



November 29, 2010

The Honorable Chris Christie  
Governor, State of New Jersey

Dear Governor Christie:

On behalf of the Governor's Council for Medical Research and Treatment of Autism, I am pleased to present the enclosed 2009 Annual Report.

It has been an honor for me to serve the citizens of New Jersey as the Chairman of the Governor's Council for Medical Research and Treatment of Autism. I have been privileged to work with highly-dedicated staff and volunteers. Many of us have committed much of our professional and personal lives to the betterment of the lives of citizens with autism, and we look forward with hope to scientific discoveries that will provide more effective treatments that will allow those with autism to live productive and satisfying lives.

As you will see in the Report, 2009 provided many opportunities for the Council to carry out the intended goals of the legislation and work toward providing a Center of Excellence in New Jersey for research and treatment of autism which will provide both basic sciences and biomedical research and treatment services. The Council also continues to fund the six Clinical Enhancement Centers that serve to increase patient access to autism evaluation, diagnosis and treatment services, as well as outreach and education to families affected by autism.

In the coming year the Council will be conducting a needs assessment of the research and treatment services available in the State to more fully assess the gaps in resources and services for individuals with autism and their families. The Council is also working diligently to advise the Department in its development of a Request for Applications (RFA), to create a Center of Excellence for Autism which we look to launch in 2011.

Our work is not yet done, and the Council is looking forward to having a productive year. I am very grateful for this opportunity to serve the New Jersey Autism Community.

Sincerely,

Caroline Eggerding, MD  
Chairman, Governor's Council for Medical Research and Treatment of Autism

Enclosure

Cc: Commissioner Poonam Alaigh, MD, MSHCPM, FACP

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**THE GOVERNOR’S COUNCIL FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM**

**ANNUAL REPORT**

**JANUARY 1, 2009-DECEMBER 31, 2009**

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# THE GOVERNOR'S COUNCIL FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM

## ANNUAL REPORT

JANUARY 1, 2009 – DECEMBER 31, 2009

### Executive Summary

#### **The Mission of the Governor's Council**

The Governor's Council for Medical Research and Treatment of Autism was created by State appropriation in 1999 and has been issuing research and clinical and educational enhancement grants since 2000. As per P.L. 2007, c.174, monies from \$1 surcharges on fines and penalties from traffic violations are deposited by the State Treasurer into the Autism Medical Research and Treatment Fund to sponsor the Council to fund autism research and treatment in the State of New Jersey.

As detailed in P.L.2007, Chapter 168, the mission of the Council is to establish a Center of Excellence in the State to advance the understanding of the potential causes and treatments of Autism Spectrum Disorders (ASDs) by supporting basic science studies and clinical research initiatives. Additionally, the Council is charged with developing and funding grant initiatives that improve the clinical diagnosis and treatment of ASDs, and families' access to autism services, in clinical centers and hospitals throughout the State.

In its discussions and deliberations, the Council has focused on developing programs that enable equal access to clinical services to families throughout the state. In meeting the charge outlined in its establishing legislation, the Council is also working to develop an integrated, statewide Center of Excellence that defines, develops and establishes best practices in evaluation, diagnosis and treatment for individuals with autism across the lifespan.

- The Council met seven times in 2009 Calendar Year and will meet eight times in Calendar Year 2010.
  - Dr. Caroline Eggerding, Executive Vice President of Pediatric and Adolescent Services for Bancroft Neurohealth, and the State Assembly Speaker Appointee to the Council, served as Chair for the Council.
  - Thirteen (13) of the fourteen (14) member seats on the Council were named.
- The \$8.55 million Clinical Enhancement Center grant initiative is in the second of a three-year cycle.
  - This program enables six clinical autism centers across New Jersey to enhance their staffing of clinical personnel and to improve early detection and increase the number of multi-disciplinary evaluations that they can provide to children suspected of being on the autism spectrum.
  - These grants represent a patient-oriented initiative aimed at establishing more uniform diagnostic, treatment and outreach services to the increasing autism spectrum disorder population.
  - The six centers that are funded through the Clinical Enhancement Center grant initiative are:
    1. The Center for Neurological and Neurodevelopmental Health (CNNH II) in Voorhees
    2. Children's Specialized Hospital in Toms River
    3. Hackensack University Medical Center, The Institute for Child Development
    4. Hunterdon Medical Center, The Child Development Center in Flemington
    5. Jersey Shore University Medical Center in Neptune
    6. UMDNJ-New Jersey Medical School, The Autism Center in Newark

