

**New Jersey Department of Health and Senior Services
Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – January 19, 2010 (ratified)**

5:00pm – 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

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

B. Madeleine Goldfarb, MA, Founder/Director of the Noah's Ark Children's Association, 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

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

Michele Adubato, MSW, MA, Deputy Executive Director, The North Ward Center, Inc.,
Public Member

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

Ketan Kansagra, MD, FAAP, Children's Hospital of New Jersey at Newark Beth Israel Medical Center,
Academic Institution Recommendation

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

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

Tyrone Bentley, MD, UMDNJ-NJMS Autism Center
Dr. Kathleen Freeman

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

Robert Titus, Public Policy Director, Autism New Jersey

Linda Walder Fiddle, The Daniel Jordan Fiddle Foundation

I. Welcome

Meeting called to order at 6:00pm by Council Chair, Dr. Eggerding. Council members, DHSS staff and public attendees introduced themselves. Dr. Gallo reported Governor Corzine recently appointed three new members to the Council:

- Michele Adubato, MSW, MA, Deputy Executive Director of The North Ward Center, Inc. fills the Public Member seat,
- Elizabeth K. Bell, MS, volunteer and independent contractor with Autism Speaks fills an Autism Organization Representative seat, and,
- Ketan Kansagra, MD, FAAP with Children's Hospital of New Jersey at Newark Beth Israel Medical Center fills an Academic Institution Recommendation.

Council members serve a term of three years.

Introductory Comments by DHSS

Dr. Gloria Rodriguez welcomed everyone. She noted New Jersey has a new Governor and Mr. Matthew D'Oria is the Acting Commissioner of DHSS. With the new administration and until a Commissioner is appointed, DHSS' priorities have not been announced. Once the Commissioner of DHSS is appointed a formal invitation to him/her to address the Council will be extended. The transition team has completed its transition document; however, it has not yet been shared with DHSS staff.

II. Chair's Report

A. Approval of the December 7, 2009 Council Meeting Minutes

Dr. Eggerding clarified that Dr. Daniel Coury, Medical Director of the Autism Treatment Network, will be speaking to the Clinical Enhancement Grantees the evening of Monday, February 8, 2010 and then speaking to the Council members the morning of the 1-day retreat, Tuesday, February 9, 2010.

MOTION by Ms. Goldfarb: to approve the December 7, 2009 Council meeting minutes with no changes.

Seconded by Ms. Reilly.

B. Overview of Chair's January 12, 2010 Meeting with DHSS

Dr. Eggerding reported that she met with the Division of Family Health Services' leadership on January 12, 2010 to discuss the Council and the partnership and evolving the partnership between DHSS and the Council. The discussion centered on the role of the Council, given that it is "in and of" the DHSS, and specifically on the important function the Council has in the strategic planning and vision for the research and treatment of children and adults with autism in New Jersey. She noted that some of the goals to accomplish in the year ahead include:

- The opportunity to guide the needs assessment process. Ensure that work that is being done to address the needs and direction of research and treatment in New Jersey reflect the thoughts and expertise of the Council members.
- Establishing criteria and vision for the Center of Excellence and Clinical Enhancement Centers. How to link the Centers to other existing programs, such as, case management, early intervention and the child evaluation centers.
- Addressing issues surrounding the Scientific Advisory Committee, such as, naming the Committee members, how the Committee is to function, and serve as a resource and guide to the Council.
- Creating a vision and direction for research, and how to support this vision in the State of New Jersey. The Council has previously discussed the role of a Coordinating Center and how that might assist the Council in its work.

Comments

- Dr. Sprott asked if there was feedback from DHSS during the meeting. Dr. Eggerding responded by saying DHSS would like to see the Council in a strategic planning role.
- Dr. Bier asked how this would be implemented and about subcommittee assignments. Dr. Eggerding said it would be an evolving process that will require significant face time to develop trust and to have honest dialogue which may require additional meetings. The subcommittee assignments were used last year to facilitate work outside of Council time; however, it was not as successful as it could have been for multiple reasons. The use of subcommittee assignments has been suggested as a major discussion item at the February 9th retreat. The Council needs to decide if the subcommittee structure is the most effective way to get work accomplished.
- Although the retreat agenda has not yet been established, major issues include:
 - The Memorandum of Agreement relative to the needs assessment.
 - What the Council wants to see in the next Request for Applications (RFAs) for the Clinical Enhancement grant program.
 - Decisions about the Scientific Advisory Committee, which include recommendations for the individuals on the Committee, the Committee's function in supporting and informing the Council about its work.
 - Determining what constitutes a Center of Excellence in New Jersey.
 - Deciding if the subcommittee structure is viable and if so, how to have the structure work effectively. Dr. Eggerding's recommendation would be to schedule subcommittee meetings before or after Council meetings. She added Council members may have other ideas for a retreat.

