

**New Jersey Department of Health and Senior Services
Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – June 7, 2010 (Ratified)**

6:00pm – 8:00pm

Location: Lakeview School, Multi-Purpose Room, 10 Oak Drive, Edison, NJ

Council Members Present

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

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

Susan P. Evans, EdD, Education Program Specialist for Early Intervention Program,
Commissioner of Health and Senior Services Appointee

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

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

Linda S. Meyer, EdD, MPA, BCBA-D Executive Director of Autism New Jersey, Autism Organization
Representative

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

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

Grace M. Reilly, RN, MSN, APN-C, Adult Nurse Practitioner for Riverview Medical Center, Individual with
Autism or Family Member Representative

Mr. Judah Zeigler, Associate Vice President of Sharp's Retail and Consumer Marketing, Senate President
Appointee

NJ Department of Health and Senior Services (DHSS) Attendees

Celeste Andriot Wood, Assistant Commissioner
Family Health Services

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

Sandy Howell, PhD, Research Scientist 1
Autism Registry

Diane DiGiovacchino, Administrative Assistant 3
Special Child Health and Early Intervention Services

Public Attendees

Kathleen Freeman, PhD, RNC
Ms. Susan Freedman, Hunterdon Regional Autism Center and Special Child Health Services
Case Management
Ms. Joanne Gere, Founder, BioScience Collaborative
Ms. Nicole Lubas, owner of Success Across the Spectrum LLC
Audrey Mars, MD, Medical Director, Regional Autism Center at Hunterdon Medical Center
Ms. Shelley Samuels
Walter Zahorodny, PhD, UMDNJ, New Jersey Medical School

I. Welcome

Meeting was called to order at 6:16pm by Dr. Eggerding, Council Chair. Dr. Eggerding noted that Ms. Celeste Andriot Wood, Assistant Commissioner, Division of Family Health Services, DHSS is in attendance to comment on the changes that have recently taken place in DHSS relative to the Council. This will also allow Council members an opportunity to ask questions.

II. Discussion of Plans for the Council's Executive Director Position

Ms. Wood said there have been a number of changes in terms of a new Governor and Commissioner of DHSS. Discussion on consolidation and changes to how DHSS operates took place. The State budget includes significant reductions in many areas including the Departments' payrolls. The Executive Directors of three Commissions, the Commission on Cancer Research (Cancer Commission), Commission on Brain Injury Research (Brain Injury Commission), Commission on Spinal Cord Research (Spinal Cord Commission), and one Council, the Governor's Council for Medical Research and Treatment of Autism (Council) were terminated effective mid-April. DHSS is reorganizing how these Commissions and Council functions. The Brain Injury Commission, Spinal Cord Commission and Council will be consolidated under one Executive Director. The Cancer Commission was previously funded through the State budget. Their revenue is limited to the check-off box on the State's income tax form and the sale of Conquer Cancer License Plates. This revenue is dedicated solely to research activities and can not be used for operational or administrative costs. The Cancer Commission is moving and will be consolidated into the Office of Cancer Control and Prevention.

The Brain Injury Commission, Spinal Cord Commission and Council are the basis of consolidation. Revenue is generated under each of the individual corresponding legislations for an Executive Director. Ms. Wood added that due to the Tobacco Control Program being eliminated from the State budget, Family Health Services is looking at a person who has a Master's degree in Public Health and experience in evaluation and research activities in conjunction with the Tobacco Control Program. This individual, currently being referred to as a Research Liaison, has agreed to work with the Brain Injury Commission, Spinal Cord Commission and Council. This also includes working with the Scientific Advisory Committees. State money is available to support the Research Liaison's salary.

Ms. Wood said DHSS has posted the Executive Director's position and received 40-45 resumes and noted Dr. Susan Walsh the Deputy Commissioner of DHSS, the Director of Human Resources, Ms. Cindy Kirchner the Senior Policy Advisor to the Commissioner, and she will be completing the first round of interviews. She anticipates interviewing 12-15 individuals over the next two weeks from which key candidates will be identified. Ms. Wood added that representation from each of the Commissions and Council will participate in the interview process with those identified key individuals.

