



June 21, 2013

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 (Council), I am pleased to present the enclosed 2012 Annual Report. During 2012, the Council continued to work with the Department of Health to meet our shared responsibilities to understand autism spectrum disorders (ASD) and best practices for treatment.

On June 28, 2012, First Lady Mary Pat Christie and Health Commissioner Mary E. O'Dowd, MPH joined the Governor's Council for Medical Research and Treatment of Autism to announce \$3.7 million in grants to create the New Jersey Autism Center of Excellence (NJ ACE) with a Coordinating Center and a separate research site. A second research site was funded in December 2012.

In December 2012 the Council released RFAs for the NJ ACE Program Sites and Pilot Projects. The NJ ACE initiative represents the Council's commitment to advancing the current knowledge pool through clinical research leading to improvements in interventions that address the physical and behavioral health needs of children, adolescents and adults with ASD. Three year funding for six Clinical Enhancement Centers and eleven Clinical and Basic Science grantees ended in June 2012 with several grantees granted no cost extensions through June 2013.

To fully meet the charge of the establishing legislation in a coordinated manner, the Council contracted with the Rutgers University Center for State Health Policy (CSHP) to conduct a needs assessment for research and treatment of autism in New Jersey. The final report was completed in May 2012. The report 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. In addition, we continued to provide ongoing financial support for the NJ Autism Registry that identifies all children with ASD in the State.

It is an honor to serve the citizens of New Jersey by being both a member of the Council and the Chairperson. I have been privileged to work with the highly-dedicated staff at the DOH. As one of the eight members who are volunteering their time to serve on the Council, I wish to thank

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you for your ongoing support of our work. We look forward with hope to exciting discoveries that will provide effective treatments, allowing those affected by autism to live productive and satisfying lives.

Sincerely,

Caroline Eggerding, M.D.
Chair, Governor's Council for Medical Research and Treatment of Autism

Enclosure

Cc: Commissioner Mary E. O'Dowd, MPH

**THE GOVERNOR’S COUNCIL FOR MEDICAL RESEARCH AND
TREATMENT OF AUTISM
ANNUAL REPORT
JANUARY 1, 2012-DECEMBER 31, 2012**

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

ANNUAL REPORT JANUARY 1, 2012 – DECEMBER 31, 2012

Executive Summary

The Governor’s Council for Medical Research and Treatment of Autism (the Council) was created by State appropriation in 1999 and has been issuing research, 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 Council is to establish an Autism Center of Excellence in the State. The mission of the New Jersey Autism Center of Excellence (NJ ACE) is to research, apply and advance best practices in the understanding, prevention, evaluation and treatment of autism spectrum disorders, enhancing the lives of individuals across their lifespans.

Marking a new, coordinated approach to autism research in New Jersey, First Lady Mary Pat Christie and Health Commissioner Mary E. O’Dowd, MPH joined the Council on June 28, 2012 to announce \$3.7 million in grants to create a New Jersey Autism Center of Excellence with a Coordinating Center and a separate research site. A second research site was funded in December 2012. This five year NJ ACE initiative represents the Council’s and State’s commitment to advancing the current knowledge pool through clinical research leading to improvements in interventions that address the physical and behavioral health needs of children, adolescents and adults with Autism Spectrum Disorder.

To advance the goal of widespread data sharing among ASD researchers, investigators funded under the NJ ACE Program Sites share those data via the NIH National Database for Autism Research (NDAR). This is the first time the Council grantees will have their clinical research data submitted to the National Database.

The New Jersey data will be made available to autism researchers from around the United States, highlighting the New Jersey effort. Furthermore, participation in NDAR demonstrates that the funded sites are capable of meeting the National Institutes of Health (NIH) requirements and will help them develop stronger proposals for submission to the NIH and biomedical research foundations.

Three year funding for six Clinical Enhancement Centers and eleven Clinical and Basic Science grantees ended in 2012 with several grantees granted no cost extensions through June 2013.

