



**Governor's Council for
Medical Research and
Treatment of Autism**

June 21, 2014

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 2013 Annual Report. During 2013, 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.

The New Jersey Autism Center of Excellence (NJ ACE), created in 2012, with a Coordinating Center and two research sites marked a new, coordinated approach to autism research in New Jersey. The NJ ACE initiative represents the Council's and the state's commitment to advancing the current knowledge pool through clinical research leading to improvements in interventions. Interventions such as early diagnosis and treatment address the physical and behavioral health needs of children, adolescents and adults with ASD.

Seven clinical research sites were funded in June 2013 and the Council anticipates up to seven additional research sites, including translational research projects, will be funded in 2014. This funding marks a true commitment to high quality research that will help New Jersey families challenged by Autism Spectrum Disorders. In addition this year the Council has committed research dollars to fund pilot projects that will explore innovative methods to improve diagnosis and treatment.

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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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 (NJDOH). As one of the six 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,

Handwritten signature of Caroline Eggerding in cursive script.

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, 2013-DECEMBER 31, 2013**

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

ANNUAL REPORT JANUARY 1, 2013 – DECEMBER 31, 2013

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. 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 (ASD), enhancing the lives of individuals across their lifespans.

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 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 Disorders (ASDs). A second research site was funded in December 2012 and seven clinical research sites were funded in June 2013. 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

"With the creation of the Autism Center of Excellence we will have one voice leading New Jersey's research of ASDs," 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."

the physical and behavioral health needs of children, adolescents and adults with ASD.

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

Note: 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.

Nine two-year basic science grants and two clinically oriented research grants awarded in June 2010 were granted no cost extensions through June 2013. The awards totaled \$5 million.

The Autism Medical Research and Treatment Fund provided \$500,000 in 2013 to the New Jersey Autism Registry. 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.

In 2014, the Council's activities will focus on awarding up to \$4 million in grants to the NJ Autism Center of Excellence (NJ ACE) Translational Research Pilot Projects and Clinical Research Pilot Projects and planning for FY 15. In addition, the Council sponsored a scientific conference in April 2014 entitled "Translational Research in Autism" for Council funded researchers and their colleagues.

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. The 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.

Note: CDC released a report in March 2014 (MMWR Surveillance Summaries, March 28, 2014 / 63(SS02); 1-21) prior to the release of this annual report. The CDC report estimates an average of 1 in 68 children in the United States has ASD and an average of 1 in 45 children in New Jersey.

Grant and Program Activities

New Jersey Autism Center of Excellence (NJ ACE). The 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 NJ ACE currently consists of a Coordinating Center, three Clinical Research Program Sites and six Clinical 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 and Rutgers University Institute for Human Genetics was awarded \$2.2 million over five years to focus on the genetics of Autism Spectrum Disorders (ASDs). 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>).

Enhancing the state's commitment to families affected by autism, Health Commissioner Mary E. O'Dowd, MPH joined the Governor's Council for Medical Research and Treatment of Autism in June 2013 to announce \$4.5 million in research grants.

The event was held at the Ben Samuels Children's Center at Montclair State University. Seven hospitals, universities and medical schools were awarded funds by the Council for a variety of projects that will develop a new screening tool for culturally diverse families; assess transportation needs; examine biological markers that

"This new funding furthers Governor Christie's ongoing commitment to support the children and families affected by autism," said Commissioner O'Dowd. "This round of awards focuses both on scientific research as well as developing tools for screening and intervention."

may help identify autism; and evaluate the influence of risk factors such as environmental pollutants, maternal health status and premature birth on those with Autism Spectrum Disorders.

"This funding marks a true commitment to high quality research that will help New Jersey families challenged by Autism Spectrum Disorders," said Caroline Eggerding, M.D., chair of the Governor's Council for Medical Research and Treatment of Autism. "In addition we have committed research dollars to fund pilot projects that will explore innovative methods to improve diagnosis and treatment."

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 were:

\$2.25 million over five years to Children's Specialized Hospital in New Brunswick to develop a new screening tool for culturally diverse families. *Development of a New Autism Screening Tool for Traditionally Underserved Families.*

\$400,000 over five years to UMDNJ (now Rutgers University)* New Jersey Medical School (NJMS) to identify biomarkers that would identify a subtype of ASD. *Autism Spectrum Disorder – Inflammatory Subtype: Molecular Characterization.*

\$399,846 over two years to Saint Peter's University Hospital in New Brunswick to examine the biological markers that can be useful in identifying children at risk for autism. *Piloting Very Early and Early Markers for Risk of Autism Spectrum Disorder in Premature and Low Birth Weight Infants*

\$399,565 over two years to UMDNJ (now Rutgers University)* School of Osteopathic Medicine (SOM) in Stratford to examine the association between environmental pollutants and ASD. *Glucuronidation and Autism.*

\$399,336 over two years to UMDNJ (now Rutgers University)* New Jersey Medical School (NJMS) to evaluate perinatal risk factors such as parental age, maternal health status, premature birth and their influence on changes in ASD prevalence over time. *Perinatal Risk Factors and their Influence on ASD Prevalence: Study of Two Birth Cohorts in NJ.*

\$394,204 over two years to Rowan University in Glassboro to compare two interventions for preschool children with autism. *Efficacy of Relationship Development Intervention and Parent-Implemented Applied Behavior Analysis/Verbal Behavior on Joint Attention and Communication of Preschool Children with Autism.*

