keep the Autism Registry/Administration Cost under \$800,000. He added if the Council develops programs that require exterior grant review a determination of where the money comes from to pay for the review will have to be made.

### **Budget Allocations**

Mr. Crosbie said based upon \$3.5 million as the projected revenue minus \$800,000 for the Autism Registry/ Administration Cost leaves a balance of \$2.7 million in Council money. He presented funding options to the Council.

### **Coordinating Center Funding Option Based on Five Years**

- Award flat funding annually, eg, \$750,000.
- Award funding based on a schedule, eg, \$1 million years 1 and 2, \$750,000 years 3, 4, and 5.
- Award flat funding annually, eg \$750,000 and use Council money in reserve, eg. \$250,000 for 1 or 2 years for a special data supplement.

### **Program Sites Funding Options Based on Five Years**

- Fund no more than 3 or 4 Program Sites at \$200,000 - \$300,000 annually.

- Cap funding for all Program Sites at \$750,000 - \$1 million per year. Number of Program Sites funded will be based upon applicants meeting RFA requirements.

Research and Fellowships - less than \$1million available based on above allocations.

### **Discussion**

- Dr. Bier said it is in the Council’s best interest to maintain consistency among the Program Sites (research reliable ) especially important if we pick-up more sites. She also said the issue related to training personnel was not discussed and if the Coordinating Center would have that responsibility. She noted it would be a good idea to have money set aside to have an individual, who is research reliable, oversee and train staff at the Program Sites.
- Mr. Crosbie said the question is does more research become clinical support as grants to these program sites to help them grow in the future or are you still going to allocate this small amount to basic sciences? Will it be enough to impact basic sciences?
- Dr. Bier noted it may be difficult to do “everything the right way for \$2.7 million”, however, it is incumbent upon the Council to do something the right way to achieve the next level. Having a Coordinating Center working with and collaborating with Program Sites that can be competitive for federal NIH (National Institutes for Health) dollars for a Center of Excellence is one way of accomplishing it. The Council’s research program has not been cohesive in that independent researchers have been funded. She said her interpretation of the Legislation is to fund pilot research ( and therefore less money is needed for allocation). This will stimulate research.
- Dr. Janvier noted the model seems very heavy on administration and sees overlap with the Coordinating Center in regards to data and the data entered into the Autism Registry. She also noted the submission of an application for an NIH autism grant requires data be entered into NDAR (National Database for Autism Research).
- There is a difference with the Autism Registry....Dr. Bier commented that it is anticipated patients are being seen for years which will allow the therapies, intervention, medical treatments, and types of medications patients are receiving to be seen as well as genetic testing results.
- Ms. Bell said part of the reason for developing a Center of Excellence is so New Jersey can secure NIH funding. The thinking of the RFA Subcommittee is to try to raise the level of service and research in New Jersey to a level that will be NIH competitive.
- Dr. Janvier said there is nothing wrong in setting high standards; however, she doesn’t think it is realistic.
- Dr. Sprott noted at some point the Council will have a budget equal to the revenue generated each year. With funds diminishing he suggested the Council consider how to support children diagnosed with autism and their families more broadly. Children with autism receive different services from multiple different sites and suggested the Council should try to coordinate and standardize autism services and evaluations across the State. For example, a Coordinating Center to include Child Evaluation Centers (CECs).
- Mr. Crosbie said having other centers participating in the Coordinating Center is envisioned and part of the Coordinating Center’s mission. However, the financial capability is not there at this time. There will be outreach in terms of education and those centers that want to join, but do not receive direct dollars from the Council, become a part of the Coordinating Center. The current focus is on addressing an Autism Center of Excellence and in doing so establish the structure that then reaches out and creates a Center that gives direction to a broader coalition.