The Council provided \$500,000 in 2012 to the New Jersey Autism Registry. The law establishing the Autism Registry within the Special Child Health Service Registry requires providers to register children diagnosed with autism. The Registry is designed to connect families of children with autism to the appropriate support services in their cities and towns.

To fully meet the charge of the establishing legislation in a coordinated manner, the Council contracted with the Rutgers University Center for State Health Policy (CSHP) to conduct a needs assessment. An interim report was presented to Council in December 2011 and the final report was completed in May 2012. The report will guide the Council's funding priorities and strategy, including the type and structure of grant-funded programs and activities that are supported.

In 2013 the Council's activities will focus on awarding up to \$6M in grants to the NJ Autism Center of Excellence (NJ ACE) Program Sites and/or Pilot Projects in June 2013 and planning for FY 14. The progress of all grantees will be periodically reviewed to ensure progress in accomplishing the goals of the grants. The Council intends to provide, based on the availability of funds, funding for clinical research in FY 14. An ad hoc committee of the Council has been charged with recommending, based on the legislation (P.L. 2007, Chapter 168), the categories of grants to be funded in FY 14. It is anticipated that the Council will continue to participate in events throughout 2013, such as Autism New Jersey's annual conference.

Overview of Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) is 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 ASD can vary from gifted to severely challenged. ASD begins before the age of three and lasts throughout a person's life. These disabilities occur in all racial, ethnic, and socioeconomic groups. The disorders are four times more likely to occur in boys than girls.

Autism is a health issue nationally. A recent Centers for Disease Control and Prevention (CDC) report (MMWR Surveillance Summaries, March 30, 2012/61 (SS03; 1-19) estimates an average of 1 in 88 children in the United States has ASD. As part of the same CDC study, the prevalence rate for the New Jersey sites was established at 1 in 49 children. This reported prevalence rate places New Jersey among the states with the highest rates of autism in the country. New Jersey's higher rates can be attributed in part to increased awareness and detection.

Grant Activities and Funding Initiatives

New Jersey Autism Center of Excellence (NJ ACE). This five year NJ ACE initiative represents the Council's and State's commitment to advancing the current knowledge pool through clinical research. It is anticipated that the initiative will lead to study outcomes that will have direct clinical impact such as earlier diagnosis and improvements in interventions that address the physical and behavioral health needs of children, adolescents and adults with ASD. The Center for Autism and Early Childhood Mental Health at Montclair State University was awarded \$1.5 million over 5 years to establish the NJ ACE Coordinating Center. The NJ ACE will provide common management and support functions in order to unify the NJ ACE Program Sites by serving as the voice of the NJ ACE and promoting the sharing of lessons learned and best practices in the conduct of clinical research. In addition, The Rutgers University Institute for Human Genetics was awarded \$2.2 million over 5 years to focus on the genetics of Autism Spectrum Disorders (ASDs). In December 2012 The University of Medicine and Dentistry was awarded \$2.1 million over five years to study the neurobiological, molecular and genetic basis of autism and to explore novel therapies for affected individuals living in New Jersey. The

Program Sites' grant awardees conduct clinical research projects that address the national priorities described in the Interagency Autism Coordinating Committee (IACC) Strategic Plan and, if applicable, grantees will also address the Healthy People 2020 autism-related objective addressed by the research project. Project abstracts and progress reports are posted on the Council's website at http://www.state.nj.us/health/autism/grant_ini.shtml.

To advance the goal of widespread data sharing among ASD researchers, investigators funded under the NJ ACE Program Sites grant program share their data via the NIH National Database for Autism Research (NDAR). NDAR houses research data of all types (genetic, imaging, clinical assessment, etc.) from human subjects involved in ASD studies. It is expected that in the next several years, ASD data from more than 90% of new investigations will be available in or through NDAR. Submitting data to NDAR is a new requirement for Council's grantees and reflects the Council's priority optimizing clinical research activities in New Jersey and also contributing to the national autism clinical research effort.

The New Jersey data will be made available to autism researchers from around the United States, highlighting the New Jersey effort, and similarly, national data will be available to NJ researchers to enhance their work and grant applications. Furthermore, participation in NDAR demonstrates that the funded sites are capable of meeting the National Institutes of Health (NIH) requirements and will help them develop stronger proposals for submission to the NIH and biomedical research foundations.

