



July 8, 2015

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 2014 Annual Report. During 2014 the Council continued to work with the Department of Health to meet our shared responsibilities to understand autism spectrum disorder (ASD) and best practices for treatment.

The New Jersey Autism Center of Excellence (NJ ACE), established in 2012, represents the State's and the Council's commitment to advancing the current knowledge pool through clinical and translational research leading to improvements in interventions. Early diagnosis and treatment address the physical and behavioral health needs of children, adolescents and adults with ASD.

The NJ ACE Coordinating Center at Montclair State University provides a collaborative approach to autism research in New Jersey. Researchers examine the implications of their research and that of their colleagues in the context of the existing body of knowledge with the goal of helping to answer questions such as: What new information has been added? How might the data influence best practices in the community? What additional research should follow?

The Coordinating Center manages and provides support services to seventeen clinical and translational autism research projects funded by the Council. An additional eleven grantees will join the NJ ACE this year including three Autism Health Needs Medical Homes projects. This funding marks a true commitment to high quality clinical and health services research that will help New Jersey families challenged by ASD.

To advance the goal of widespread data sharing among ASD researchers, investigators share their clinical research data via the National Institutes of Health (NIH) National Database for Autism Research (NDAR). The Interagency Autism Coordinating Committee (IACC) Strategic Plan Update released on April 30, 2014, included the State of New Jersey in the section on NDAR as a participant along with the Centers for Disease Control and Prevention (CDC), the Department of Defense, the Simons Foundation, and Autism Speaks. As a result of this recognition, NDAR accepts data directly from the Council's grantees and enables the grantees to access data from researchers nationwide.

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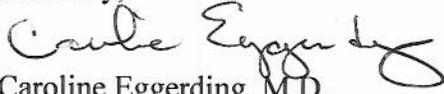
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It is an honor to serve the citizens of New Jersey by being both a member of the Council and the Chairperson. I have been privileged to work with the highly-dedicated staff at the New Jersey Department of Health. As one of the twelve members who are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

A handwritten signature in cursive script, appearing to read "Caroline Eggerding".

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, 2014-DECEMBER 31, 2014**

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

ANNUAL REPORT JANUARY 1, 2014 – DECEMBER 31, 2014

Executive Summary

The Governor's Council for Medical Research and Treatment of Autism (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.

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 the New Jersey Autism Center of Excellence (NJ ACE), marking a new, coordinated approach to autism research in New Jersey. 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 and Rutgers University Institute for Human Genetics was awarded \$2.2 million over 5 years to focus on the genetics of Autism Spectrum Disorder (ASD). A second research site was funded in December 2012, seven clinical research sites were funded in June 2013 and seven in June 2014. The 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 ASD.

"With the creation of the Autism Center of Excellence we will have one voice leading New Jersey's research of ASD," said Commissioner O'Dowd. "These grants advance New Jersey's strong commitment to enhancing the lives of individuals with Autism and will put our state at the forefront of Autism research."

To advance the goal of widespread data sharing among ASD researchers, investigators share their clinical research data via the National Institutes of Health

(NIH) National Database for Autism Research (NDAR)*. Submitting data to NDAR reflects the Council's priority optimizing clinical research activities in New Jersey and also contributing to the national autism clinical research effort.

The Autism Medical Research and Treatment Fund provided \$500,000 in 2014 to the New Jersey Autism Registry. The law establishing the Autism Registry within the Special Child Health Service Registry requires all licensed providers to register all children through the age of 21 who are diagnosed with autism. The Registry is designed to connect families of children with autism to the appropriate support services in their counties.

The Council sponsored a scientific conference in April 2014 entitled "Translational Research in Autism" for Council funded researchers and their colleagues.

In 2015, the Council's activities will focus on awarding up to \$6 million in grants to the NJ Autism Center of Excellence (NJ ACE) Translational Research Pilot Projects, Clinical Research Pilot Projects and Autism Health Needs Medical Homes Pilot Projects.

In addition to supporting research and treatment the Department of Health works to connect families affected by autism to programs and services. For information about these services, please visit <http://nj.gov/health/fhs/eis/index.shtml>.