Ms. Wood said the consolidation also includes two Executive Assistants and a grants manager. One of the Executive Assistant positions is vacant, has been posted and resumes have been received. The second Executive Assistant and grants manager are individuals who have been working with the Spinal Cord Commission. An Executive Assistant will be assigned to the Council as a permanent contact. Responsibilities will cross over the two Commissions and Council.

Ms. Wood said she expects to bring in representation from the two Commissions and Council no later than the end of the month and anticipates there can be a consensus on a potential candidate and that person can be offered the position quickly. Ms. Wood noted DHSS is moving to an electronic grant system for State Fiscal Year (SFY) 2011. DHSS is also looking to develop similar, if not exact, research grant applications to be used by all of the research Commissions and the Council.

Comments/Questions

- Dr. Spratt expressed concern with the overall rational and cost savings. Ms. Wood said consolidation and efficiencies in personnel were looked at. She added the Council will only be responsible for one-third of the cost to support the "Commission Office" positions. Each Commission and Council was to be staffed with an Executive Director, an Executive Assistant, and a grants manager. Therefore, four positions exist as opposed to nine. There is a savings to the Council in how its money is allocated.
- Ms. Goldfarb asked if this consolidation is in violation of the specific legislations that enables each of the Executive Directors. Ms. Wood said the legislations were reviewed and each Commission and Council calls for an Executive Director, but there is no requirement for a full time Executive Director.
- Ms. Bell asked if the mission of the Brain Injury Commission and Spinal Cord Commission are similar to the Council's. Ms. Wood said each has a research agenda, looks at quality clinical services, each has the same grant process and have their own Scientific Advisory Committee.
- Dr. Bier asked if the members of the other Scientific Advisory Committees are paid and if anything could be done in terms of merging. Ms. Wood said she is not aware of anything that can be done in terms of merging. Most of the Advisory Committee members of the Cancer Commission are voluntary and the grant reviewers are paid. The individual members of each Advisory Committee can be looked at for existing overlap, and if any, review possible coordination. This will depend upon the types of activities with or without content expertise. Ms. Wood stated DHSS is looking at assigning an

individual who has experience working with research activities and to work with the Scientific Advisory Committees in existence. This individual will also work with the Council to provide assistance in creating its Scientific Advisory Committee. Ms. Wood added the Executive Assistant with the Spinal Cord Commission brings her experience in this area and is interactive with its Advisory Committee.

- Dr. Bier also noted the struggle the Council had with whether or not its Advisory Committee members should come from in-state or out-of-state. Ms. Wood said in terms of the Cancer Commission, the peer review for the grant process is done externally. It is not the role of Scientific Advisory Committee unless a member of the Advisory Committee is outside of the State and qualified to be a peer reviewer.
- Dr. Eggerding asked for more information about the research liaison position. Ms. Wood responded by saying the position is to be developed with input from each of the Commissions and Council. This individual is displaced due to the elimination of the Tobacco Control Program, she has a Master's in Public Health, is an epidemiologist, has extensive experience with evaluation and worked in other content areas. Ms. Wood added her experience with evaluation and working with researchers would enable her to help and assist in working with the Scientific Advisory Committee and the Council at large.

Dr. Linda Meyer arrives.