With a goal to build capacity for the NJ ACE, Council announced a \$6 million Notices of Grant Availability (NOGA) on December 10, 2012 with awards to grantees in June 2013. The NOGA calls for applicants for both program sites and pilot projects and responds to the needs of the autism community through funding for the development of projects and programs with clinical impact designed to improve interventions that address the physical and behavioral health needs of children, adolescents and adults with ASD.

The Clinical Enhancement Centers. The Clinical Enhancement Center (CEC) grant initiative enabled six clinical autism centers across New Jersey to enhance staffing of clinical personnel,

improve early identification of ASD and increase the number of multi-disciplinary evaluations provided to children suspected of being on the autism spectrum. The third year of a three-year cycle ended on June 30, 2011 with three of the six Centers continuing with no cost extensions through June 30, 2012.

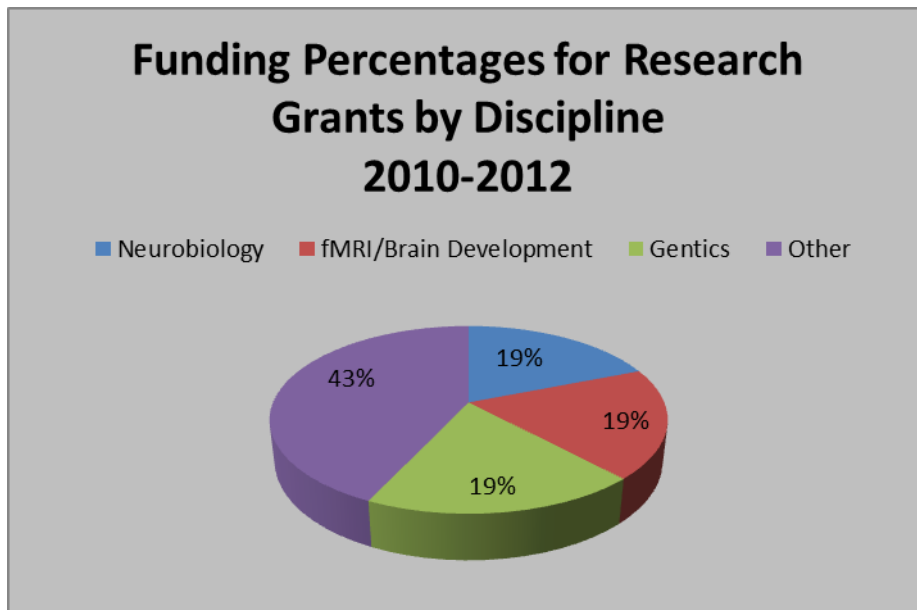
Funding totaled \$8.55M for the three year period (July 1, 2008 – June 30, 2011). The Council funding resulted in increased accessibility to diagnostic and treatment services through the addition of new clinical programs and specialized medical personnel and expanded hours of operation. In the third year of funding 5,414 patients received care at the six Clinical Enhancement Centers with a total of 15,370 patient visits. Diagnostic autism evaluations were conducted for 2,570 patients, resulting in 1,131 diagnoses of ASD. 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.

2008-2011 Clinical Enhancement Centers
***no cost extensions through 2012**

Principal Investigator	Institution	Total Funding (3 Years)
Mark Mintz, M.D.	The Center for Neurological and Neurodevelopmental Health Gibbsboro, New Jersey	\$ 1,500,000
Yvette M. Janvier, M.D.	Children's Specialized Hospital Toms River, New Jersey	\$ 1,500,000
Randy Huron, M.D.	*Hackensack University Medical Center - Institute for Child Development, Hackensack, New Jersey	\$ 1,500,000
Audrey Mars, M.D.	*Hunterdon Medical Center – Child Development Center, Flemington, New Jersey	\$ 1,050,000
Denise Aloisio, M.D.	Jersey Shore University Medical Center, Neptune, New Jersey	\$ 1,500,000
Tyrone Bentley, M.D.	*University of Medicine and Dentistry, New Jersey Medical School Newark, New Jersey	\$ 1,500,000