- In preparing for the retreat, Ms. Bell suggested members look at the NIH standpoint of what a Center of Excellence is and to also look at other Centers of Excellence in advance of the retreat to facilitate this part of the discussion.
- Dr. Rodriguez recommended the Council review PL 2007, c. 168 as the minimum criteria for the creation of a Center of Excellence in New Jersey is described. At the very least, a Center of Excellence in New Jersey must accomplish what this legislation says. However, additions to the Center of Excellence can be made.
- Dr. Sprott noted that with the original legislation the Council was the Center of Excellence and that the intent was to try and create an infrastructure within the State that could apply for and become a National Institutes for Health (NIH) Center of Excellence. The goal was to acquire NIH money.
- Dr. Eggerding read Section 5 of PL 2007, c. 168:

“The council shall make awards of grants and contracts to public and nonprofit private entities to pay all or part of the cost of planning, establishing, improving and providing basic operating support for a Center of Excellence for Autism in the State where basic and applied biomedical research, diagnosis and treatment for autism shall take place.

The council shall define the scope of programs to be undertaken at the center with the understanding that the center shall conduct:

- (1) basic and clinical research into the cause, diagnosis, early detection, prevention, control and treatment of autism, including research in the fields of developmental neurobiology, genetics, psychopharmacology, neuroimaging, immunology, infectious diseases, gastroenterology and endocrinology;
- (2) training programs on biomedical treatments, diagnosis and prevention for autism for physicians, scientists and other health care and allied health care professional in the State, and
- (3) information and continuing educational programs on the latest advances in biomedical research on autism for physicians and other health care and allied health care professionals who provide care for patients with autism in the State.”

- Dr. Eggerding noted that in the past this Council has said that there is a Center and that there are six Clinical Enhancement Centers, and that the sum of the Council-funded activities shall meet all those criteria. The Council can discuss for the next RFA if it wants to continue with this model. However, the Council needs to ensure that if it is not asking for the same model of five, six or seven, that the sum of those Centers lead to a Center of Excellence and meet all the criteria in PL 2007, c. 168.
- Dr. Bier asked how \$500,000 was determined as a grant award for the Clinical Enhancement Centers. Dr. Sprott indicated that it was an evolving process. The Council initially began with awards of \$50,000 for Basic Science and Clinical Research grants. Large sums of money were accumulated and were difficult to spend. At that time the Council did not have an Executive Director; however, Dr. Gallo was eventually appointed. Although the Council funded research projects for a period of time, the Council was not sure of any great breakthrough with the research being done and there was a clinical gap in services that needed to be filled around the State. One of the things the Council thought it could do with its money was to standardize the evaluation and services that took place and hoped to fund Centers distributed throughout the State. The thought would be to continue with research and increase the awards. NIH funding leveled off and as the Council increased awards to the Basic Science and Clinical Research grants the number of applicants increased. The Clinical Enhancement Centers were established

and though the Clinical Enhancement Centers were not mandated in what they had to do, it was hoped as the Centers met, and were under the guidance of DHSS, a consensus would develop and standardized testing at all Centers would occur. With the transition of the Council from UMDNJ to DHSS more money has accumulated and though the Council has completed another round of Basic Science and Clinical Research grants one concern is that with the starts and stops of the transition the accumulation of money, if not spent, will be redistributed to New Jersey's general fund.

- Dr. Bier expressed concern with awarding large amounts of money to clinical sites and at the same time addressing the research needs (of the children and adults with autism in New Jersey). In looking towards the needs assessment, the Council should not only look to how it can spend money to service clients in New Jersey that have autism but look to building of the Center of Excellence. Also, since the initial funding of the Clinical Enhancement Centers additional information is available. There has been a change in information that can be helpful in building what is needed for clinical and treatment centers throughout New Jersey and that information needs to be translated into future plans.
- Dr. Gallo agreed and noted the grant periods are smaller to allow for any needed changes.
- Dr. Rodriguez noted per PL 2007, c. 168 a report is due to the Governor March 1 of each year. She added the month of January is coming to an end and with these issues being discussed she reminded the Council that a report is due to the new Governor by March 1, 2010.

