

**New Jersey Department of Health and Senior Services
Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – March 1, 2010 (Ratified)
6pm - 9pm**

Location: Lakeview School, Multipurpose Room, 10 Oak Drive, Edison NJ

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

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

Susan P. Evans, EdD, Education Program Specialist for the 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

Kendell R. Sprott, MD, JD, Acting Director of Pediatrics, University of Medicine and Dentistry New
Jersey Medical School, Academic Institution 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

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

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

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

Agnes Cushing-Ruby

Kathy Freeman, PhD, RNC

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

Lisa Huguenin

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

Amy Perrine, Autism New Jersey

Shelley Samuels, Lakeview School

I. Welcome

Meeting called to order at 6:19pm by Council Chair, Dr. Eggerding.

Introductory Comments by DHSS

Dr. Gloria Rodriguez welcomed everyone and thanked the Council members for their continued support and commitment.

II. Chair's Report

A. Approval of the January 19, 2010 Council Meeting Minutes

Dr. Gallo noted that Dr. Bier submitted revisions to the January 19, 2010 minutes.

MOTION by Dr. Sprott: to approve the January 19, 2010 minutes with Dr. Biers' revisions.
Seconded by Ms. Goldfarb.

B. Update on the Governor's Cuts to the Council's Budget

Due to Governor Christie's reallocation of \$5 million from the Autism Medical Research and Treatment Fund to the State's General Fund the Council has agreed to write a letter objecting to this action. Dr. Eggerding reported that in leading up to tonight's Council meeting there were a number of discussions by members of the Council on this subject. Dr. Eggerding noted that the following issues regarding sending a letter were brought up by the members:

o Appropriate person to which the letter should be addressed.

▪ Dr. Eggerding drafted the letter to the Acting Commissioner of DHSS, Matt D'Oria, as the new Commissioner, Poonam Alaigh, MD, MSHCPM, FACP has not been approved.

• After a brief discussion it was determined that Dr. Eggerding will write and send a letter to each person.

- Appropriate letterhead.
 - The development of DHSS Council letterhead is pending the appointment of all Council seats. In the interim DHSS, Division of Family Health Services' letterhead will be used along with the incorporation of letterhead developed by Dr. Guberman. This includes the Council's ribbon and names and seats of current Council members.
- Number of Copies.
 - Dr. Eggerding reported Council members recommended the Governor, Assembly Speaker and Senate President receive a copy of the letter. Dr. Rodriguez said it is not DHSS policy to cross the line into the legislative branch. She added that individual members of the Council can write the legislatures; however, as a Council the letter must go through appropriate DHSS channels. Mr. Zeigler said being that the Council is objecting to the Governor's action, out of respect, a copy of the letter should be sent to him. Dr. Eggerding will ensure each Council member receives a copy of the letter as finished and signed.
- It was noted that Ms. Bell made revisions to the drafted letter which she emailed to all Council members. Dr. Evans said New Jersey no longer has the highest rate of autism in the nation, and that Missouri and Arizona now do. She said DHSS is using the language "New Jersey has one of the highest rates of autism in the nation". Dr. Evans also added she liked the use of supporting pieces of research; however, was unsure about how to best incorporate these into the letter to the Governor. Dr. Eggerding will include some of Ms. Bell's ideas into the final letter.
- Dr. Eggerding thanked everyone for their hard work at the February 9, 2010 Council retreat. A motion to accept the final report received from the facilitator, Ms. Marilyn Dunning, will be made at the April 5, 2010 Council meeting.

III. Executive Director's Report

Dr. Gallo noted the attendance of one of the Council's newly appointed members, Dr. Ketan Kansagra. At this time Council members, DHSS staff and public attendees introduced themselves.

