

**New Jersey Department of Health and Senior Services
Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – April 5, 2010 (Ratified)**

6:00pm – 8:00pm

**Location: Department of Human Services, Division of Developmental Disability Services
Conference Room 199A
5 Commerce Way, Hamilton, NJ 08691**

Council Members Present

Caroline Eggerding, MD, Vice President Clinical Services, Bancroft NeuroHealth,
Assembly Speaker Appointee,
Chair of Governor's Council for Medical Research and Treatment of Autism

Elizabeth K. Bell, BS, volunteer and independent contractor with Autism Speaks,
Autism Organization Representative (participation by teleconference)

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

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

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

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

NJ Department of Health and Senior Services (DHSS) Attendees

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

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

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

Jean Hewens, Autism Center at Hunterdon Medical Center

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

Walter Zahoradny, PhD, UMDNJ, New Jersey Medical School

I. Welcome

Meeting was called to order at 6:31pm by Council Chair Dr. Eggerding.

A. Approval of March 1, 2010 Council Meeting Minutes.

It was noted that Dr. Bier submitted minor revisions to the March 1, 2010 Minutes.

MOTION by Ms. Goldfarb: to approve the March 1, 2010 meeting Minutes with Dr. Bier's revisions.

Seconded by Dr. Bier.

B. Approval to put into the Minutes the February 9, 2010 Council Retreat Report Submitted by the Facilitator, Ms. Marilyn Dunning.

Dr. Bier's comments about the Report:

- Establishing a Center of Excellence, Components of Model, page 4, "Provides standardized diagnostic and comprehensive evaluation throughout the state – uses CEC and/or ATN minimum evaluation standard as base;". Dr. Bier noted this statement should be clarified. There is no standard CEC evaluation but a core minimum of specialists.
- Establishing a Center of Excellence, Components of the Coordinating and Clinical Centers, page 4, "Uses state CEC evaluation criteria as base". Dr. Bier noted no standardized evaluation criteria.
- Page 5, first paragraph, "Dr. Rodriguez described how agencies currently receiving DHSS funds could access additional dollars for specialized projects though budget modification." Dr. Bier asked for more specifics about this process.

Dr. Bier's comments to be entered into the Minutes.

MOTION by Ms. Goldfarb: to enter Report into the Minutes.
Seconded by Dr. Janvier.

Vote

In favor - 7

Oppose - none

Motion passes.

C. Approval of the Memorandum of Agreement (MOA) between DHSS and Rutgers University, Center for State Health Policy

Dr. Gallo said the original MOA to conduct a needs assessment for the Council was drafted by Dr. Garg. It was presented to the Council for feedback which was then shared with Dr. Gaboda at Rutgers University, Center for State Health Policy regarding them. Dr. Gallo noted the revisions received by Dr. Bier and asked other Council members for any revisions.

Dr. Bier's revisions to the MOA.

- Page 6, Section III. Obligation and Rights of Service Provider Agency, A. Rutgers Center for State Health Policy's Obligation, 4. Service to be Provided, first paragraph, second sentence "This study will also identify and document the strengths, as well as the needs and gaps in autism a) biomedical research, b) training, c) education and d) clinical services (diagnosis and treatment) in the State." Dr. Bier questioned who will be trained and who will be educated.
- Page 6, second paragraph of same section as noted above, "This will include information, including a needs assessment/gaps analysis, that will be used to develop a strategic plan for the Governor's Council for Medical Research and Treatment of Autism." Dr. Bier wanted to loosen the parameters and suggested "a part of the information used..." be included.
- Page 8, Phase 2, first bullet, "Conduct key informant interviews/focus groups, in person or by phone, to identify and document the following information." Dr. Bier suggested spelling out how these informants are chosen and to include a sample representative of population.
- Page 10, bullet describing what detail information and study findings obtained during Phase 1 and 2 will include, "1) an identification, description, and relevant analysis of what currently exists...in New Jersey with respect to autism a) biomedical research, b) training, c) education, and d) clinical services (diagnosis and treatment)..." Dr. Bier questioned training and education of who and of what and ages is being referred to in regards to clinical services.

No additional revisions received.