III. Executive Director's Report

A. Vote for Council Chair Position for the 2010 Calendar Year

- **Overview Presented by Dr. Gallo**

- One of the mandates in PL 2007, c. 168, is that at the first Council meeting of each calendar year the Council shall elect a person for the seat of Council Chair who shall serve as the Chair until the first meeting held in the next calendar year.
- Council members in attendance are eligible for candidacy.
- Members can nominate him/herself, another member, or the current Chair. Each candidate will be given the opportunity to say a few words about his/her vision for the Council and what he/she would like to bring to the Council.
- After comments a blind ballot vote will be taken based on Roberts Rules of Order which requires a plurality of votes to elect a Chair. With seven Council members in attendance this evening, four votes are needed to elect a Chair. Additional voting rounds will be take place as needed and a candidate can remove his/her name at any time during the voting process.

Some Council members voiced concern with voting this evening as two new members are not present and inquired about voting at the Council retreat. Dr. Gallo responded by saying the agenda for this evening's meeting had been distributed to all Council members and postponing this action was not possible due to it being mandated by PL 2007, c. 168.

- **Call for Nominations by Dr. Gallo**

Dr. Spratt nominated Dr. Eggerding, current Council Chair, if she accepts.

Dr. Eggerding accepted nomination.

Dr. Gallo asked for other nominations. None received.

- **Council Vote**

Dr. Gallo requested a vote by a show of hands.

Yes – 5

Abstain – 2

Dr. Caroline Eggerding elected as Council Chair.

B. Update on the Council Sponsored Needs Assessment

- Council members voted and agreed to have Rutgers University Center for State Health Policy conduct a needs assessment on autism research and services in the State of New Jersey. Dr. Gallo noted as discussed at the December 7, 2009 Council meeting Dr. Garg created the MOA (Memorandum of Agreement) template and shared it with Dr. Dorothy Gaboda at the Rutgers University Center for State Health Policy to include more specifics and incorporate the Center for State Health Policy's criteria for data collection. Dr. Gaboda has reviewed the MOA and the Center for State Health Policy's legal team is reviewing.
- After Rutgers University Center for State Health Policy has completed its review the MOA will be returned to DHSS and the Office of Legal and Regulatory Affairs will review. After the completion of this step the document will be released to Council members for feedback.
- The needs assessment includes two phases over a 12 month period:

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 key states and of published literature in autism research. At the completion of Phase One the Center for State Health Policy has 30 days to draft a report to the Council. At this point the Council will have the opportunity to help direct Phase Two.

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. At the end of Phase Two the Center for State Health Policy will draft a recommendation document to guide the Council in the development of a strategic plan.

- The work plan section of the MOA will be made available for Council members to review for the February 9th retreat. It is anticipated the earliest the needs assessment will start is April 1, 2010.

C. Update on the February 9, 2010 One Day Retreat

- Dr. Gallo reported the February 9th retreat will be located at the Department of Human Services, Division of Developmental Disabilities in Hamilton, Conference Rooms 199A and B.
- A Consultant Request asking for authorization to hire a facilitator has been submitted to DHSS management for approval. The DHSS process includes the collection of three bids from potential facilitators and DHSS authorizing the selection of the facilitator.
- All three individuals who submitted bids are familiar with the state government system and Dr. Gallo reported he has spoken to each individual over the phone. He stated that any person selected as the meeting facilitator will be a good fit for the Council. The names of those who submitted bids are: Mr. James Davy, Mr. Roger L. Chaufournier and Ms. Marilyn Dunning.
- Dr. Gallo reported DHSS has selected a facilitator; however, final approval is pending.
- The Council will be informed when approval is received at which point the facilitator's CV will be forwarded to members. Once approval is received and in preparation for the retreat Dr. Gallo will meet with the facilitator and the facilitator will also be contacting each Council member.
- Ms. Bell noted she reviewed NIH's Developmental Grants for Autism Centers of Excellence. She also asked if there was a way to attract a researcher to New Jersey through another mechanism. She suggested pulling in someone from another state in order for New Jersey to be viewed at the federal NIH level. Dr. Eggerding suggested an out of state member of the Scientific Advisory Committee could be a source of help with this.