Overview of Autism Spectrum Disorders

Autism Spectrum Disorder (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.

* The IACC (Interagency Autism Coordinating Committee) Strategic Plan Update released on April 30, 2014 included the State of New Jersey in the section on NDAR as a participant along with the Centers for Disease Control and Prevention (CDC), the Department of Defense, the Simons Foundation, and Autism Speaks. As a result of this recognition, NDAR accepts data directly from the Council's grantees and enables the grantees to access data from researchers nationwide.

Autism is a health issue nationally. The Centers for Disease Control and Prevention (CDC) report (MMWR Surveillance Summaries, March 28, 2014 / 63(SS02); 1-21) estimates an average of 1 in 68 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 45 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 and Program Activities

New Jersey Autism Center of Excellence (NJ ACE). The NJ ACE initiative represents the State's and the Council'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.

"New Jersey continues to be a national leader in our commitment to find new and innovative ways to help New Jersey families affected by autism," said Commissioner O'Dowd. "These grants will help us better understand autism and allow families with special needs children to benefit from the excellent research New Jersey institutions offer."

The NJ ACE currently consists of a Coordinating Center, three Clinical Research Program Sites and fourteen Clinical and Translational Research Pilot Projects. In June 2012 the Center for Autism and Early Childhood Mental Health at Montclair State University was awarded \$1.5 million over five years to establish the NJ ACE Coordinating Center. Rutgers University Institute for Human Genetics was awarded \$2.2 million over five years to focus on the genetics of Autism Spectrum Disorder (ASD). In December 2012 the University of Medicine and Dentistry of New Jersey- Robert Wood Johnson Medical School (now Rutgers University-Robert Wood Johnson Medical School) 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. Details of the awards are included in the Council's 2012 Annual Report (<http://www.state.nj.us/health/autism/report.shtml>).

Grant Awards – 2014. On July 15, 2014 Health Commissioner Mary E. O'Dowd announced \$2.5 million in grant funds to advance research and treatment of autism. The funding went to medical

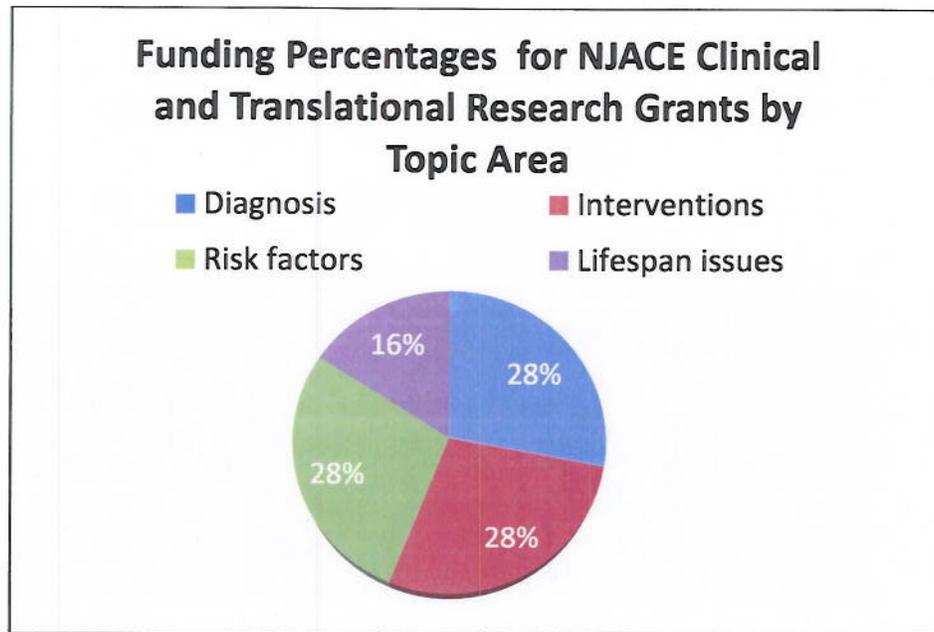
schools, universities, a hospital and a specialty medical center. The Council awarded grants for a variety of projects including: testing for genetic abnormalities, analysis of special transportation services for those with autism, and an examination of video as an interventional therapy. A primary goal of these awards is to foster innovations that lead to clinical impact and therefore improvements for individuals and families.