- Dr. Sprott stressed his concern with the Council's money being taken. Given the Council will only have \$2.7 million in annual recurring funds and currently has money he suggested the Council think about having other centers initially become a part of the Coordinating Center and in a couple of years coordinate the entire State. He said the only way to minimize the disappearance of money is to obligate it now.
  - Dr. Bier noted the Council needs to focus on what programs it has and continue to build a credible program as opposed to focusing on spending money. She added the Council has that responsibility to the Legislation and children with autism. The Council needs to think about building a Center in which program sites are consistent and begin to answer some very important questions in terms of what is needed and what is help to children with autism. She added it is in the best interest of the centers to use their dollars in a fiscally sound manner and added a Coordinating Center is needed for this. The Coordinating Center should make sure Program Sites involved look at their own programs and show they are fiscally sound and not duplicative of services.
  - Dr. Evans said in planning for a Center of Excellence, the Council should only consider the revenue being generated each fiscal year. The Council does have an accumulation of money and questioned if this was the opportune time to be more creative. In her opinion it's a different discussion that can take place if the legislature does not take the \$4 million. She added the Autism Center of Excellence which the Council has decided on will include a Coordinating Center and Program Sites, which can only be supported with the Council's annual recurring funds.
  - Mr. Crosbie said the Council can not commit the \$4 million fast enough through the Coordinating Center program which is to be funded through the competitive process. He added the RFA has to reflect reality and in the future additions can be made.
  - Dr. Sprott said his concern is with losing the \$6 million unless it is obligated. The Council did not disagree, however, it is not a discussion to take place at this time.
  - Dr. Janvier noted Dr. Sprott's concept of expanding our reach to Child Evaluation Centers is appropriate and could be an issue for the Coordinating Center to develop.
  - Ms. Goldfarb inquired if the Council made plans to spend the \$4 million would that be sufficient. In trying to do so Mr. Crosbie said the Council's ability to spend the money over the next six months would be very restrictive while another program can use the money now. He also noted New Jersey is facing a \$10 billion deficit.
  - It was noted that large amounts of money are being looked at by the Governor and legislature and it is unlikely an account with a balance of a little over \$2 million will be touched.
  - Dr. Janvier said the Council does deserve credit as it has spent down its money. There was a balance \$20 million at one time. The Council created the Clinical Enhancement Centers and continued funding for three years.
  - Dr. Eggerding raised the issue of location in regards to the Program Sites and their function. She reviewed two basic types for consideration:
    - Regionalization – Program Sites will attempt to cover New Jersey in a comprehensive way. Geographically divide the State and provide a regional resource for individuals who have autism within the State and connect to a Coordinating Center.
    - Non-regionalization – Program Sites not based on geographic locations. Allows for any number of Program Sites as funding is based upon ability to meet RFA criteria.
- She noted these are very different concepts and questioned if the RFA Subcommittee wanted input from the Council about their preference. She also noted this could change the percentages of money put into the Program Sites versus the Coordinating Center.

- Dr. Evans said the thoughts of the Subcommittee are that the sites would be sites of excellence and meet the criteria based on the RFA. This may or may not result in geographic clusters. Ideally the Program Sites funded would also geographically help New Jersey. Ultimately, the final benchmark is sites of excellence.
- Dr. Eggerding said if the Subcommittee is not thinking of regional Program Sites the issue of tying in the Clinical Enhancement Centers is more relevant because the CECs are regional sites. This to some extent potentially informs the Council as it relates to ensuring excellent care is given and the Council has an obligation to equal access. It was noted DHSS does not look favorably upon providing unequal access.
- Ms. Wood said if the ultimate goal is clinical services accessible to the population, as long as more than one site is funded, there will be access on a regional level. However, how that region is defined may be very different. Geographic access and quality of services is key for DHSS, but it is really going to depend on the dollar distribution. She added equal distribution of money to each site is not required by virtue of the volume of population served at each individual site.
- It was noted that the RFA for the Coordinating Center and RFA for the Program Sites will be announced simultaneously as the two refer to each other and will be helpful to the applicants with knowing expectations. It was also noted the start dates for the Coordinating Center and Program Sites can be different. Ideally the Coordinating Center would start before the Program Sites.
- Dr. Eggerding noted the Council needs to think about and should consider what the minimum amount of money would be effective at driving program excellence.

Dr. Eggerding called for comments from the General Public before the Council makes a Motion on Funding Options.

**Dr. Audrey Mars**

Dr. Mars noted the RFA process and grant funding of the Program Sites will take some time and there is discussion of the Coordinating Center starting sooner than the Program Sites. The current Autism Clinical Enhancement grants have been funded by the Council for three years, which included a one year extension for year three. As someone who has a current Clinical Enhancement grant with no guarantee of future funding, she asked about the possibility of the Council putting funds toward extending current Clinical Enhancement grants.

Ms. Wood and Mr. Crosbie reviewed how the Council made clear at the awarding of third-year funding that this was the last extension and funding would end June 30, 2011.

**Dr. Frank Costello**

Dr. Costello said a major issue for the children in New Jersey is access and noted the need for short term and long term plans for training clinicians. He also noted the need to attract scientists to the field of autism, especially in regards to applying for an NIH grant. He said hopefully the RFA for the Coordinating Center includes language to facilitate recruitment of patients for study, coordination and dissemination of information. If it does not, there will be no advancement. Dr. Costello commented on the money being directed to Early Intervention and suggested some of it should be earmarked to answering the questions of what the right amount of therapy for a child is and how to define that. He spoke about medication trials saying New Jersey has numerous pharmaceutical companies and suggested getting them interested.