D. Update on the 2010 Basic Science and Clinical Research Grant Program

- Dr. Gallo reported that at the December 7, 2009 Council meeting the Council voted to authorize the top 11 grant applications that were recommended for funding by the five-member Study Section Panel.
- DHSS has requested a start date of March 1, 2010 for the Basic Science and Clinical Research grants. However, as reported at the December 7, 2009 Council meeting, the grant applications recommended by the Council require the approval of the transition team of the new Governor. As such, a memo was written to the Commissioner of DHSS requesting approval of the Council's authorization to fund the top 11 grant applications. The transition team responded by asking DHSS to hold moving forward until the transition is completed. We were requested by DHSS' management to write a memo explaining the ramifications in delaying the funding of these grants. This has been done and DHSS is waiting on a response.
- Dr. Gallo added that for those grants awaiting final funding approval, a stipulation in accepting grant funding is also accepting the responsibility to present research findings at a conference or poster session
- Dr. Sprott noted the grant cycle of the Basic Science and Clinical Research grant program does not necessarily have to be based on a 2-year award. He asked the Council members to think about the grant cycle of this program as reviewers will be reviewing NIH grants as well.
- Ms. Goldfarb asked Dr. Gallo if he was currently receiving reports from the 2007 Basic Science and Clinical Research grantees that are coming to completion.
- Ms. Bell inquired as to how this information becomes public. Dr. Gallo stated the 2010 Basic Science and Clinical Research grant abstracts will be published on the Council's website once final approval is received. Currently, the abstracts from the 2007 Basic Science and Clinical Research grants are on the Council's website.
- Dr. Bier noted that reports from the 2007 Basic Science and Clinical Research grants have not been seen by Council members. She expressed concern about the possibility of funding some of these same researchers for the 2010 Basic Science and Clinical Research grant program who have not completed the 2007 grant reporting requirements.
- Dr. Gallo stated if a researcher from the 2007 Basic Science and Clinical Research grant cycle has applied for and been approved to receive a grant with the 2010 cycle, any outstanding reports must be completed and submitted in order to receive grant funding. Grant money is distributed on quarterly basis and is contingent upon receipt of required grant reports. In the past, yearly reports were required as research goals are set for year 1 and year 2. However, biannual reports can be requested. Ms. Bell questioned if there was any benefit to more frequent reporting and added measurable points need to be agreed upon.
- Dr. Rodriguez noted DHSS has the authority not to issue grant money and has done so with other grantees. DHSS can also request grant money be returned. Dr. Gallo also pointed out that DHSS does monitor a grantee's fiscal projections and expenditures.
- Dr. Bier inquired if DHSS has the manpower to fund and monitor all of the Council's grants. Dr. Gallo responded by saying it is one of the issues of a Coordinating Center and once some of the larger issues, such as the needs assessment and upcoming Council retreat are completed, this will allow him to focus on monitoring. Dr. Gallo reported that he has visited three of the six Clinical Enhancement Centers and is scheduled to visit the remaining three Centers within the next three weeks. Once the site visits to the six Centers for the first round are completed a report will be provided to the Council members and subsequently to the public via the Council's website. He will then begin the second round of site visits. Dr. Gallo will review

the 2007 Basic Science and Clinical Research grants to note outstanding reports and request submission.

- Ms. Bell inquired if a review of the published research has been conducted to determine if funded research is worthwhile. Dr. Gallo has in his records the research that has been parlayed into peer reviewed publications and presentations but no, this has not been published. He added the 2010 Basic Science and Clinical Research grant awards are more money than what most federal organizations are awarding. Ms. Bell added if New Jersey is trying to attract researchers to the field of autism this can be used as a marketing tool.
- It was noted by Dr. Bier that PL 2007, c. 168 does specify the areas of research to be funded (which has not all been targeted) and large grant awards do take away seed money. In order to fund innovative research a mechanism is needed to fund smaller pilot grants. For example, She stated the American Academy of Pediatrics recently published guidelines for GI issues in autism. In moving the six Clinical Enhancement Centers to a model of a Center of Excellence, and the need for research as part of the Center of Excellence, it is in the Council's best interest to initiate those types of grants sooner.
- Dr. Gallo added Council money can be used to include a research fellowship.
- Dr. Eggerding suggested the subject of what happens after Council funding of basic research grants, what is required as communication to the Council and public, and how the Council uses this to promote itself and the State of New Jersey can be a discussion at a second retreat.
- Ms. Bell asked Dr. Gallo if it were possible to review the research grants that have been funded and categorize them into the areas of research specified in PL 2007, c. 168 and if so, she suggested an RFA be announced to address any gaps.