Update on Council's Budget

Dr. Gallo reported that with the \$5 million reallocation, the \$500,000 allocated to support the Autism Registry each year, and the money used for the Clinical Enhancement grants and Basic Science and Clinical Research grants the Council will have a balance of \$9.4 million. The projection is that this summer \$4 million will be deposited into the Autism Medical Research and Treatment Fund. Once this action has occurred, the Council will have \$13.4 million going into State FY 2011.

Dr. Gallo continued to say that the \$5 million reallocated by Governor Christie is listed on the State's budget sheet as "in reserve," and that this money is technically frozen. Ms. Goldfarb attended the Assembly Budget Committee's request to hear from the State Treasurer. She said no declarative statement was made regarding moving the money to the General Fund. It was agreed that the Governor has the ability to freeze money, but there was disagreement as to whether Governor Christie can re-purpose this money. Mr. Zeigler said the Governor has no legal authority to remove this money, that he has to seek legislative relief to be able to do so.

It was also noted that the Council is part of the Executive Branch and should not collectively engage in political lobbying.

Ms. Bell asked about the \$500,000 per year that is allocated to the Autism Registry. Dr. Gallo affirmed that \$500,000 from the autism research money is legislated for the operation of the Autism Registry. It was noted that approximately 3,000 - 3,200 individuals are registered. Ms. Bell said this was a lot of money per person. Dr. Gallo noted a portion of the \$500,000 also supports the salaries of the staff that work on the Registry.

A. Update on the Basic Science and Clinical Research Grant Award Process

Dr. Gallo reported DHSS received approval to move forward with the 2010 Basic Science and Clinical Research grants. As soon as possible letters will be mailed to the 11 grant recipients and to those whose applications will not be funded. The critiques generated from the application review process and the Study Section Review panel will also be mailed.

Dr. Gallo also said part of the conditions to receiving grant funding include the submission of the agency's Internal Review Board approval, agreeing to present the research funded by the Council, and the submission of outstanding reports from the 2007 Basic Science and Clinical Research grant program.

B. Present Hunterdon Medical Center's Proposal

• Overview

Dr. Gallo said the Council funds six Clinical Enhancement Centers which includes Hunterdon Medical Center. The Clinical Enhancement grant program is a 2-year \$3 million program with the availability of \$500,000 awarded yearly to each Center. Hunterdon Medical Center requested and was awarded \$350,000 per year and is the only Center not funded at the \$500,000 level. The Clinical Enhancement grant program is currently in its second year and in October 2009 the Council voted to extend the program for a third year to allow DHSS to construct a new Request for Applications (RFA), for a clinical initiative. Dr. Gallo said Hunterdon Medical Center is doing an excellent job and added that it is clear that Hunterdon Medical Center can expand services with additional funding in the third year of the grant program.

DHSS asked Hunterdon to submit a proposal to bring their funding level up to \$500,000. The proposal was emailed to all Council members last week for their review. The Synopsis of Hunterdon Medical Center's proposal is as follows:

- o Increase access to psychiatric care.
- o Expansion of services for the growing Hispanic/Latino population in Hunterdon County and neighboring regions.
- o Expanding Hunterdon Medical Center's catchment area to include surrounding counties.

MOTION by Dr. Sprott: to increase funding.

Seconded by Dr. Evans.

Note: It was agreed by the Council that those members associated with a Clinical Enhancement Center should not be part of this discussion or vote to avoid the appearance of a conflict of interest.