MOTION by Ms. Goldfarb: to approve this MOA.
Seconded by Dr. Bier.

No discussion initiated.

Vote

All in favor - 7

Oppose – none

Introductory Comments by DHSS

Dr. Rodriguez stated Poonam Alaigh, MD, MSHCPM, FACP was sworn in as Commissioner of DHSS and noted DHSS' 2011 budget is being reviewed by the Legislature. April 12, 2010 is the Assembly Budget Hearing and April 27, 2010 is the Senate Budget Hearing. Dr. Rodriguez welcomed the Council members and thanked them for their interest, commitment, time, effort and work put into this extremely complex field. Dr. Rodriguez also thanked the public members who participate and share an interest.

Dr. Rodriguez noted Governor Christie made an appearance for World Autism Day. He expressed his interest in the field and in forging a partnership between government and the private sector and he is looking forward to seeing these types of partnerships flourish and develop in the years to come. He is also looking forward to hearing the Council's ideas. Dr. Rodriguez noted a challenge for the Council is to think about how it can foster and develop private and public partnership into treatment, intervention, education and outreach.

II. Chair's Report

A. Update on the Center of Excellence RFA (Request for Application) Development Process

- Dr. Eggerding said there was a call for members for the subcommittee to work on the RFA for the Clinical Enhancement grants. The RFA subcommittee includes Ms. Bell, Dr. Evans, Dr. Eggerding and Drs. Garg and Gallo. The subcommittee has begun to meet once or twice per week to take the ideas generated at the Retreat and identify how that gets written into an RFA. This process is ongoing and can not be a full Council discussion due to those Council members who either have received or are planning to apply for Clinical grants. Dr. Eggerding continued to say the subcommittee wants to respect all Council members' flexibility in being able to receive these funds and once the subcommittee has completed its work the RFA will come to the full Council for a vote at which time those members who are able will vote.
- Dr. Gallo said he asked the six Clinical Enhancement Centers' principal investigators for a vision statement of a Center of Excellence along with other institutions including Cooper Hospital and Montclair. Through Autism New Jersey, the Clinical Enhancement Centers, and POAC (Parents Of Autistic Children) he has reached out to their constituents and families they are working with for comments to help shape the RFA. Dr. Gallo welcomed comments from the general public and said comments can be emailed to him or sent by letter. He has received three letters from the public and as additional comments are received he will share them with the RFA subcommittee. The National Institutes for Health (NIH) and other organizations have templates for clinical grants which can be used and fit to content. Dr. Gallo also noted that the RFA subcommittee is working on an overall mission statement of a Center of Excellence.

III. Executive Director's Report

A. Update on the Status of the 2010 Basic Science and Clinical Research Grant Award Program

Dr. Gallo noted the list of the 11 approved 2010 Basic Science and Clinical Research grants included in the packet of materials for the Council members which includes the names of the principal investigators, affiliation, title of grant and funding level. This information is in the

process of being posted on the Autism Council's website. Also, as stipulated by PL 2007, ch 168 an Annual Report is to be submitted to the Governor and Legislature each year. Dr. Gallo stated he is currently working on the 2009 Annual Report and when completed it will be submitted through channels for DHSS approval and then forwarded to the Governor and Legislature. Dr. Gallo said due to the new administration the function of the Council's grant programs are included in the Annual Report along with the progression of the grants and how they are being used to write peer-reviewed articles, presentations at conferences, and being leveraged into federal grants. Dr. Gallo also noted the list of peer-reviewed journal articles, grant awards and presentations generated by the 2007 Basic Science and Clinical Research funding included in the packet of materials for the Council members this evening. This list includes the ten principal investigators from that grant program and what they have done as result of being funded. Dr. Gallo continued to say the clinical work is directly serving families in need and the research funding is having a great impact in forwarding different theories, building up a body of research, and also bringing in federal dollars to New Jersey. Ultimately the aim of a Center of Excellence is to meld the clinical practice with top notch research which is the aim of the next RFA being developed.

Abstracts of the 11 funded 2010 Basic Science and Clinical Research grants will also be posted on the Council's website. Dr. Gallo said he intends to have published articles and grants that have been received from the 2007 Basic Science and Clinical Research grant program posted on the Council's website.