- Basic Science and Clinical Research Grants
  - The \$3 million, 2007-2010 Basic Science grant initiative funded research in the areas of Environmental Exposure, Epidemiology fMRI/Brain Development, Genetics, Immunology and Neurobiology. In April 2009 the Council announced the Request for Applications (RFA), for its \$5 million, Basic Science and Clinical Research grant program. Thirty-nine research proposals were received and evaluated by 13 national and international review panels. Two-year grants will be awarded in 2010.
  
- The NJ Autism Registry in DHSS receives funding from the Council's operating expenses.
  - The New Jersey Autism Registry rules were adopted on September 21, 2009. Prior to the 2007 Mandatory Reporting Law, there were 2,360 autism cases registered as a non-mandated condition. As of February 2010, 3,423 children with ASD have been registered, with 1,060 of these children being registered since May of 2009. These figures include newly diagnosed and previously diagnosed children and are expected to increase significantly as more health care providers report previously and currently diagnosed children to the Autism Registry. Based on the number of children within one birth cohort and the current autism prevalence rates, it is expected that approximately 1200 children will be registered each year.

## **Overview of Autism Spectrum Disorders**

Autism Spectrum Disorders (ASDs) are a group of Neurodevelopmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual or restricted behaviors and interests. The thinking and learning abilities of individuals with ASDs can vary from gifted to severely challenged. Autism spectrum disorders begin before the age of three and last throughout a person's life and occur in all racial, ethnic, and socioeconomic groups. The disorders are four times more likely to occur in boys than girls, and the often devastating emotional and financial tolls on the family of an autistic child have been well-documented. According to the Centers for Disease Control and Prevention's (CDC), NJ has an ASD prevalence rate of 1 in 94. This reported prevalence rate places New Jersey among the states with the highest rates of autism in the country. The CDC estimates that 1 out of every 110 children nationally has an ASD.

## **Report of the Governor's Council Activities**

### **Council Meetings**

The Council met seven times in 2009. Following are summaries of the Council Meetings.

#### **February 9, 2009**

The Council discussed and ratified its Rules of Order and authorized the announcement of an RFA to include areas of basic science and clinical research. The intent of the grant program is to fund up to ten grants at a funding level of up to \$500,000 over a 2- year period. Twenty percent of Principal Investigator's salary will be covered in the grant award, but the grant will not support funding for equipment.

#### **April 6, 2009**

At the meeting, the Council considered a request by DHSS Research Scientist 1, Dr. Sandra Howell, to have the Governor's Council approve \$1 million in funding to develop a relational database to collect patient-level data from the Council's six Clinical Enhancement sites, as well as from the 11 Child Evaluation Centers throughout the State. Dr. Howell explained that having the database funded by the Council would then allow the DHSS to leverage that development project to apply for an NIMH grant to link the data that would be collected in the database with State databases such as the Electronic Birth Certificate (EBC) database and Medicaid. The NIMH grant would also allow DHSS to link the relational database with the National Database for Autism Research (NDAR), the data collection site for the National Institutes of Health (NIH). After a lengthy discussion, the Council voted five to one in favor of funding the development of the relational database contingent upon the DHSS being awarded a NIMH grant (the DHSS grant was notified in July, 2009 that it did not receive a grant award).

Dr. Gallo stated that the Commissioner of Health and Senior Services, Heather Howard and Governor Corzine are going to mark National Autism Awareness Month by holding a town hall meeting on April 30<sup>th</sup> at the Center for Neurological and Neurodevelopmental Health in Voorhees, NJ, one of the Council-funded Clinical Enhancement Centers.

#### **June 1, 2009**

The Council heard reports from the three subcommittees created by Council Chair, Dr. Caroline Eggerding: 1) the subcommittee for determining the role of the Scientific Advisory Committee and the process for developing a strategic plan for the Council, 2) the subcommittee addressing the integration of the Council's goals with goals of the IACC and other Federal Organizations, and 3) the subcommittee formulating the Council's policies and procedures for supporting other Autism organizations. Dr. Gallo presented to the Council a recommendation list of individuals to serve on the Council's Scientific Advisory Committee, and the Council discussed supporting other autism organizations in a way that is not duplicative of the efforts of the Clinical Enhancement Centers.