Discussion

- Mr. Zeigler stated this issue has merit; however, he expressed concern with the precedent setting effect.
- Dr. Garg noted Hunterdon Medical Center requested and received \$350,000 per year for two years. The grant was extended for a third year. DHSS knew this agency could use more money and that this is a \$3 million grant program, allowing \$500,000 to be awarded to each agency. The first two years no action was taken about potentially asking for more money, but because the Centers were funded for a third year this is where the idea came from.
- Mr. Zeigler reiterated that the initial request came from DHSS and Hunterdon Medical Center did not approach DHSS.
- Dr. Bier expressed concern as this year is a transitional year and programs may change and what is being built on may not continue. Also, the proposal is that funding will be increased for those programs that are doing well, but that it will not be decreased for those programs not doing well.
- Mr. Zeigler added perhaps other Centers need more money beyond the \$500,000. He stated that the process seems completely arbitrary and again expressed concerned about the precedent setting effect.
- Dr. Garg stated though no formal discussions took place, rather, comments were heard from Hunterdon Medical Center that additional money could be used. Dr. Garg further stated that Hunterdon asked for less then what was available and disagrees that it was arbitrary. The request was based on a need for expansion, a possible monetary source being available, and a clear breaking point of a third year.
- Dr. Bier noted the RFA stipulated what the second course of funding entailed and noted that feedback has not been received. An external review would be helpful in this piece and organizing the next RFA cycle as it is better to fund things that are working then are not working. She previously asked for an external review of initial grants and what they did.
- Dr. Gallo said the in next round the Council will select the model and vision for clinical centers, and that it is possible for the programs to be evaluated by an external organization. Dr. Gallo stated that the Council can not be in a position to monitor the grants, but the monitoring function can report to the Council.
- Ms. Bell expressed concern with measurability. She stated additional money should be used for building and asked what happens to the Centers in a year when grant funding ends. She questioned if this money is keeping the agencies afloat as opposed to building an infrastructure and is hesitant to funding additional monies due to where the Council is in the process.
- Dr. Gallo responded by saying this issue of funding for infrastructure development has been discussed at DHSS, and that the new Clinical Enhancement RFA will focus more on building infrastructure. Dr. Gallo stated that the next cycle of funding will focus on supporting clinical activities that are not reimbursable. Therefore, the commitment will come from the institutions selected to bring on personnel.
- Dr. Bier said unless the Council continues with the model currently in place, it is likely that funding will not remain at the same level.
- Dr. Gallo noted with the next cycle of Clinical Enhancement grants the scope will be spelled out, and then each applicant organization will need to inform DHSS how much money is needed to provide that scope of services.

- Mr. Zeigler said this is what Hunterdon Medical Center did. The Centers were funded at the level requested.
- Dr. Bier said that the argument can be made that this has been run as a child evaluation center grant in that all the Centers were funded and renewed together. If extra money is available DHSS contacts a Center and requests a proposal. The question is whether this really is a service or research model. If we are looking to change that model how do you transition from one grant program to the next. She added she would very much like to get to the substance of what a Center of Excellence is.
- Dr. Eggerding asked to comment as a participant and not as the Council Chair. She said in reviewing the proposal what is being recommended are poorly reimbursed. Services will be provided that otherwise might not. She also added that the Council does have money to be spent and noted that these funds are vulnerable unless spent.
- Mr. Zeigler said this statement is unfair and the Council is now being asked to make a decision based on fear.
- Dr. Eggerding said she did not mean to imply fear but that funds are available.
- Mr. Zeigler said the Council would be going down a slippery slope if it were to spend money just because funds are available. Where does it end?
- Dr. Bier spoke about the process of transitioning. It is difficult for families to start treatment at one place then when funding is no longer available to have to look for treatment elsewhere. You may think you're helping, but you're really not.
- Dr. Eggerding noted that this happens every day with every time there is an insurance change.
- Mr. Zeigler noted a problem with the process in that there is a problem with the initiated motion. Therefore, a new motion is required to be made.

MOTION moved by Dr. Evans.

Second: none.

Motion dies before vote.