- It was noted the money generated under PL 2007, c 174 (Autism Research Fund) and deposited into the Department of Treasury is allocated to DHSS and the Governor has the ability to freeze money. Ms. Wood said based on the way the State budget is crafted there is no indication this will happen with revenue sources. Also, based on DHSS' anticipated approved budget the money for the two Commissions and Council remain intact. It was also asked if the \$5 million of Council funds that are frozen will be available once a State budget is passed. Ms. Wood clarified that this money is not frozen, but put in reserve. The dollars allocated to health service grants and operational costs are not frozen and it is not known if funds currently in reserve will be available once a State budget is passed. The money put into reserve was identified to cover this current fiscal year and the budget gap. All unobligated dollars across the board were looked at to cover the current fiscal year budget.
- Dr. Spratt asked with the anticipated July 1, 2010 budget is DHSS looking for further reductions as it enters a new fiscal year. Ms. Wood said reductions in the budget have been identified and is unsure of what will happen between now and June 30, 2010.
- Dr. Bier asked about a job description for the Executive Director's position. Ms. Wood said the job description at this time is very broad and can be sent to the Council members.
- Dr. Kansagra asked because the Council does not have a Scientific Advisory Committee in place would the Executive Director look upon the Council as more of a priority. Ms. Wood stated the Brain Injury Commission, Spinal Cord Commission and the Council are now located within the Office of the Assistant Commissioner and the Executive Director will report directly to her. The Council is more of priority in that it is newly formed, continues to develop, and meets more frequently so there is more interaction with the Council in terms of the other two Commissions. Ms. Wood added all are equal in priority, however, the two Commissions have their processes in place. Ms. Wood also said time lines for all projects within the two Commissions and Council will need to be managed and coordinated by the Executive Director.
- Ms. Wood will be in contact when key candidates for the Executive Director's position have been identified.

III. Presentation on the Autism Registry by Sandy Howell, PhD, Research Scientist 1

Dr. Howell began her presentation with some background about the Autism Registry (Registry) noting in 2007 legislation was passed concerning the reporting of autism diagnosis to DHSS and signed into law (PL 2007, c 170) requiring DHSS to maintain the Registry. The Administrative Rules (NJAC 8:20) were adopted September 21, 2009. This allowed DHSS to add the Registry to the existing Birth Defects Registry, hire 2 new staff which included herself and her colleague, Dr. Nancy Scotto Rosato, Research Scientist 2, to develop the Registry form, and develop the rules and regulations to administer the Registry. Dr. Howell stated the Rules (NJAC 8:20-2.3) require DHSS have an up-to-date Registry for surveillance purposes and requires health care professionals licensed pursuant to Title 45, and qualified by training to make a diagnosis of autism, to register a child from birth through age twenty-one years who is a resident of New Jersey. Parents have the right to Opt-Out of the Registry with respect to their personal information, however, the child must still be represented in the Registry. Providers are required to inform the parent of the child and also required to obtain a written statement requesting to Opt-Out, these remain in the provider's case file. DHSS had to define autism and did so using the DSM IV (Diagnostic and Statistical Manual of Mental Disorders) criteria. Licensed professionals can register children either by using the electronic Birth Defects and Autism Reporting System (BDARS), which is currently available at all birthing hospitals in New Jersey, or by downloading the SCH-0 (Special Child Health Services form) and the SCH-1 (Autism Supplemental Information form) pages from the DHSS website, completing the paper forms, and mailing or faxing them to DHSS. Five of the six Governor's Council Clinical Enhancement grantees are using the BDARS. Dr. Howell spoke of the information collected on the SCH-0 and the SCH-1 forms and noted registration can be done in three ways: autism only, anonymous autism, or combined Birth Defects Registry and Autism. The set up of the system is complex, but highly secured to maintain confidentiality. Dr. Howell reviewed the BDARS pages. She also noted the Registry is new and said the understanding of the Registry and data quality is 3-5 years to start looking for prevalence. Before the 2007 law, autism was a voluntary condition and over 1,000 children were registered. Currently, a little over 3,000 children are registered. The goal of the Registry data is to refer children with autism and their families for case management services, plan for services and policy decisions, and conduct more thorough epidemiological analysis of autism in New Jersey. Two Registry information brochures have been developed: one for providers and one for families.