### August 3, 2009

The Assistant Commissioner of Family Health Services, Celeste Andriot-Wood, was in attendance. At this meeting the Council agreed to invite Dr. Joel Cantor from Rutgers University's Center for State Health Policy to the Council's October 5<sup>th</sup> meeting to present a proposal for conducting a needs assessment on the autism clinical and research services in the State of New Jersey. Following the presentation, the Council members will vote whether or not to contract with the Center for State Health Policy to have this needs assessment conducted. The Council also requested from the Division of Family Health Services (DHS), of the Department of Health and Senior Services (DHSS), a scope of work and detailed budget for an autism database development project that the Division would like to undertake using Council funding. The budget for this one-time development project would be \$1 million, and developing such a database that would collect patient-level evaluation, phenotype and demographic data on autistic patients throughout the state would allow the Division to link this database to other statewide databases such as the Medicaid and Electronic Birth Certificate databases, and to national data repositories such as the National Database for Autism Research (NDAR), the database that is administered by the National Institutes of Health (NIH).

Dr. Gallo stated that 39 grant applications were received in response to the Basic Science and Clinical Research grant RFA, and that this is the largest response the Council has received to one of its RFAs. Twenty-six applications were basic science projects and 13 were clinical research projects.

### September 15, 2009

The Governor's Council met to discuss proposals made by the DHSS regarding the development of an RFA for a coordinating center for all of the Council's grant initiatives, and for granting a two-year, non-competing renewal to the existing six Council-funded, Clinical Enhancement Centers. Dr. Gallo stated that at the October 5<sup>th</sup> Council meeting there will be a vote on a future funding approach for the Clinical Enhancement grant initiative. The three funding options available to the Council will be to grant a non-competitive renewal to each of the currently-funded Centers, to open up the Clinical Enhancement program to competitive bid at the end of the current, 2-year Clinical Enhancement initiative, and to terminate the program at the conclusion of Fiscal Year 2010. If the Council chooses to open the program up to competitive bid, the DHSS will extend the current grant awards by 6 to 12 months so that the current programs will remain operational until the new program begins. If the Council chooses to terminate the Clinical Enhancement program, the DHSS will extend the current grant awards by six months, so that there is not an abrupt end to the services being provided to the New Jersey autism community.

The Council decided to postpone its discussion on developing an RFA for a coordinating center until the December 7<sup>th</sup> meeting. It was agreed upon that the October 5<sup>th</sup> meeting will be dedicated to discussing the issues of contracting with an organization to conduct a needs assessment of the clinical services needed and the research initiatives being undertaken in the State of New Jersey, and to selecting a future funding approach for the Clinical Enhancement program. The Council has invited Dr. Joel Cantor from Rutgers University's Center for State Health Policy Research to the October 5<sup>th</sup> meeting to present a proposal for conducting a needs assessment on the autism clinical and research services in the State of New Jersey. Following Dr. Cantor's presentation on October 5<sup>th</sup>, the Council members will vote whether or not to contract with the Center for State Health Policy Research to have this needs assessment conducted.

Dr. Gallo has sent the 39 Basic Science and Clinical Research grant applications to the 13-member, independent review panel. A conference call study section meeting will be conducted in November 2009 to discuss and rank order the grant applications. Once the panel has ranked the grants, the study section panel will then make funding recommendations to the Governor's Council.

### October 5, 2009

At this meeting Drs. Joel Cantor and Dorothy Gaboda from Rutgers University's Center for State Health Policy presented a proposal for conducting a comprehensive needs assessment of the autism clinical and research services in the State of New Jersey. Following the presentation, the Council members voted to develop a Memorandum of Agreement (MOA) to enable the Council to contract with the Institute for State Health Policy to have the Institute conduct the needs assessment. The Council will begin formulating a list of the specific tasks that it would like the

Institute to perform in this needs assessment process. The Council also voted to grant a 1-year, non-competing renewal to the six Council-funded Clinical Enhancement Centers. The Clinical Enhancement grant program will now run until June 30, 2011.