MOTION by Ms. Goldfarb: to ask the question of the Council to fund the Coordinating Center at \$1 million for years 1 and 2, \$750,000 for years 3, 4 and 5, fund all Program Sites at \$1 million per year, and fund Research and Fellowships at \$1 million. The Council's funds in reserve will be used toward additional funding for the Coordinating Center.

Seconded by Dr. Evans.

### **Discussion**

- Dr. Sprott suggested separating Research from Fellowships. Mr. Crosbie said the number of fellowships each year can change. Grouping them together allows the most flexibility.
- Dr. Sprott said he suggested the separation because the Council is going from a significant dollar amount of awards for research grants to a considerably small amount. He noted as the grant amounts increased there was more interest in the number of applicants. This is the first time creating money for fellowships. Previously the Council has made multi-year commitments and did not want to create a situation where the Council is unable to fund fellowships when there is such a critical need.
- Mr. Crosbie suggested amending the current motion to include a target, eg, \$100,000 or \$150,000 for fellowships per year and try to aim for it.
- Dr. Sprott noted that three years is a significant commitment
- Mr. Crosbie noted the types of fellowships need to be discussed as a subcommittee of the Council to determine the types of fellowships and dollar amounts associated with each. Clear definition is needed before a commitment can be made. As an Action Item, he suggested the subcommittee move forward with a meeting and report to the Council at the December meeting for discussion.
- Mr. Crosbie said once programs are in place, the Council will have the ability to move money if needed.

Dr. Eggerding called for a vote by asking Council members to raise hands.

### **Vote**

All in favor - 10

Oppose - 0

Motion passes.

### **IV. Action Items**

- Council members interested in serving on the Research Subcommittee are to contact Mr. Crosbie. He anticipates the Subcommittee will meet in four weeks. He said it is an open Subcommittee and wants everyone's viewpoint. No conflict of interest exists for Council members as criteria and budget will not be discussed.
- Council members interested in serving on the Specialized Training Subcommittee are to contact Mr. Crosbie or Dr. Eggerding. Mr. Crosbie anticipates scheduling a meeting by phone within the next few weeks with the Subcommittee reporting to the Council at its December 6, 2010 meeting.

Note: Council members agreed to use the term Specialized Training in place of Fellowships.

### **V. Public Comments**

#### **Dr. Frank Costello**

In reference to the recently accredited Developmental/Behavioral Pediatrics fellowship, a joint program between UMDNJ-Robert Wood Johnson Medical School and Children's Specialized

Hospital, Dr. Costello submitted a letter of support from the New Jersey Council of Children's Hospitals for consideration by the Council.

**Kathleen Freeman, PhD, RNC**

Dr. Freeman spoke of the need for adult providers and expressed her disappointment with the possibility of losing \$4 million if the legislature passes the one-time adjustment bill. She noted how Autism New Jersey often sends out alerts to parents asking them to contact legislators and asked if this was something organizations would be taking on. Dr. Freeman noted the Council's vacancy and asked how soon an appointment would be made and she also inquired about other Council vacancies based on the changes made to the Council's Rules of Order.

**Comments by Council Members**

In regards to generating an alert, Dr. Meyer said the "train has left the station" on this issue and noted advocacy efforts want to be directed to the improvement of all things that can be changed. Dr. Eggerding noted how the autism community is split on the \$4 million one-time adjustment bill. Dr. Eggerding also said the Council's Rules of Order were recently revised and Council members can not be held accountable ( for the attendance at Council meetings)for 12 months. It was noted all appointments to vacant Council seats are made by the Governor's office.

It was also noted that Mr. Jonathan Sabin was appointed as Associate Director to the Office of Autism within the Department of Human Services, Division of Disability Services. The establishment of the Office of Autism was one of the recommendations submitted by the Adults with Autism Task Force, August 2009.

In closing, Dr. Spratt publicly thanked Ms. Wood for her years of service advocating for children and overseeing programs. He added she brings an institutional memory to this area, she will be missed, and wished her well.

**VI. Adjournment**

The next meeting of the Governor's Council for Medical Research and Treatment of Autism is scheduled for December 6, 2010, 6pm – 8pm. Location to be determined.

Meeting adjourned at 8:28pm.