Comments/Questions

- Ms. Bell asked if there was any recourse to not registering. Dr. Rodriguez noted the State Birth Defects Registry is also mandated and DHSS has monitors who visit hospitals to conduct audits. For the hospitals that should have registered children but did not, a letter is sent to the hospitals' CEOs advising them they are out of compliance with the law. There are repercussions, such as the potential jeopardy of a hospital's license. It was noted this is more difficult with primary doctors. Dr. Rodriguez said DHSS eventually wants to implement this type of auditing with the Registry to ensure children are registered. She added the State can not fine, however, DHSS can recommend that happen.
- Ms. Bell asked if there is a way to check first if a child has previously been registered or not, and if older children are being registered, especially in regards to anonymous registrations. Dr. Howell said due to confidentiality reasons DHSS is unable to check as the child's name is needed. If a child is connected to a hospital system the facility can look at its own records. In lieu of that, not knowing if a child is registered a registration can be submitted to DHSS and DHSS has the ability to match registrations if the child has previously been registered. Dr. Howell added providers are

asked to note on the bottom of any evaluation form that is sent to a provider that the child is registered.

Dr. Ketan Kansagra takes leave of the meeting.

- Dr. Eggerding noted her attendance at an American Academy of Pediatrics Council for Children with Disabilities meeting saying she would bring the following consensus to the State:
 - the Registry does fall as an unfunded mandated and there is a substantial time commitment in explaining the Registry and the completion of forms, and
 - the psychiatric community is currently naive in terms of their understanding of the Registry and the obligation to report.

Dr. Howell noted the first and second pages of the Registry forms include “same as” check off boxes which, in some cases, can expedite completion. The third page, to be completed by the provider, is time consuming in regards to pulling and looking through charts for information. Dr. Howell spoke of some recommendations and hints made to providers to facilitate the completion of the forms. Dr. Eggerding said it would be helpful to have those hints and recommendations communicated. She also noted in moving away from hospital-based systems resources are not available and the process is not as smooth.

- Ms. Bell said from a parents’ perspective the ability to fill out forms on-line or in advance is important. Dr. Howell noted this is done in some facilities and it is not a requirement for the registration forms to be completed at the first visit.
- Ms. Goldfarb asked if a lot of duplication registrations have been seen so far. Dr. Howell responded by saying when duplications are seen they are seen with older children who have been registered at birth with a condition and are also seen in children ages 1 to 1½ with a need for language development, but not screened for autism.
- Ms. Goldfarb also inquired about the service cohort. Dr. Howell said registrations are entered within one to two days of being received, unless her colleague and she are both out of the office. A profile is created, sent to Case Management and they contact the family. DHSS sends registrations to Case Management multiple times per week. In addition, DHSS generates a letter which is mailed to the family informing them the child has been registered. If the family has not heard from Case Management they call DHSS.
- Dr. Sprott asked about the percentage of anonymous registrations. Dr. Howell said a tally hasn’t been done and added it is important to rely on the doctors to educate the family on the importance of including the name.
- Ms. Bell asked about adults being added to the Registry and if they are referred to services. Dr. Rodriguez said the registration of adults is voluntary and DHSS recommended the adult registry be placed under the Department of Human Services as this is where services for the adult population are located. It was noted by Dr. Howell that no adult registrations have been received.
- Dr. Sprott asked based on some of the surveillance data about incidence does DHSS have a sense of how many registrations should be in the Registry. Dr. Howell said she and her colleague started out doing preliminary estimates. However, the registrations being received are not all newly diagnosed and include those previously diagnosed.

V. Approval of April 5, 2010 Council Meeting Minutes

MOTION by Ms. Goldfarb: to approve the April 5, 2010 Meeting Minutes without corrections.
Seconded by Dr. Bier.

VI. Discussion of Amendment to the Rules of Order – Council Members Responsibilities with Respect to Attendance

Dr. Eggerding raised two issues for discussion as they relate to the Rules of Order that were agreed upon by the Council. She added due to all Council members not in attendance, she asked members to think about the issues so that they can be brought to a vote at the next Council meeting. The first issue raised by Dr. Eggerding, as noted on the agenda, is the Council members' attendance at meetings. Dr. Eggerding noted 13 seats of the 14 member Council have been filled with the vacant position to be filled by a basic science individual. She read from the Rules of Order:

Page 7, Section 4, "It is grounds for recommending the removal of a member from the Council if that member: 3. is absent from more than half of the Council meetings that the member is eligible to attend during a calendar year without providing notification to the Council prior to such absences;...."