December 7, 2009

The Governor's Council voted to recommend that 11 Basic science and Clinical Research grants be awarded funding. The Council received 39 applications in response to its RFA. Dr. Gallo chaired the grant review process and recruited 13 nationally and internationally renowned researchers and clinicians to evaluate and rank the applications. The review panel recommended that the Council fund the applications falling within the "Outstanding" and "Excellent" range (which translates to a range of 1.00 – 3.00, using the NIH scoring system). There were 11 grants that fell within this range, and the Council voted to fund all 11 grants at a total funding allocation of \$5 million.

### **The Members of the Governor's Council**

**Michele Adubato, MSW, MA**, Public Member, Deputy Executive Director, North Ward Center

**Elizabeth K. Bell, BS**, Autism Organization Representative; Volunteer and Independent Contractor with Autism Speaks

\***Caroline Eggerding, MD**, the Assembly Speaker Appointee; Executive Vice President of Pediatric and Adolescent Services for Bancroft NeuroHealth.

**Susan P. Evans, EdD**, the Commissioner of Department of Health and Senior Services Appointee, and the Education Program Specialist for the Early Intervention program in the DHSS.

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

**Jessica C. Guberman, PhD**, Autism Organization Representative; Executive Director for Community Options, Inc.

**Yvette Janvier, MD, FAAP**, Health Care Organization Representative; Medical Director for the Children's Specialized Hospital in Toms River.

**Ketan Kansagra, MD, FAAP**, Academic Institution Representative; Division of Neonatal Medicine, Children's Hospital of New Jersey at Newark Beth Israel Medical Center

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

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

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

**Mr. Judah Zeigler, BS**, the Senate President Appointee, Associate Vice President of Sharp's Retail & Consumer Marketing Group and a father of an autistic son.

**Barbie Zimmerman-Bier, MD**, Academic Institution Representative; Rutgers University appointment; Department of Pediatrics at St. Peter's University Hospital

\*Denotes Council Chair

## **Governor's Council Funding Initiatives**

### **Clinical Enhancement Center Grants**

The Council is currently funding the second year of its Clinical Enhancement Center grant initiative. This program has enabled six clinical autism centers across the State of New Jersey to improve the early identification of children suspected of being on the autism spectrum, and to conduct a greater number of multi-disciplinary evaluations.

The six Centers also conducted extensive outreach and education programs to primary care physicians to improve screening and early identification efforts across the State. In addition, the Centers provided outreach to pediatric residency programs, nurse practitioners, daycare providers and preschool teachers. The Centers also developed education and information resources such as a regional autism telephone answer line and a website listing autism services and provider information.

An important aspect of the Clinical Enhancement Center grant program is the opportunity for the six clinical sites to collect patient-level information for the purpose of grant monitoring and future research opportunities. The collaborative database containing patient-level data will be a powerful tool for basic and clinical researchers in the State enabling them to characterize the population who visit these clinical sites and derive subsamples of individuals for future research on phenotypes, genotypes, and other areas of interest.

### **Highlights of the Clinical Enhancement Centers**

#### **Clinical Practice Highlights:**

- In the first year of funding of the Autism Clinical Enhancement Center grant initiative, the six programs had more than 8,500 patient visits, provided care to more than 2,500 unduplicated patients and conducted more than 1,200 diagnostic autism evaluations.
- The Council funding enabled the Centers to reduce wait times for those receiving developmental evaluations from several months to eight weeks.
- Council funding allowed Children's Specialized Hospital, Jersey Shore University Medical Center and UMDNJ's The Autism Center to create developmental screening clinics for children up to 3 years of age.
- Centers were able to increase the number of professionals trained to conduct Autism Diagnostic Observation Schedule (ADOS) evaluations.
- Centers were able to increase the number of clinic days in which children suspected of being on the spectrum could be evaluated.
  - Jersey Shore Medical Center doubled both its clinic days and the hours of its Psychologist.
- Council funding enabled UMDNJ's Autism Center and The Center for Neurological and Neurodevelopmental Health (CNNH II) to expand their transition services for patients ages 12 to adult.

#### **Education and Training Highlights:**

- Council funding enabled centers to exceed their goals of training pediatric healthcare providers in the early detection of ASD.
  - Children's Specialized Hospital exceeded its goal of training pediatricians by 120% in the first year of the grant program.
- Hackensack University Medical Center created the Parent Training and Education Program (PTEP) to educate families with newly diagnosed children about autism and the services available to them. This



program, which includes home visits by Hackensack’s behavioral staff, educated 46 families in the first year of the grant.