Questions/Comments

- Dr. Meyer said the list of the 2007 Basic Science and Clinical Research grant program peer-reviewed journal articles, grant awards and presentations seems completely random. She noted some researchers have done nothing and she wants to make sure they are not being funded with the 2010 Basic Science and Clinical Research grants.
- It was noted that the researchers were not told what was required or expected and some researchers have received other grant funding.
- Ms. Bell said the usual stipulation of a grant is that if money comes in from elsewhere you adjust. This is the mission of the Council and as stipulated in the legislation the Council is looking for money elsewhere. It was noted that turning Council money into federal money is ideal.
- Dr. Meyer asked for any researcher that turned Council money into federal money, what else did that researcher do? She again noted the randomness and suggested the Council stipulate what the minimum expectations are with future research grants.
- Dr. Bier added and not reduplicate some of the clinical and research efforts.
- Dr. Gallo said this was done with the 2010 Basic Science and Clinical Research grant review process. The reviewers were made aware of the types of grants funded in the past.
- Dr. Janvier noted with part of the peer-review process there is no guarantee that something will be published. The Council can sponsor a yearly conference and ask the funded researchers to present.
- Dr. Gallo noted in this last round the expectation is that researchers will present. Not necessarily at a Council sponsored program, but at some type of platform. The expectation is that researchers are going to publish, however, there is no guarantee. He added the expectations for the 2010 Basic Science and Clinical Research grants are addressed in the Attachment C form.

- Dr. Meyer inquired about checking the reliability of what is written and in moving forward would like to see how the Council's money made a difference.
- Dr. Janvier said it is not the kind of level you have a detective research and added this research is wonderful and very encouraging to see. It shows internationally known autism researchers and those just starting.
- Dr. Gallo said the 2007 Basic Science and Clinical Research grant program was funded prior to PL 2007, ch 168 and we are at a point now as programs are developed for the Basic Science and Center of Excellence that evaluation measures and what constitutes success into the grant programs can also be created.
- Ms. Goldfarb suggested how the Council's money has made a difference be included and illuminated in the 2009 Annual Report.
- Dr. Bier expressed concern as to where the Council is now and where the Council is read the following statement:
 - I wanted to thank everybody for the opportunity to participate in the creation of a Center of Excellence in New Jersey. Over the last few months we made progress in identifying priorities and processes to achieve this goal. This includes selecting a Scientific Advisory Committee, creating and releasing an RFA for clinical Centers of Excellence with a clinical research coordinating center, and conducting a needs assessment to provide additional information as it relates to the creation of a Center of Excellence. In review of the previous meeting notes it is also clear we have experienced programmatic changes, including revised deadlines, substantive program revisions, addition of new Council members, and administrative changes. It has been documented that we are currently in the second year of funding of a grant program with Clinical Enhancement of Autism Centers that have not been declared our model for a Center of Excellence. We do not yet have a Scientific Advisory Committee selected and approved by the Council and yet have just awarded over \$3 million in grant research and \$1.5 million in a non-competitive renewal. We have not as yet as a Council received progress reports or summaries from our grant program for July 2009 through March 2010. The Council has not funded, completed any quality improvement or quality assurance initiatives for our clinical program. I would like to make a motion to have an independent review of our programs including scientific summaries of projects and legal review of our legislative mandate. This would inform the Council of the quality of programs, assist current grantees in achieving excellence, inform the Council of necessary changes of further initiatives and ensure the Council members we are truly in compliance with the legislation.

MOTION by Dr. Bier: an independent review of our current grant programs.

Seconded by Dr. Meyer.