C. Discussing the Role and Membership of the Scientific Advisory Committee

- Scientific Advisory Committee subcommittee members: Dr. Eggerding, Dr. Bier and Ms. Goldfarb
- Overview of legislative charge presented by Dr. Gallo.
 - The establishment of a Scientific Advisory Committee is a legislative charge as stipulated by PL 2007, c.168 and is an obligation of the Council. The Council is to provide guidance and direction to the Executive Director who is responsible for establishing the five-member Scientific Advisory Committee. The Advisory Committee members shall include: three biomedical researchers and two medical clinicians. Dr. Gallo added any members of the Advisory Committee who are from New Jersey would not be eligible to apply for any funding from the Council. This would present an ethics issue and a conflict of interest. A list of possible members, both in-state and out-of-state, to the Advisory Committee compiled by the subcommittee members and Dr. Gallo was distributed to the Council members.
 - Role of Committee as stipulated by PL 2007, c.168: “The committee shall identify and make recommendations to the council regarding grants for the most promising pilot studies for biomedical research, diagnosis and treatment for autism and autism spectrum

disorders;...” Dr. Gallo noted initially the Council awarded research grants in the amount of \$50,000 and that these projects were known as pilot studies. The 2010 Basic Science and Clinical Research grant awards are in the amount of \$500,000 for a 2-year grant period.

- Role of Executive Director as stipulated by PL 2007, c.168: “Present the recommendations of the Scientific Advisory Committee to the Council, which shall select the final grants for pilot studies;...” Dr. Gallo noted the word “select” allows room for Council interpretation; however, he added the grant application review process must be unbiased. Full disclosure of the researcher’s name or title of application is not possible due to the small size of New Jersey.

Scientific Advisory Committee Membership Discussion

- Dr. Evans stated there is merit to having members from both in-state and out-of-state.
- Dr. Eggerding said the discussion in the subcommittee was since this is a New Jersey Council, New Jersey Committee members would have more intimate knowledge of what resources exist in the State. Dr. Eggerding noted that the Advisory Committee members will bring their own biases. Therefore, the Committee needs to be balanced with what resources New Jersey has as compared to what exists in other states and nationally.
- It was noted the charge of recommending research relative to the State of New Jersey can be given to the Advisory Committee.
- Dr. Eggerding said when discussions started in the subcommittee the Council had not agreed to conduct a needs assessment. The needs assessment will also help the Scientific Advisory Committee because it will identify what resources exist in New Jersey as it relates to research efforts and research issues. An out-of-state Committee will be less hindered because of this knowledge.
- Ms. Goldfarb noted with the appointment of new members to the Council the current list of recommendations to the Advisory Committee is incomplete. New members may know of other individuals appropriate for the list.
- Mr. Zeigler suggested the Council first decide if the Advisory Committee will be made up of individuals from in-state or out-of-state then a list can be completed.
- Dr. Evans said she has worked with individuals from out-of -state who did not understand the state system, and that this situation created difficulties.
- It was noted that whoever is selected the Council could take time to educate the members on what is current in New Jersey and hopefully the workings of the New Jersey system will not matter.

MOTION by Mr. Zeigler: Create a Scientific Advisory Committee exclusively with all out-of-state members.

Seconded by Ms. Goldfarb.

Vote

All in favor – 8

Oppose – 1

Motion passes.

Role of Scientific Advisory Committee in the Grant Review Process Discussion

- Dr. Gallo said that the primary function of the Committee is to provide guidance to the Council on the types of grant programs the Council could initiate through clinical and biomedical RFAs.

How this intersects with the review of grant applications is open to interpretation. The grant review process requires time and because autism is a multidisciplinary field it requires the grant reviewers possess the topic matter expertise reflected in the grant applications, and therefore it is not prudent to ask the five-member Advisory Committee to review all of the applications. Dr. Gallo suggested following the NIH (National Institutes for Health) approach and recruit reviewers for the grant process and the Advisory Committee could guide and inform the Council in writing RFAs.