- Hunterdon Medical Center developed an Autism answer line and provided bilingual diagnostic and evaluation services.

**Grantees**

The Center for Neurological and Neurodevelopmental Health, Voorhees, New Jersey  
Dr. Mark Mintz, Center Director  
\$ 1,500,000 over three years

Children’s Specialized Hospital –Toms River, New Jersey  
Dr. Yvette M. Janvier, Center Director  
\$ 1,500,000 over three years

Hackensack University Medical Center - Institute for Child Development,  
Hackensack, New Jersey  
Dr. Randy Huron, Center Director  
\$ 1,500,000 over three years

Hunterdon Medical Center – Child Development Center, Flemington, New Jersey  
Dr. Audrey Mars, Center Director  
\$ 1,050,000 over three years

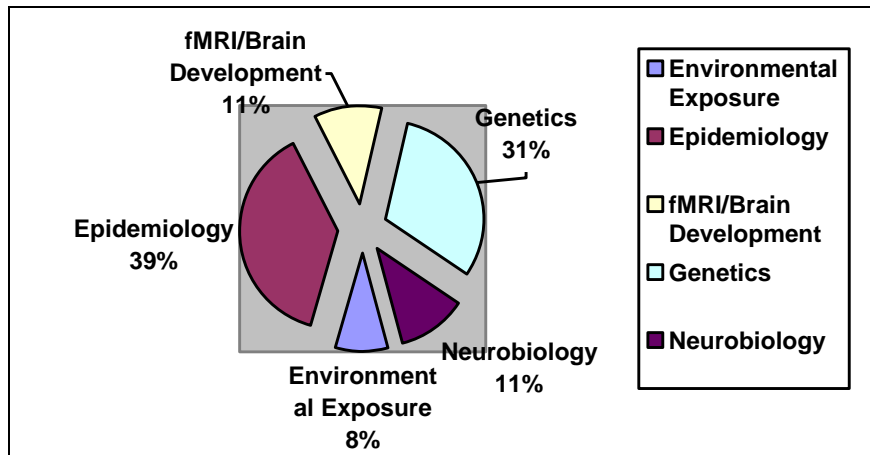
Jersey Shore University Medical Center, Neptune, New Jersey  
Dr. Denise Aloisio, Center Director  
\$ 1,500,000 over three years

University of Medicine and Dentistry, New Jersey Medical School - The Autism Center  
Newark, New Jersey  
Dr. Kendell Sprott, Center Director  
\$ 1,500,000 over three years

**Basic Science and Clinical Research Grants**

**The 2007-2010 grant cycle:**

The \$3 million, 2007-2010 Basic Science grant initiative funded research in the areas of Environmental Exposure, Epidemiology fMRI/Brain Development, Genetics, Immunology and Neurobiology. The following chart illustrates the percentage that each of these disciplines was funded during this grant cycle:



## **Grantees**

Emanuel DiCicco-Bloom, MD, UMDNJ-RWJMS, *Functional Characterization of the Autism-Associated Gene, Engrailed-2*  
\$214,244

Michael Lewis, PhD, UMDNJ-RWJMS, *Brain Maturation and Self Representation in Young Children with Autism Spectrum Disorders*  
\$295,821

John Pintar, PhD, UMDN-RWJMS, *Opioid System Contributions to Autism Linked Behavior*  
\$299,930

Gleb Shumyatsky, PhD, Rutgers University, *Amygdala-Enriched Genes may be Involved in Gating Behaviors that are Critical for Survival*  
\$300,000

T. Peter Stein, PhD, UMDNJ-SOM, *Oxidative Stress and Brain Metabolism in Autism*  
\$299,478

Pauline Thomas, MD, UMDNJ-NJMS, *Understanding the Scope of Autism in New Jersey: Characteristics of Children Diagnosed with Autism Spectrum Disorder by the Age of 8*  
\$202,014

George Wager, PhD, Rutgers University, *Protection against Early Toxicant Exposure in a Mouse Model of Autism*  
\$224,324

Daniel Wartenberg, UMDNJ-RWJMS, *An Exploratory Epidemiology Study of Autism in New Jersey and Some Possible Environmental Risk Factors*  
\$299,982

Walter Zahorodny, PhD, UMDNJ-NJMS, *New Jersey Autism Study: Population-Based Surveillance of Autism Spectrum Disorder in New Jersey*  
\$300,000