Discussion

- Dr. Janvier said though not independent, Dr. Garg was hired to address some of these issues. As a recipient of Council funds under the Clinical Enhancement Program she reports what her grant was funded to do. All the Centers have submitted quarterly reports and she is unsure why they have not been shared with Council members. Having Dr. Dan Coury meet with the Clinical Enhancement grantees was a major effort to bring in an external expert. She added three years ago the original Clinical Enhancement grants were written and are in place today and doesn't see the point in bringing back the people who originally did site visits. The Council voted to fund a third year of the six Clinical Enhancement grants and she is not sure investing money in looking at the past is a good

thing. What is happening now and what needs to be looked at is a year from now and what does the Council want a Center of Excellence to entail. These issues take a lot of time

- Dr. Bier said it is not about did a Center do what it said it would do, but about did you make a difference in the improvement of quality of care.
- Dr. Gallo said the argument can be made you wouldn't be creating an RFA for a Clinical Enhancement Program unless you felt the end product is helping the community and creating better care. As a program Dr. Bier is asking is it really making a difference.
- Dr. Bier said she is asking for somebody to look at the different Centers and the research grants funded. What are some of the good things we have in terms of structure within the State.
- Dr. Gallo noted that is what the needs assessment is driving at.
- Dr. Bier said she did not think that level of information would be received. She continued to say her perception is that all her patients understand what she is saying, however, having someone else do that type of inquiry and monitoring might see something different.
- Dr. Gallo noted that is an audit of the programs.
- Dr. Bier said it is more in terms of quality. It helps in terms of getting to a Center of Excellence and coming into a common language. Just because the Council funded the Clinical Enhancement Centers another year does not mean we can't make improvements and how do you do that.
- Dr. Eggerding wanted to know more about Dr. Bier's comment about an independent review and how that would be funded.
- Dr. Bier said in looking at the legislation the Council is allowed to fund things to help build a Center of Excellence. The MOA mechanism can be used. There is a lot of information that is not reported to DHSS and getting lost, such as, what percentage of people from our ADOS (Autism Diagnostic Observation Schedule) training have been research reliable, how many people are using standardized assessments, and what has come out of genetic testing. The Council can help develop guidelines from the clinical data already received, but is not being looked at. This data could help develop and further the areas of clinical research and treatment.
- Ms. Reilly said when discussing the development of a Center of Excellence at the Council Retreat she thought the role of the Center of Excellence was the independent centers would be depositing their data into the Center of Excellence so that some of the questions being asked could be answered.
- Dr. Bier expressed her concern in not doing anything now and waiting until next year for improvements and asked why couldn't we have a Center of Excellence now?
- Dr. Gallo noted the components are being built now and understands the impatience.
- Ms. Goldfarb said there is data being reported and suggested bringing in a biostatistician with specific goals in mind to look through the data and determine what data has not been coming in as opposed to an independent review.
- Dr. Janvier said that is very difficult. As an example, if one person says upgrading video equipment in my office which will improve reliability that may have nothing to do with me going out and teaching a pediatrician how to do an M-CHAT (Modified Checklist for Autism in Toddlers). How do you compare those things?
- Dr. Garg said from the beginning benchmarks must be set-up regarding what is to be measured.
- Dr. Gallo said that for the 3rd quarter, the Centers will be answering the same set of questions.
- Dr. Bier said she reviewed last year's reports from the Centers and noted there is a lot of information included. There are things that we can start to make better and better for everyone involved to get to that Center of Excellence. The current Centers are not a Center of Excellence. She said she is not sure what they currently are, but the Council is funding them and we still have some responsibility until we get to the next place. It behooves us to get an independent analysis of what is going on.