- Dr. Bier disagrees and believes it comes down to the interpretation of legislation PL 2007, c. 168. The Council is to develop a Center of Excellence and the Advisory Committee is to help with funding pilot research not grants funded at the NIH level. It was hoped that by funding pilot research it would lead researchers in the New Jersey academic institutions to apply for NIH level funding. She said there is nothing in the legislation that refers to external review and added the infrastructure to manage grants funded at \$500,000 is not available. When the legislation was revised “pilot studies” was not changed.
- Mr. Zeigler, who participated in writing PL 2007, c.168, said for those at the forefront of this vision thought it more important to move forward and also understood the Council’s mission moved beyond pilot studies due to the \$1 surcharge. More money is available.
- Dr. Gallo noted as with most legislation, PL 2007, c.168 is written in broad brush strokes and it is up to the Council to interpret the legislation.
- Dr. Evans suggested the Advisory Committee review and provide comments to Year 1 and Year 2 of the Basic Science and Clinical Research grants.
- Dr. Eggerding said that the pilot study versus NIH may be a distinction without a difference from the standpoint of the function of the Advisory Committee. She said the role of the Advisory Committee could include providing guidance regarding the types of research, the Advisory Committee could be invited as non-voting members of the Council to sit in on meetings and provide expertise, assist in the RFA writing process, and assist in conference preparation.
- Mr. Zeigler asked if there was a best practice for a Scientific Advisory Committee.
- Dr. Janvier said she has worked with many out-of-state researchers. The Council needs to narrow down the recommended list of individuals, come up with core groups and alternatives.
- Dr. Sprott stated the Council needs to define the role of members before narrowing the list. He suggested once a review of grant applications has been completed, the Advisory Committee could look at the grant applications. He questioned how the Committee will interact with the Council, for example, have the Advisory Committee meet with us a certain number of times or participate in meetings via video conference. The Advisory Committee’s role, amount of time expected from them, and reimbursement need to be defined.
- Dr. Janvier said her work with the NIH research plan included multiple conference calls and a two-day conference. She suggested at a minimum meet with the Advisory Committee two days per year to include an on-site meeting in New Jersey and telephone conferences. The on-site meeting could include a ½ day presentation to the Clinical Centers, and a presentation or collaboration with the Council as was recently done with Dr. Coury. The telephone conferences could be split-up into various amounts of times and at different times throughout the year. This is a challenging area as national and international researchers can not devote a lot of time.
- Dr. Sprott asked about the Advisory Committee advising the Council on the new RFA. Should the Advisory Committee be involved in our discussions as we make decisions about voting.
- Ms. Bell said at Autism Speaks the role of the Scientific Advisory Committee is to review, score and discuss grant applications. In addition their role is to also establish importance, relevance

and priorities. The highest scoring grants are not always important or relevant to autism. Though the Council now has more money, she asked if there was more benefit to funding a \$500,000 grant or a \$50,000 grant? She said the Advisory Committee might be able to help the Council with using its money efficiently and fund areas relevant to the field of autism.

- Dr. Gallo noted the 2010 Basic Science and Clinical Research grant application review process that closely followed the NIH review criteria included the questions of relevance/significance. He stated that he used the five-member Study Section Review panel as a Scientific Advisory Committee in which the question of relevancy was part of the discussion.
- Dr. Rodriguez added she has been a part of many NIH internal review committees and it was known that the applications scored would go to the Scientific Advisory Committee and they made the final determination.
- Dr. Gallo said the Council could use the Advisory Committee as a study section panel.
- Dr. Bier noted the subcommittee's recommendation regarding the role of the Advisory Committee:
 - Inform the RFA Process – provide guidelines to areas of potential dispute including adherence to the RFA process, grant extensions and regular review of grant recipients (interim progress reports).
 - Inform Council regarding trends in autism research and demographics worthy of Council focus.
 - Guide Council regarding the development of comprehensive programs that build on prior and current research projects as well as New Jersey resources.
 - Provide direction for yearly conference on Council-funded research.
 - Provide scientific leadership at planning groups (i.e. think tanks), to address designated issues of importance to New Jersey.
- Dr. Evans said she did not think there were enough ideas in what the Council was asking the Advisory Committee members to do. The Advisory Committee will be used as a study section review panel, however, there are other areas noted. Dr. Evans proposed seeing a written job specification regarding the role of the Advisory Committee.