Basic Science and Clinical Research Grants. The Council awarded eleven two-year Basic Science and Clinical Research grants (2010-2012) for a total of \$5M. The grant program funded research primarily in the areas of genetics, fMRI/brain development, and neurobiology. Accomplishments of the grantees are impressive with significant progress in meeting or exceeding the goals of the projects as evidenced by publications in professional peer reviewed journals. Grantees have also received additional funding through federal agencies and foundations, another indication of the quality of their research.

Grantees' progress reports, including accomplishments, are posted at www.nj.gov/health/autism under "Current Initiatives".



2010 – 2012 Basic Science and Clinical Research Grantees

***no cost extensions through 2013**

Principal Investigator	Title	Institution	Type of Study	Funding Level
Bharat Biswal, Ph.D.	Altered brain connectivity in Autism Spectrum Disorder patients	*UMDNJ-NJMS	Basic Science	\$469,550
Gabriella D’Arcangelo, Ph.D.	Reelin abnormalities in synaptogenesis and ASD	*Rutgers University	Basic Science	\$381,700
Bonnie Firestein, Ph.D	Regulation of synaptogenesis by Cypin and Neuroligin-1	*Rutgers University	Basic Science	\$469,550
Emanuel DiCiccio-Bloom, M.D.	En2 Regulates Forebrain Monoamines and Behavior	*UMDNJ-RWJMS	Basic Science	\$469,550
Yvette Janvier, M.D.	Autism outreach /screening in underserved areas	Children’s Specialized Hospital	Clinical Research	\$469,550
G. Miller “Mill” Jonakait, Ph.D.	Mediators of maternal inflammation	*NJIT	Basic Science	\$392,162
Michael Lewis, Ph.D.	Self representation and brain Development in Autism	*UMDNJ-RWJMS	Clinical Research	\$469,550
James Millonig, Ph.D.	Genetic and epigenetic Engrailed-2 ASD risk factors	*UMDNJ-RWJMS	Basic Science	\$469,550

Principal Investigator	Title	Institution	Type of Study	Funding Level
Maggie Shiffrar, Ph.D.	Perceptual-motor anticipation in individuals with ASD	*Rutgers University	Clinical Research	\$469,550
Gleb Shumyatsky, Ph.D.	Amygdala-enriched genes in behaviors Related to ASD	*Rutgers University	Basic Science	\$469,550
Harvey Weiss, Ph.D.	Autism and control of cerebral metabolism	*UMDNJ-RWJMS	Basic Science	\$469,550

New Jersey Autism Registry. The Autism Medical Research and Treatment Fund provided \$500,000 in 2012 to the New Jersey Autism Registry. The State launched the web-based NJ Autism Registry statewide on September 22, 2009. The law establishing the Autism Registry within the Special Child Health Service Registry requires providers to register children diagnosed with autism. The Registry is designed to connect families of children with autism to the appropriate support services in their cities and towns. 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.

As of December 2012, over 10,000 children with ASD were registered. These figures include newly diagnosed and previously diagnosed children. Based on the number of children within one birth cohort and the current autism prevalence rates, it is expected that at least 1,200 newly diagnosed children per birth year cohort will be diagnosed and registered. Registry staff continues to educate more health care providers about their responsibilities to register both previously and newly diagnosed children. As health care providers register both those children diagnosed prior to 2009 and those whom they have newly diagnosed, the Registry staff expects the number of children registered in the first few years to be higher than the annual expected rate.

After the previously diagnosed children have been registered, staff expects that most children registered will be those who are newly diagnosed. In 2012, 1,736 children were entered into the Registry.