- Ms. Bell noted that she has also been looking at last year's reports from the Centers and said at times it seems each quarter she is reading the same report and understands Dr. Bier's frustration. She senses that by the time the Council is able to establish the review, determine who is allowed to do the review, and receive DHSS approval the grant funding would end. She said all of Dr. Bier's concerns are valid but she is concerned if the Council spends time looking at something in which one more year of funding remains it is better to focus on the Center of Excellence and current Clinical Enhancement RFA. She continued to say the RFA subcommittee is also discussing these same concerns of trying to systematize, trying to organize, and create benchmarks at the beginning. The subcommittee is committed and she is concerned about the large amount of effort involved and by the time the Council receives the information it is not going to really make a whole lot of changes. She doesn't know if an outside consultant is needed and Dr. Gallo has reached out for a lot of input from other people but doesn't know if into the RFA process that's an issue and she asked what other members thought.
- Dr. Bier said all of the Centers are doing early diagnosis and there are ways these assessments could be standardized over the next year. It should not be a lost cause that information can not be collected.
- Dr. Gallo said when the Council voted in October 2009 to extend the Clinical Enhancement Centers for a third year one stipulation was not to rework the grant substantially. Minor modifications are being made with standardizing the data collection and DHSS was asked to wait until the next grant cycle to make major changes. DHSS was pushing for more changes in year three, but the Council did not want that.
- Dr. Bier said it looks bad that we had a non-competitive review.
- Dr. Gallo responded by saying DHSS is complying with the Council's request.
- Dr. Meyer noted she voted to approve funding the six Clinical Enhancement Centers for a third year with increased accountability. She has seen some progress, but said it is not occurring fast enough or good enough. She has been involved in program development for 25 years and knows it takes time and a system is being put in place. She continued to say she hesitates to look for an external review or independent review if she is hearing assurances that small steps towards progress are being made. She added if we are so messed up we don't need someone from the outside to tell us that and she doesn't usually look for an external evaluation until her own house is cleaned up. She suggested an independent review now is not how she would like to spend time and money and added she would like to clean up our own house, but needs to see more evidence.
- Ms. Bell said is it crossing the line to ask those Council members who are not allowed to be part of the RFA subcommittee for what their more specific measures of accountability might be so that the RFA subcommittee can stagger them as areas of discussion to ensure crucial components have not been missed.
- Dr. Gallo said he did not want to create a situation in which people in giving input have undue influence but is not sure evaluation fits into that criteria of what constitutes success.
- Dr. Eggerding said she thinks it's important that existing Centers weigh in on what has been and not been challenging about the last two years. It is an important part in creating a plan for the future.
- Ms. Goldfarb said in talking about how our own house is not in order and we are so messed up she requested to get on record that she knows the funded Centers care very deeply about children, try to see as many individuals as possible and open its doors as wide as possible.
- Dr. Meyer said she would like to see additional evidence of that.
- Dr. Bier said a lot of the Centers are very good and can be replicated as a Center of Excellence, but said she has struggled over the last year with what the Council can expect DHSS to do, such as, standardized assessment form and a certain amount of database development.

- Dr. Gallo said when the Council was moved to DHSS one of the first steps it tried to do was standardize a battery of evaluations. DHSS tried to make NDAR (National Database for Autism Research) the standard, but there was a lot of push back from the grantees who argued this was not written into the grant. Therefore, DHSS said how can we keep the spirit of what we are asking for without overloading the Centers so that they can still do their clinical practice but get the data we want.
- Dr. Rodriguez noted there were struggles when the Council moved to DHSS. The original RFA was written by a different Council not housed at DHSS and stated that the Council would write these standards. When the Council moved to DHSS it took months for Council members to be appointed and the Clinical Enhancement grants already began. DHSS was going to do everything Dr. Bier mentioned, but that is not what the Centers were funded to do. It has been very difficult and she stated she appreciates Dr. Bier's comments and concerns as they have been DHSS's concerns from day one.
- Dr. Bier said in moving forward the Council can get excellent information from the reports submitted by the Clinical Enhancement Centers, such as the data bases developed.
- Dr. Rodriguez said it is DHSS' intent to get the Clinical Enhancement grantees together to share information, discuss their successes and challenges, and learn from each other which is happening. She noted that the third grantees' meeting is Monday evening, April 19, 2010.
- Dr. Janvier said there were no meetings the first year and noted the short time frame in starting July 1, 2008. The second year of the grant cycle Dr. Garg was hired by DHSS and there has been much more collaboration. She asked if the Council members could be invited to the quarterly grantees' meetings. She noted there is no consensus and said it is hard to mandate what is not black and white. She recommended the Centers present to the Council to diffuse some of the issues.

Note: after a brief discussion it was decided that the Council members who are recipients of grant money abstain from voting.

Vote

All in favor - 0

Oppose – 3

Motion does not pass.

B. Update on Creating a Scientific Advisory Committee

Dr. Gallo reported that a packet of information about all the individuals recommended for the Scientific Advisory Committee was sent to each Council member. This included a CV, narrative and some articles information. If public is interested in this information, please let him know. He said he asked each Council member to rank order 1 though 5 their selections from the list of candidates. He has currently heard from four Council members and asked those that did not respond to give him this information this evening or fax or email the information to him tomorrow.