Compensating Scientific Advisory Committee Members Discussion

After a brief discussion it was noted by Dr. Eggerding that due to the fiscal climate of New Jersey issues with receiving approval for travel requests exist; however, there is a potential to pay individuals a consultant fee which will possibly increase an individual's ability to participate as a member of the Advisory Committee.

D. Discuss the Council's Recommendations for a Model of a Center of Excellence

- In developing a Center of Excellence in New Jersey, two areas emerge: clinical and research. Dr. Garg asked Council members to clarify the description and meaning of these areas. This will impact what will be funded in the next round of Clinical Enhancement grants and individual members may have different interpretations.
- Ms. Goldfarb noted at the retreat a minimum standard of care was discussed.
- Ms. Bell added then the quality control piece is the meeting of standards on a consistent basis.
- Dr. Eggerding asked what is it that stands out from the standpoint of medical treatment for autism that is distinct from what already exists and is funded. She personally thinks the difference is the level of expertise in pharmacology/pharmacologic management. This is an area where there is not a uniform level of experience or comfort. The basic components of a clinical center are managing challenging behaviors along with pharmacology/pharmacologic

management. She added every Center should be collecting data on outcomes based on developmental progress. The basic criteria for being part of a clinical program as a Center of Excellence is monitoring individual's progress and reporting information to a coordinating center or central registry to get a sense of what is effective and what is not. An essential component is outcome measurement.

- Ms. Bell said given the heterogeneity across the spectrum she does not see an outcome measure that could be applied universally to all children. This is what is good about the ATN (Autism Treatment Network), i.e. research that does not apply to all enrolled children can be done with a subpopulation. However, there is also a basic piece of information about all enrolled children that can be used.
- Dr. Janvier said to follow a cohort of children with a comprehensive initial assessment, standardized treatment approach with a control group, and then outcome measures is very expensive. If you have an excellent clinical center and a large cohort there is the opportunity to join together with research as the two attract each other.
- Dr. Sprott said initially that the Council was looking to establish Centers around New Jersey to begin to standardize evaluation and data collection. The thought process was that through meetings the Centers would develop standardized ways of doing evaluations and New Jersey would be unique in trying to develop a statewide program that was aimed at trying to standardize evaluation and collect data.
- Ms. Bell said the Council and this RFA needs to be very specific in what those core minimum things are that are operational and realistic from a clinical standpoint. We have six Centers of which we can ask those questions. How can we standardize? Ideally, to receive NIH funding data needs to be sent to NDAR (National Database for Autism Research).
- Dr. Garg asked beyond evaluation, is the Council desiring to move toward the level of providing excellent treatment not available at other places?
- Dr. Janvier said the treatment of autism does not have a core clinical approach to put in place. Assessment and intervention are important, but to her it is not medical.
- Dr. Bier said in discussing the models of a Center of Excellence she likes the horizontal model of the clinical sites. It is best to have many clinical centers because you get a broader sample around the state. She added with the horizontal model we get the added benefit of enhanced care and we can be a Center of Excellence with a heart. Many of the Centers of Excellence are not about care. Rather, ATN are primarily clinical services centers that include: standardized assessment, physical examination, history taking, diagnostic assessment, treatment of medical comorbidities, on-site behavioral services or providing liaisons to outside providers. For the most part it is community based treatment.
- Dr. Garg asked do we pay for part of the non-reimbursable parts of a behaviorist?
- Dr. Eggerding noted part of the intent of the legislation, PL 2007, c.168 is looking at treatment not just diagnosis.
- Dr. Bier said one organization center attracting top level researchers or a horizontal model of centers meeting, sharing data, and working together putting in applications to do trials would be needed.
- Ms. Bell stated common language is needed to start which is challenging in autism due to the heterogeneity. The Council needs to work on raising the core level of care.
- Before closing discussion Dr. Bier said the service piece that is part of the grants is not really in line with the legislation in that a lot of outreach and education should be directed toward professionals. There is an opportunity to get the advocacy and outreach agencies in New

Jersey involved in the clinical and start to standardize outreach, instead of competing with each other to use our resources.