Dr. Eggerding expressed her concern with this as the Council has struggled with achieving a quorum at the last few meetings. She said theoretically a member could not attend any meetings since all that is required is to give notice. She added it is difficult to have a truly representative Council and suggested revising the Rules of Order to say missing more than one half of the meetings in the course of a year, excused or not, a member should think about whether or not he/she has the time to participate. She also noted that members of the Council are appointed and understands it is a major time commitment.

The second issue raised by Dr. Eggerding is that there is no provision in the Rules of Order if the Chairman is unable to attend a meeting. She asked members to think about a plan of who should preside over a meeting if the Chairman is unable to attend. There is no Vice-Chair as defined by PL 2007, c 168 (Legislation) and stated possible options include an informal decision of who shall run the meeting, as long as there is a quorum, if the Chair can not attend or a formal election of a Vice-Chair.

Discussion on Council Members' Attendance

- Ms. Goldfarb noted there should be a level of expectation that if you are appointed or have the desire to be appointed you have ability and time to perform the function of being a member of the Council.
- Dr. Evans said it doesn't look good that the Council can not get a quorum especially given the amount of work to be accomplished. She also pointed out that at the next Council meeting a new Executive Director may be in place to help lead and may have some ideas and thoughts on this issue.
- Dr. Sprott suggested defining the number of meetings per year and setting a minimum requirement.
- It was noted a member's participation via conference call is difficult, however, it should be considered if it enables the Council to reach a quorum.
- Dr. Meyer suggested posting Council members' attendance on its website and Dr. Eggerding said if that is done she recommends the meeting schedule be posted.
- It was noted that some Council seats expire in October 2010. Under the Legislation a member remains until a recommendation is made.
- Because Council members are appointed, Dr. Sprott suggested whoever is responsible for the

appointment be made aware of the absences.

- It was agreed that it would be helpful to have this discussion with more members.

Discussion on the Absence of the Council Chair

- Dr. Meyer suggesting the idea of a parliamentarian. Someone who is able to run a meeting effectively and understands Roberts Rules of Order.
- Dr. Eggerding said the Legislation and the Rules of Order do not address this issue. She suggested having a statement noting it be the Chair's responsibility to name someone willing to Chair the meeting and the Council will accept the individual.

VII. Status Updates

A. 2010 Basic Science and Clinical Research Grants

Dr. Garg reported these grants are currently being processed to ensure all information and forms are correct. The end of June 2010 is the expected start date.

B. Clinical Enhancement Grants for SFY 2011 (Year 3)

Dr. Garg said with SFY 11 DHSS has gone to an electronic grant system called SAGE (System for Administering Grants Electronically). All six grant renewal applications have been submitted electronically and being reviewed.

C. Memorandum of Agreement (MOA) to be conducted by Rutgers University Center for State Health Policy (Rutgers) for a Needs Assessment

Dr. Garg noted after the last Council meeting she made the suggested revisions to the MOA and it was forwarded to a lawyer at DHSS for review where additions were made. The MOA was then reviewed by Rutgers and DHSS has been informed of a conflict. Dr. Rodriguez said the conflict involves a clause used, per DHSS policy, in which any funded research or activity must be reviewed and approved by DHSS before it is submitted for publication or public viewing. This issue has been raised before and has been resolved in the past. The MOA is currently being reviewed by a lawyer at DHSS.

D. Scientific Advisory Committee

Dr. Garg noted that Dr. Gallo asked the Council members to submit their top 5 researchers and top 5 clinicians in rank order. Currently, 11 of the 13 Council members have submitted rankings.