Walter Zahorodny, PhD, UMDNJ-NJMS, *Young Adults with Autism: A Pilot Epidemiologic Investigation*  
\$203,628

Steven S. Zalcman, PhD, UMDNJ-NJMS, *Treatments for the Prevention of Autistic-like Behavior in Offspring of Mothers Infected with Influenza Virus during Pregnancy: An Animal Model*  
\$299,765

## **The 2010-2012 grant cycle:**

Basic Science and Clinical Research grants will be awarded in early 2010. The Council received 39 proposals in response to the Request for Applications (RFA) for its \$5 million grants program. The 39 research proposal is the largest number of applications that the Council has ever received in response to one of its RFAs. Thirteen (13) national and international review panelists were recruited to evaluate the grant applications.

## **Governor's Council Collaborations**

### **The NJ Autism Registry**

The State launched the web-based NJ Autism Registry statewide on October 1, 2009. The Registry is designed to make it easier for families of children with autism to be connected to the appropriate support services in their cities and towns. It is anticipated that over 1,000 children will be newly diagnosed with autism each year in New Jersey. Over the next few years, it is expected that medical professionals will be registering thousands of children previously diagnosed with one of the Autism Spectrum Disorders, in addition to those newly diagnosed.

The Council collaborates with the NJ Autism Registry staff and acknowledges their outstanding accomplishments in providing outreach and education to both providers and families throughout the State. Examples include training staff from medical centers specializing in child development and evaluation including the six Governor's Council-funded Clinical Enhancement Centers; presentations at the Autism New Jersey, Inc. annual meeting, and at The New Jersey Pediatric Council on Research and Education (PCORE) meeting; creating educational materials on autism and the NJ Registry and distributing to hundreds of providers, organizations and families.

## **Future Directions**

### **Conducting a Needs Assessment**

In order to fully meet the charge of the establishing legislation in a coordinated manner, the Council will be conducting a needs assessment of the services and gaps in the areas of autism research and treatment in the State of New Jersey. The needs assessment findings will be used to develop a strategic plan for the Governor's Council for Medical Research and Treatment of Autism. This plan will guide the Governor's Council with its funding priorities and strategy, including the type and structure of grant-funded programs and activities that are supported. The DHSS is contracting with the Rutgers University Center for State Health Policy (CSHP) to conduct this needs assessment for the Council. The CSHP will catalogue the existing autism research and medical services in the State and synthesize the results of interviews with key stakeholders in the New Jersey autism community with the response to autism by other states. The Council is currently developing a Memorandum of Agreement (MOA) between the DHSS and the CSHP for the needs assessment.

### **Grant Funding Activities**

In Fiscal Year 2011, the Governor's Council will be announcing the Request for Applications (RFA) for its next clinical grant initiative. An out-of-state review panel will be contracted to evaluate the grant applications and to conduct site visits of the finalist organizations.

The Council is scheduled to discuss developing an RFA for a postdoctoral fellowship program. The purpose of a postdoctoral fellowship program is to provide support to fellows (number to be determined) in the State of New Jersey who will conduct basic science and clinical research projects to encourage these fellows to pursue the field of autism research. The grant initiative is also intended to promote mentorship between established autism researchers and postdoctoral fellows, and to bring more researchers into the field of autism.

### **Developing an Integrated Model for a Center of Excellence**

The overarching goal of the Council in the coming year is to develop and fund an RFA to develop an integrated, statewide Center of Excellence for Autism in the State of New Jersey. The envisioned Center will follow a systems approach where the research and clinical components of the Center of Excellence will be coordinated through a central coordinating center. The Center of Excellence will focus on providing a standardized level of clinical care for ASD individuals and those suspected of being on the spectrum, while also conducting biomedical research that will serve to inform the research and clinical communities, and the autism community at large about causes and treatments of ASD. The central coordinating center will also be responsible for developing education and outreach curricula to inform physicians, healthcare and educators to improve the early identification of children who may be

on the spectrum. The Center of Excellence will have a great impact, as the integrated nature of its design will allow individuals throughout the State to have equal access to the highest level of care and information. The Center will also promote the sharing of ideas among researchers, clinicians, educators and the public, as well as position New Jersey as a leader in responding with innovative approaches to the needs of the autism community.