Grantees 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.

The grant awards are:

- \$400,000 to Rutgers University's Robert Wood Johnson Medical School in New Brunswick to study autism-linked stress at the cellular level and initial testing of therapeutic strategies
 - \$400,000 to Rutgers University Robert Wood Johnson Medical School in Piscataway to study human stem cells from individuals with autism in order to determine metabolic abnormalities that may contribute to autism and have the potential to be reversed through the use of pharmaceuticals
 - \$399,558 for the Center for Neurological and Neurodevelopment Health II (NeurAbilities) in Gibbsboro to test for specific genetic abnormalities, assess for their clinical manifestations, and discover new biological causes of Autism Spectrum Disorder (ASD) and associated complications
 - \$398,908 to Rutgers University Robert Wood Medical School in Piscataway to provide a new objective instrument that detects micro-movements present in social behaviors with the potential of leading to earlier diagnosis of autism, using the standardized structures of the Autism Diagnosis Observation Schedule (ADOS), a reliable instrument based on observation
 - \$398,282 for Rutgers University's Center for Advanced Infrastructure & Transportation in Piscataway to perform an assessment to aid adults on the autism spectrum in finding safe, accessible and appropriate paratransit transportation services
- \$397,547 to Saint Peter's University Hospital in New Brunswick to analyze early electroencephalogram (EEG) features to predict risk of ASD and Related Disorders in Premature and low birth weight infants
- \$125,899 to William Paterson University in Wayne to examine imitation from video in children with ASD with a controlled experiment to support, or not, the proliferation of video and touchscreen based imitation interventions for ASD

The research topics in the following chart are defined by the Interagency Autism Coordinating Committee (IACC) and are presented in the IACC Strategic Plan Update (<http://iacc.hhs.gov/strategic-plan/2013/index.shtml>) as a set of questions each referring to a topic with related research objectives.



2014 Clinical and Translational Research Grants

Principal Investigator	Institution	Funding Level
Davide Comoletti, Ph.D.	Rutgers University- RWJMS	\$400,000 (2 yrs.)
Emanuel DiCicco-Bloom, M.D.	Rutgers University- RWJMS	\$400,000 (2 yrs.)
Cecilia Feeley, MS	Rutgers University- RWJMS	\$398,908 (2 yrs.)
Amy E. Learmonth, Ph.D.	William Paterson University	\$125,899 (2 yrs.)
Mark Mintz, M.D.	NeurAbilities (CNNH II)	\$399,558, (2 yrs.)
Elizabeth B Torres, Ph.D.	Rutgers University- RWJMS	\$398,908 (2 yrs.)
Barbie Zimmerman-Bier, M.D.	St Peter's University Hospital	\$397,547 (2 yrs.)

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). Pilot project grantees are encouraged to share data via NDAR if compatible with the research design. 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 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 NIH requirements and will help them develop stronger proposals for submission to the NIH and biomedical research foundations.

New Jersey Autism Registry. The Autism Medical Research and Treatment Fund provided \$500,000 in 2014 to the New Jersey Autism Registry. The law that created the NJ Autism Registry was passed in 2007 and the rules and regulations were adopted on September 22, 2009. The law establishing the Autism Registry within the Special Child Health Service Registry requires providers to register all children through the age of 21 who are diagnosed with autism. The Registry is designed to connect families of children with autism to the appropriate support services in their counties. 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 2014, 13,567 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 for New Jersey (1 out of 45 children), it is expected that at least 2200 newly diagnosed children per birth year cohort will be diagnosed, with even more children being 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

New Jersey is one of only four states with an Autism Registry that requires reporting by neurologists, pediatricians, nurses and other autism providers so children can be referred for resources and services.

expected rate. Once the previously diagnosed children have been registered, staff expect that going forward most children registered will be those who are newly diagnosed. In 2014, 2,441 children were entered into the Registry.