Events and Programmatic Activities

Scientific Meeting of Research Grantees. A scientific meeting of the basic and clinical science researchers funded by the Council was held on March 23, 2012 at the Holiday Inn in East Windsor. Eighteen researchers from Rutgers University, the University of Medicine and Dentistry of New Jersey, Princeton University and Children’s Specialized Hospital attended the meeting. The meeting provided a unique opportunity for research colleagues to share information and set the stage for possible future collaborations. The intent of the Council was to raise the level of awareness among stakeholders of the impact of New Jersey autism research while positioning grantees to compete for federal funding. This is a new initiative by the Council and the start of what we hope to ultimately be a statewide program to bring all autism researchers together annually for a summit to present and hear about the “*State of the State in Autism Research in New Jersey*”. The “Proceedings: Scientific Meeting of the Basic and Clinical Sciences Research Grantees” is available on the Council’s website at www.nj.gov/health/autism.

Autism New Jersey 30th Annual Conference. The Basic and Clinical Science Research grantees funded by the Council were invited to participate in a poster session event on October 9, 2012 at Autism New Jersey’s 30th Annual Conference in Atlantic City. The session was a tremendous success in highlighting the contributions of the Council in supporting autism research statewide.

Rutgers University Center for State Health Policy. To fully meet the charge of the establishing legislation in a coordinated manner, the Council contracted with the Rutgers University Center for State Health Policy (CSHP) to conduct a needs assessment. The CSHP catalogued the existing autism research and medical services in the State and synthesized the results of interviews with key stakeholders in the New Jersey autism community with the response to autism by other states. The results 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. An interim report was presented to Council in December 2011 and the final report was completed in May 2012.

The Council's Membership and Meetings

The Council's membership is made up of representatives from academic institutions, autism and healthcare organizations, appointees of the Senate President, Assembly Speaker, Commissioner of Health, a member from the general public, and an individual with autism, or family member with autism. Dr. Caroline Eggerding, Division Head, Department of Pediatric Neurology and Development, Cooper Children's Regional Hospital, served as Chair for the Council. The Council met four times in 2012. Council members, meeting calendar and minutes are posted on the Council's website at www.nj.gov/health/autism.

Moving Forward to 2013

The Council's activities will focus on awarding up to \$6M in grants to the NJ Autism Center of Excellence (NJ ACE) Program Sites and/or Pilot Projects in June 2013 and reviewing progress in grantees' accomplishing the goals of the grants. The awards will be posted on the Council's website at http://www.state.nj.us/health/autism/grant_ini.shtml in July 2013. These awards are made through one-year contracts. Support for the continuing years of all grants is contingent upon availability of funds and submission and approval of annual comprehensive progress reports.

In addition, the Council intends to provide, based on the availability of funds, funding for clinical research in FY 14. An ad hoc committee of the Council has been charged with recommending, based on the legislation (P.L. 2007, Chapter 168), the categories of grants to be funded in FY 14.

It is anticipated that the Council will continue to participate in events throughout 2013, such as Autism New Jersey's annual conference.

Fund Balance Statement

	SFY 2012	SFY 2012	SFY 2013
	<i>Projected</i>	Actual	<i>Projected</i>
Opening Fund Balance (July 1)	\$9,474,627	\$9,474,627	\$9,580,475
Revenues			
Assessments ¹	\$3,600,000	\$4,068,725	\$3,600,000
State Appropriated Funds	\$500,000	\$500,000	\$500,000
Total Revenue:	\$4,100,000	\$4,568,725	\$4,100,000
Total Funds Available	\$13,574,627	\$14,043,352	\$13,680,475
Disbursements and Expenses			
Disbursements to Grantees	\$10,526,301	\$3,746,920	\$10,250,000
Total disbursements	\$10,526,301	\$3,746,920	\$10,250,000
Expenses			
Administrative & Office expense	\$476,000	\$191,225	\$450,000
Professional Review Panel	\$24,000	\$24,732	\$50,000
Autism Registry	\$500,000	\$500,000	\$500,000
Total expenses	\$1,000,000	\$715,957	\$1,000,000
Total Disbursements and Expenses	\$11,526,301	\$4,462,877	\$11,250,000
Closing Fund Balance (June 30)	\$2,048,326	\$9,580,475	\$2,430,475
¹ <i>Net revenue variance</i>			