E. Update on the Clinical Enhancement Centers Information to the Council

- Dr. Gallo stated that all of year one quarterly reports for the six Clinical Enhancement Centers have been received by DHSS along with the first quarterly reports for year-2. The second quarterly reports for year-2 are due to DHSS the end of January 2010. If any Council member is interested in reviewing any of these reports to let him know.
- Dr. Gallo reported in response to many things brought up at past Council meetings, but specifically to Dr. Meyer's written request on behalf of herself, her organization and the constituents she serves, Dr. Gallo has asked each Center to submit an additional summary specifically for the Council with the submission of the agency's second quarterly report. This summary is to include basic data information on wait times, information on new patient and follow-up patients, what evaluations were done, and patient referral information. If any Council members have questions about the quarterly reports as the monitoring arm, Dr. Gallo asked members to contact him directly as opposed to using Council meeting time.
- The summaries are to be signed and dated by the Principal Investigator along with his/her supervisor's signature. Dr. Gallo will review and also sign summaries.
- As part of the monitoring process Dr. Gallo will conduct three site visits per year to each Clinical Enhancement Center. Summaries of these site visits will be completed and available to the Council when site visits have been completed.
- Dr. Gallo noted when reviewing the quarterly reports from each of the six Centers he asked Council members to keep in mind that data is not consistent across the Centers. Benchmarks are in the process of being determined. Dr. Garg created a listserv with the six Centers which allows them to share information.
- If any Council member would like to review the 2008 Council's Annual Report and/or any of the Clinical Enhancement health service grant applications Dr. Gallo asked Council members to notify him and he will forward the requested documents. He added each Clinical Enhancement Center has a different mission statement and each Center's health service grant application will outline the context of its quarterly reports.

- Dr. Gallo also reported that as part of the monitoring process, and in the future, he will make formal presentations to the Council on a biannual basis to update them on the status of the Clinical Enhancement Centers.
- Dr. Bier inquired about having someone clinically involved with the evaluations. Dr. Gallo noted this is done with two of the Centers. The possibility of using a Coordinating Center with a clinical component would support DHSS' monitoring. She said that the six Centers initial grants had a mission: ie of providing more intensive evaluation, monitoring of patient outcomes/changes with treatment and collection of data. Though each Center is different each had an objective, goals and a plan. Data has already been generated and essentially a research project has been done. She expressed concern that information is lost to the Council when only the number of patients is given in reports. The Center's success in meeting goals and objectives need to be looked at and the outcomes of these projects needs to be looked at.
- Dr. Gallo clarified that two types of data exist:
 - collaborative database – setting stage to have a pool to draw from for research, and
 - monitoring data – to help DHSS evaluate the effectiveness of the Centers.
- Dr. Sprott noted the Centers were not designed to do research. They were funded and required to collect data with the anticipation of creating a structure that would allow for statewide research. Also, the Centers were not told they had to do anything specifically. With discussions it was anticipated that as the Centers continued to meet they would develop a consensus of evaluations, and Dr. Sprott stated that progress has been made. The Council talked about some of the issues around the cost of the data input process related to the Registry and how we might develop support for this effort as we start to collect data and put it into a database that can be used for research.
- Dr. Meyer noted those Council members who are also part of a Clinical Enhancement Center have additional information than those members who are not. She requested a summary of the grantees' meetings.
- Dr. Eggerding noted the huge burden of registering autistic patients and enforcing the registration process. She also noted these topics have not yet been discussed by the Council.