- Dr. Eggerding recommended setting aside time at the next Council meeting to discuss what element or role research has in the Clinical Centers and how to coordinate it.

V. Identify Action Items for March 2010

- Mr. Zeigler requested a copy of the written policy regarding correspondence/contact to the legislative branch.
- Dr. Gallo is to investigate protocol of copying the letter from the Council to the Governor stating its objection to the \$5 million reallocation of autism research money.
- Dr. Gallo will forward to Ms. Bell the briefing which includes the number of individuals registered with the Autism Registry.
- Council members are to submit to Dr. Gallo additional names of individuals for recommendation to the out-of-state Scientific Advisory Committee. Biographical information will be circulated to Council members and each member is to submit to Dr. Gallo their top five researchers and top five clinicians in rank order.
- Dr. Gallo will work with Dr. Rodriguez with regard to the parameters of what monetary compensation can be offered to the Advisory Committee members as consultants.
- If any Council members have other thoughts about the recommendations for a model of a Center of Excellence contact Dr. Garg or Dr. Gallo.
- Develop a job description for the Scientific Advisory Committee members.

VI. Comments by Public Attendees

Kathleen Freeman, PhD, RNC

Dr. Freeman noted the importance of awareness and said Autism New Jersey has started a petition to reinstate the \$5 million reallocated by the Governor. She suggested that the Council send a letter to other New Jersey organizations informing them about this action. This will help to get the word out and get parents involved. She questioned the organization of Council meetings in that public comments are asked for at the end and perhaps the Council could look to the public for comments before taking a vote. She added due to the composition of the Council she felt the members should know the priorities in New Jersey and should also decide the areas of importance. She agrees with the Council in regards to not reinventing the wheel and suggested the Council look at other models of a Center of Excellence, for example CHOP (Children Hospital of Philadelphia), and other places to be able to move forward. She also asked the Council not to lose the \$5 million.

Council Comments:

It was noted that the Council as a whole can not politically lobby. Dr. Eggerding said according to Roberts Rules of Order there is not a place for public comments prior to a vote. She added that in her experience with Councils and Advisory Councils public comments are asked for at the end of meetings.

Agnes Cushing-Ruby

Ms. Ruby has a 23 year old daughter with autism. She said the transitional work included in Hunterdon Medical Center's proposal is important and she would like to see funding in this arena. When talking about medical issues on autism we are not speaking the same language because you are talking about psychiatric issues and I am talking about the underlying medical issues that are

going on such as gastrointestinal issues. We have to take a good look at those things that require treatment and she would like to see the integration with the early intervention type centers and that they should be referring them further. She added from her perspective a lot of money is being spent on research and that leads us almost nowhere. She said her daughter is not better off and the children coming along now are not either.

Council Comments

Dr. Eggerding noted the Council has talked about, at some level, how all of the Clinical Enhancement grants are in pediatric programs which inhibits looking at care and process for adults with autism. The Council recognizes the need to expand ideas especially in the next RFA.

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

Dr. Mars suggested with the upcoming funding of the 2010 Basic Science and Clinical Research proposals to have these grantees, where possible, affiliate themselves with a Clinical Center.

VII. Adjourn

The next meeting of the Governor's Council for Medical Research and Treatment of Autism is scheduled for April 5, at the Department of Human Services, Division of Developmental Disabilities, Conference Room 199A, 5 Commerce Way, Hamilton, New Jersey.

MOTION by Dr. Evans: meeting adjourned.

Meeting adjourned at 9:01pm.