C. Presentation on the Autism Registry

Dr. Gallo noted the information regarding the Autism Registry included in the Council members' folders which includes a brochure developed by DHSS, a briefing developed by the Autism Registry staff and lists presentations they have given, forms for the registry imbedded with the Birth Defects Registry, and information specific to the collaborative database which is the collective databases of the six Clinical Enhancement grantees. He noted that Sandy Howell, PhD, Research Scientist 1 who works for the Autism Registry will be at the May 3, 2010 Council meeting to give a presentation on the Autism Registry.

Dr. Gallo will ask Nancy Scotto Rosato, Research Scientist 2 who also works on the Autism Registry if she is available to participate in tomorrow's RFA subcommittee conference call so that questions can be asked how that ties into research to ensure there is no duplication of what currently exists and to answer questions about the Registry and information being gathered.

D. Discuss and Develop the Mission Statement and Goals for the Center of Excellence in Autism

Dr. Gallo said the RFA subcommittee will continue to discuss the mission statement for the Center of Excellence and via email will get written comments from members. He will present all ideas to the Council. Dr. Gallo also clarified that the mission statement is owned by the Council and not the RFA subcommittee.

IV. Action Items

- Dr. Gallo will follow-up on the researchers who have not produced anything.
- Dr. Meyer asked Dr. Gallo to clean up the 2007 Basic Science and Clinical Research peer review list.
- Dr. Bell requested the minutes from the grantees' meetings for the RFA subcommittee.
- Dr. Gallo to speak with Dr. Rodriguez about compensation for the Scientific Advisory Committee members.

V. Public Comments

Audrey Mars, MD

Dr. Mars said there is a lot of discussion about transparency and accountability and in speaking about her own agency she noted the Yale Autism Center presented at her agency and in her view did an independent review of her program which was favorable. She continued to say the difficult piece for her, as she is not privy to the reports from the other Clinical Enhancement Centers, and is important as one of the six Clinical Enhancement Centers is a vision where she can view all inter-related information. To know and understand how she fits and how the other Centers fit and be able to share information and learn from one another. Dr. Mars also said she does her own assessments, thinks it's important and encourages ADOS. She does some ADI (Autism Diagnostic Interview). She noted that the Yale Autism Center asked her "why are you spinning your wheels if you are not an NIH Center?"

Note: The Clinical Enhancement Centers have not reviewed each other's progress reports with the exception of those Council members who are also part of a Clinical Enhancement Center.

Council Members' Comments

Dr. Bier said what Dr. Mars spoke about in regards to standardized assessments is helpful to share. Dr. Meyer suggested posting the Centers' quarterly reports on the Council's website. Dr. Gallo noted that benchmarks need to be in place so the reports are not confusing to the public.

Walter Zahoradny, PhD

Dr. Zahoradny said he is a researcher at the New Jersey Medical School and he congratulated and applauded the work of the Council. He attended this evening to learn about current and recent activities.

Kathleen Freeman, PhD

Dr. Freeman said as a parent and consumer she can relate to some of the issues Dr. Bier raised and noted they are very important. She thinks the Council needs to define who a key informant is depending upon how priorities are identified. As a consumer she sees the value of shared recommendations because doesn't that translate into the quality of life, which is key, for individuals who have autism. She noted the problems heard regarding data and the need to support in some way some type of investment into data collection and standardization. She suggested making it simplistic for the Centers as they have a large amount of paperwork. She sees importance of data driving what we do and in regards to the development of the Clinical Enhancement RFA and welcoming comments she suggested Dr. Gallo contact PACT (Parents of Autism Children Together).

VI. Adjourn

The next meeting of the Governor's Council for Medical Research and Treatment of Autism is scheduled for May 3, 2010 at the Lakeview School, Multipurpose Room, 10 Oak Drive, Edison, New Jersey.

MOTION by Ms. Goldfarb: to adjourn meeting.

Meeting adjourned at 8:17pm.