Translational Research in Autism Conference. April is Autism Awareness Month, and with CDC recently releasing a study estimating that autism impacts 1 in 45 children in New Jersey and 1 in 68 children nationally, the importance of ongoing research into the care and treatment of autism cannot be overstated.

On April 9, 2014 the Council hosted the “Translational Research in Autism” Conference with experts in attendance committed to advancing autism research. The conference was held at Montclair State University, home of the NJACE Coordinating Center.

Nationally recognized speakers Dr. Helen Tager-Flusberg, Professor, and Director of the Center for Autism Research Excellence at Boston University and Dr. Alycia Halladay, Senior Director of Research at Autism Speaks presented on *Pathways toward Translational Research Programs and Translational Research: A National Perspective*, respectively.

Other topics discussed by attendees of the conference included:

- The new DSM classification system for autism spectrum disorder: What does it mean for the Clinician and Researcher?
- Early Identification of ASD – Animal Models and Human Behavior: What are the latest advances in genetics and behavioral research which may aid us in identifying early ASD?
- New Methods of Intervention: the role of technology for the delivery of services?

Cathleen Bennett, Director of Policy and Strategic Planning for the Department of Health

“The NJACE’s translational research capability is the critical next step towards real world application of research discoveries” said Cathleen Bennett.

delivered remarks at the conference where she noted that *“During the last year, the state has worked closely with Montclair to build out NJACE capabilities to include Translational Research to help researchers translate what they have learned in their controlled lab studies to other settings, such as schools and provider offices. The NJACE’s Translational Research capability is the critical next step towards real world application of research discoveries.”*

The “Proceedings: Translational Research in Autism” is available on the Council’s website at <http://www.state.nj.us/health/autism/report.shtml>

Autism New Jersey 32nd Annual Conference. The NJ ACE Coordinating Center staff represented the Council at the October 23, 2014 Autism New Jersey’s 32nd Annual Conference in Atlantic City. The staff distributed materials from several of the NJ ACE research sites while responding to inquiries from conference attendees including family members, providers, service systems administrators and other researchers. The table display with NJ ACE information including the names of grantees and their research projects was well received. As always, the conference was a success and provided an opportunity to highlight the contributions of the Council in supporting autism research statewide.

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, serves as Chair for the Council. The Council met five times in 2014. Council members, meeting calendar and minutes are posted on the Council’s website at www.nj.gov/health/autism.

Moving Forward to 2015

With a goal to build capacity for the NJ ACE, the Council announced a \$6 million Notice of Grant Availability (NOGA) on November 17, 2014 with awards to grantees in June 2015. The NOGA calls for applicants for translational research pilot projects, clinical research pilot projects and Autism Health Needs Medical Homes Pilot Projects. The NOGA 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 awards are posted on the Council’s website at http://www.state.nj.us/health/autism/grant_ini.shtml. 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 progress reports.

FUND BALANCE STATEMENT

	SFY 2014	SFY 2014	SFY 2015
	<i>Projected</i>	Actual	<i>Projected</i>
Opening Fund Balance (July 1)	\$3,862,442	\$4,682,834	\$3,561,976
Revenues			
Assessments ¹	\$3,600,000	\$3,993,893	\$3,600,000
State Appropriated Funds	\$500,000	\$500,000	\$500,000
Total Revenue:	\$4,100,000	\$4,493,893	\$4,100,000
Total Funds Available	\$7,962,442	\$9,176,727	\$7,661,976
Disbursements and Expenses			
Disbursements to Grantees	\$4,020,000	\$4,364,751	\$6,000,000
Total disbursements	\$4,020,000	\$4,364,751	\$6,000,000
Expenses			
Administrative & Office expense	\$400,000	\$341,140	\$450,000
State Appropriated Funds ²		\$115,260	
Professional Review Panel	\$100,000	\$43,600	\$50,000
Autism Registry	\$750,000	\$750,000	\$750,000
Total expenses	\$1,250,000	\$1,250,000	\$1,250,000
Total Disbursements and Expenses	\$5,270,000	\$5,614,751	\$7,250,000
Closing Fund Balance (June 30)	\$2,692,442	\$3,561,976	\$411,976
¹ Net revenue variance			
² Unexpended funds			