IV. Set Council Meeting Dates for the 2010 Calendar Year

- At the December 7, 2009 Council meeting members agreed to meet once every month through June 2010 and every other month thereafter unless adjustments are needed. The Council meeting dates for calendar 2010 are: March 1, April 5, May 3, June 7, August 2, October 4, and December 6.
- The North Brunswick Municipal Center will be looked at as a possible location for meetings, as this is a more central location.

V. Action Items

- Email PL 2007, c. 168 to all Council members.
- On a yearly basis, email Council's Rules of Order to all Council members.
- Dr. Garg asked Council members to inform her via email, of any resources or reference materials members anticipate will be useful for the February 9, 2010 retreat.
- If Council members have suggestions on the types of public presentation of funded research that they would like to see, inform Dr. Gallo so it can be included in the terms of agreement to the 2010 Basic Science and Clinical Research grants.
- In response to Ms. Bell's request, Dr. Gallo will breakdown the funded research grants into the research areas as noted in PL 2007, c. 168. He will also contact previously Council funded researchers to request their publication list.
- Establish link to the Autism Registry on the Council's website.

VI. Public Comments

Linda Walder Fiddle, The Daniel Jordan Fiddle Foundation and member of the New Jersey Adults with Autism Taskforce

Ms. Fiddle stated this is the first Council meeting she has attended and inquired about what information is available to the public in terms of reports and information requested by Council members so that the public can be informed.

Dr. Gallo responded by saying currently the Council's meeting agendas and minutes are posted on the DHSS, Governor's Council for Medical Research and Treatment of Autism's website. Annual or biannual reports on the research grants will be posted, and if approved by DHSS, the summaries of the Clinical Enhancement grantees' meetings will be posted. As previously noted the reports generated by the Clinical Enhancement Centers are not based on consistent reporting requirements. Information made available to the public should be standardized. Disclosure to the Council members is not the same to the public.

It was noted an OPRA (Open Public Records Act) request can be filed; however, there may be some information available that would not present a problem with disclosure to the public. Dr. Eggerding stated the Council is struggling with this issue as it is a work in progress and noted the public's comments are valuable to the Council.

Dr. Kathleen Freeman

Dr. Freeman asked the Council not to rehash research that had been done and to choose priorities that affect New Jersey. For example, access to medical care. She suggested seed money used for research be tied to an academic institution, for example, funding a chair at a university that the Council would sponsor.

In regards to the payment schedule of research grants, payments could be made in stages, such as before or after data collections and final payment be made if research is published in a reputable journal. She also noted how difficult it is to understand how the Autism Registry works. She suggests using someone from outside New Jersey to conduct a research study into streamlining how best to get information.

Robert Titus, Public Policy Director of Autism New Jersey

Mr. Titus is the parent of an autistic son and stated he was glad to see the beginning of a sense of urgency. He watched the Governor's inauguration and senses Governor Christie is going to look for all groups in New Jersey who use State resources to maximize them. In listening to this evening's discussion, we are going to be doing something really great to show for the money that has been granted to us as a community. He knows how difficult it is to get funding and thanked the Council for its work and as a parent will be looking for great results.

Dr. Eggerding noted it is not just what the issues are in New Jersey, but also where New Jersey's resources exist. These are the resources the Council should maximize and focus on.

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

In looking at some of the Clinical Enhancement Centers it was my thought if a Center is not actively doing a research project it is to be identifying and defining specific phenotype of the individual cared for and obtain consent not only to be part of a data base, but to also give consent for additional research. As far as the individuals that we can attest to, many children are being registered with Special Child Health Services, at least in Hunterdon, Somerset, Warren and Mercer Counties, the families that are registered are being notified because they have not

opted out. By explaining services to the family she has had more success. If a family does not sign up a letter is sent explaining the process. Dr. Mars also added that she has been involved in several research projects funded by the Council and without this funding she doesn't know what would have happened to the projects.

Dr. Eggerding noted that beyond registration, part of Council work is how those individuals not followed by a Clinical Enhancement Center can still benefit from Council funding from the Centers. How to set things up so there is some ability for all individuals in New Jersey who wish can have access to that resource.

VII. Adjourn

The next meeting of the Governor's Council for Medical Research and Treatment of Autism is scheduled for March 1, 2010 at the Lakeview School, Multipurpose Room, 10 Oak Drive, Edison, New Jersey.

MOTION by Dr. Eggerding: meeting adjourned.

Meeting adjourned at 8:21pm.