Dr. Garg will contact the two members whose rankings are outstanding. It was suggested that the ranking results and its process be put on hold until until the new Executive Director is in place. After a brief discussion Dr. Eggerding said the advantage of sharing an Executive Director is that the Brian Injury Commission and Spinal Cord Commission have effective and working Scientific Advisory Committees in place. Once an Executive Director is hired the Scientific Advisory Committee models of the two Commissions can be looked at and learned from. This may help to advance the process of the Council putting its own Scientific Advisory Committee in place. There still remain unresolved issues, such as will the Scientific Advisory Committee members be paid, the development of a job description, and how often the Advisory Committee will meet

The issue of Council money was raised in terms of how to encumber funds. Dr. Sprott expressed concern about additional money being put into reserve. Dr. Rodriguez said going into SFY 2011,

which starts July 1, 2010 the Council has \$11.6 million. It was also noted that at about this same time monies generated under PL2007, c 174 will be deposited in the Autism Research Fund. Dr. Rodriguez said if the Council decides to increase year three funding to any of the Clinical Enhancement Centers for increased activities it can be done through the budget modification process. Dr. Eggerding reminded the Council that it recently did vote down a recommendation to increase funding to Hunterdon Medical Center for additional services.

E. Requests for Applications (RFA) for the Autism Center of Excellence

Dr. Evans noted because of the release of Dr. Gallo and the withdrawal of Dr. Eggerding due to a potential conflict, the remaining Subcommittee members include Ms. Bell, Dr. Garg and herself. Dr. Evans said the Subcommittee is working towards creating a Center of Excellence as discussed at the Council retreat to include a Coordinating Center and satellite sites. The Subcommittee discussed various names including NJACE (New Jersey Autism Center of Excellence). Two RFA's are being designed: one for the Coordinating Center and its responsibilities and the second for the satellite sites and their responsibilities.

Many questions are being sorted through by the Subcommittee, including a mission statement for the Center of Excellence. The Subcommittee has looked at the Legislation and Dr. Evans asked Council members to think about what the mission for the Center of Excellence is. Dr. Evans presented two suggested mission statements. In order for the Subcommittee to move forward a final mission statement is needed. It was decided that a brief Council meeting via telephone conference will be scheduled for the last week in June to allow the Council to vote on a mission statement for the Center of Excellence.

There was a discussion regarding the dollar amounts for the Center of Excellence grant program and the Basic Science grant program noting budget considerations need to be looked at. Dr. Eggerding suggested a broad overview of the current Council dollars should be included as an agenda item at the next meeting. She added part of the reason the 2010 Basic Science grants were funded generously was due to the amount of money the Council had available and continued to say the Council will not always fund the Basic Science grants at the 2010 level. The context of the mission statement and what the Council wants the Coordinating Center and Center of Excellence to do needs to be taken into consideration. Drs. Eggerding and Spratt acknowledged the hard work of the Subcommittee.

DHSS' Application for a Federal Grant announced by HRSA (Health Resources and Services Administration)

Dr. Eggerding informed the Council that DHSS is applying for a state implementation grant through the federal government. The purpose of the grant is to look at coordinating health care and related services for children and youth with ASD and other developmental disabilities. Dr. Eggerding said there is a collaboration of individuals who are writing the grant application which will address access to cultural competent family centered medical homes that coordinating care with pediatric subspecialties and community based services and transition to adult health care. Dr. Eggerding asked Dr. Evans if she would be willing to be the liaison to Council. Dr. Eggerding said as the Chairman of the Council she has been asked and will write a letter of support.

VIII. Action Items

- Dr. Eggerding will email Council members about attendance at meetings pointing out the challenges with reaching a quorum. The Council is considering changing the Rules of Order and a discussion has been had on whether the Council member's attendance record will be posted on the Council's website. The attendance record will be included in the email.
- Council members are to send comments/concerns and questions regarding the Center of Excellence mission statement in writing to Dr. Evans.
- A telephone conference is to be scheduled for the last week of June to allow Council members to vote on the Center of Excellence mission statement.
- The August 2, 2010 agenda is to include a vote to change the Rules of Order related to attendance, to also vote on the recommended statement made by Dr. Eggerding in regards to the Chairman's absence at a Council meeting, and a discussion of the 5-year plan on the Council's budget.

IX. Public Comments

Nicole Lubas

Ms. Lubas is the owner of Success Across the Spectrum, which provides individualized home based services for children with ASD. Ms. Lubas offered her help to the Council.

Kathleen Freeman, PhD, RNC

Dr. Freeman noted the month of August is a popular vacation month and therefore, not the best time to hold a meeting, especially being that the Council members' attendance is to be addressed. As a parent in regards to the Registry she spoke of some of the difficulties encountered. She suggested a sample letter be sent out. She also noted the many tools and instruments used in making a diagnosis noting the reliability and validity of the tests. The process presented looked clear, but as a parent sees many problems with the Registry.

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

As one of the six Clinical Enhancement Centers, Dr. Mars inquired as to what is happening with the information that is being obtained from the collaborative database. She added over the next year she would like to see more work in determining that information and how it is utilized. She understands the Registry takes a lot of time, but parents are not expected to fill out the Registry form nor are parents expected to be uninformed in that process. Her goal is that all parents understand the Registry process and every effort is made to obtain information. However, with or without a name the purpose is to refer children to case management.

Walter Zahorodny, Phd

Dr. Zahorodny stated he is unsure if it's possible for one Executive Director to delegate fairly and equitable over two Commissions and a Council. He said he would do everything possible to advocate for the autism agenda. He also said he is in favor of quality first, but everything seems to take too long. He noted it took over 18 months for the 2010 Basic Science and Clinical Research grants to be funded since the initiative started. He noted the discussion of the MOA took approximately nine months and if awarded it will take 21 months to get to the end product and something that takes three and a half years is questionable just by virtue of taking so long. He said there should be much more urgency undergirding the efforts of the Council as autism prevalence is increasing and so many more families are affected.

Joanne Gere, Founder of BioScience Collaborative

Ms. Gere said she has been funded this year by the BioOne Wire project to develop the neuroscience network which is the reason she is in attendance. The BioScience Collaborative is about bringing researchers together with caregivers, funders, and companies helping to build that interface that stimulates collaboration.

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

As a case manager, Ms. Freedman commented on the steps and time taken to acquire and complete the Registry form. She noted when actually speaking to a family about every area of the child's and family's life the process takes two to three hours. She noted the Birth Defects Registry is less time consuming and understands in the context of autism and their families it's overwhelming. She noted that New Jersey's Birth Defects Registry system is recognized nationally by the American Academy of Pediatrics because it is so comprehensive and is actively used. Her understanding is New Jersey is the only State that has a Birth Defects Registry and now an Autism Registry which is used to contact families. In addition, she noted New Jersey has some really good systems in place already to support families.

Note: Dr. Rodriguez added the CDC (Centers for Disease Control and Prevention) and HRSA also recognize New Jersey as best practice for its Birth Defects Registry and the connection to case management and services to children with special needs.

Comments from Council Members and DHSS

Dr. Bier said the idea of a Coordinating Center is to facilitate projects. She knows the processes have been slow and there is an enormous amount of work to be done. However, with one Executive Director and one grant manager from DHSS work was unable to move faster. Dr. Bier also noted the Registry will generate data in many areas and should be a prerequisite for the six Clinical Enhancement Centers in their third year.

Dr. Sprott said the amount of work the Registry brings to the Case Managers need to be taken into account. Dr. Rodriguez said there is one Case Management Unit in each of the 21 counties in New Jersey which are funded jointly by DHSS and county freeholders. Dr. Rodriguez also said DHSS has given extra money to the counties that have a higher number of cases reported to augment the hours of a case manager but not a full time person

In closing, Dr. Eggerding acknowledged all the people who have "stepped up to the plate" in Dr. Gallo's absence. She said it has been a challenge the last month and everyone has worked hard to make sure the Council can continue to move forward and she expressed her appreciation.

X. Adjourn

The next meeting of the Governor's Council for Medical Research and Treatment of Autism is scheduled for August 2, 2010 from 6pm – 8pm at the Department of Human Services, Division of Developmental Disabilities, Conference Room 199A, 5 Commerce Way, Hamilton, New Jersey.

Meeting adjourned at 9:03pm.