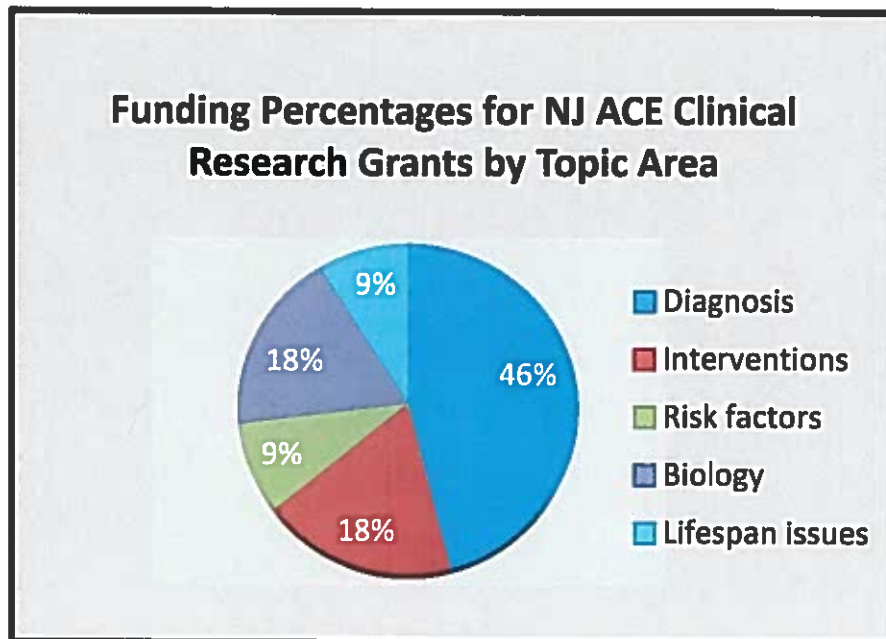
\$321,253 over two years to Rutgers University to research the transportation needs of people with ASD and develop policies, procedures and accommodations to improve the quality of life of those on the autism spectrum. *An Assessment of the Transportation and Mobility Needs and Barriers of Adults on the Autism Spectrum Disorder in New Jersey.*

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

**The changes in the higher education infrastructure in New Jersey as a result of the Rutgers-University of Medicine and Dentistry of New Jersey (UMDNJ) merger, effective July 1, 2013 are as follows: UMDNJ-New Jersey Medical School is now Rutgers University-New Jersey Medical School, UMDNJ-Robert Wood Johnson Medical School is now Rutgers University-Robert Wood Johnson Medical School and UMDNJ-School of Osteopathic Medicine is now Rowan University-School of Osteopathic Medicine.*

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 National Institutes of Health requirements and will help them develop stronger proposals for submission to the NIH and biomedical research foundations. 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.

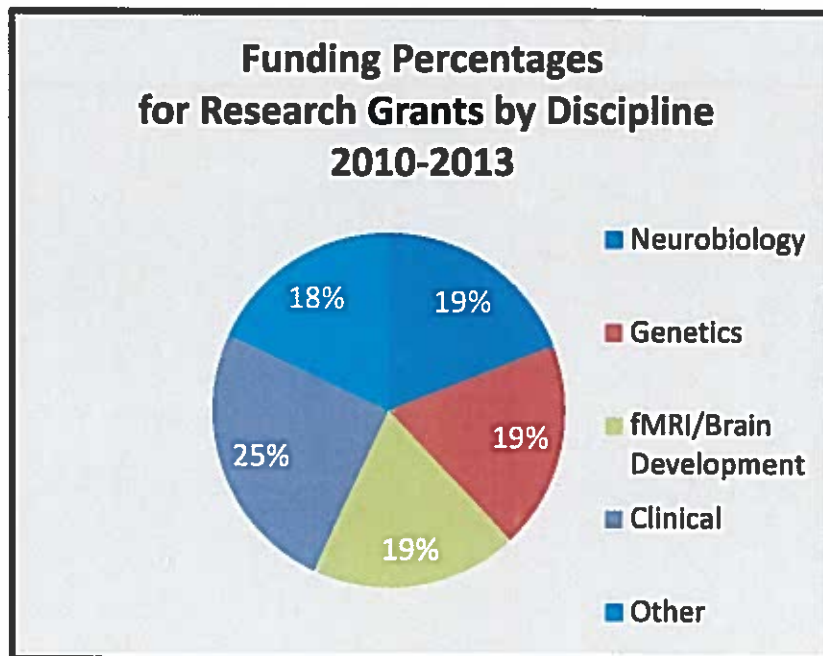


2013 Clinical Research Grants

Principal Investigator	Institution	Funding Level
Cecilia Feeley,MS	Rutgers University	\$321,253 (2 yrs.)
Yvette Janvier, M.D.	Children's Specialized Hospital	\$2,250,000 (5 yrs.)
Harumi Jyonouchi, M.D.	UMDNJ-NJMS (now Rutgers University)*	\$400,000 (2 yrs.)
Mary Louise Kerwin, Ph.D.	Rowan University	\$394,204 (2 yrs.)
T. Peter Stein, Ph.D.	UMDNJ-SOM (now Rutgers University)*	\$399,565 (2 yrs.)
Walter Zahorodny, Ph.D.	UMDNJ-NJMS (now Rutgers University)*	\$399,336 (2 yrs.)
Barbie Zimmerman-Bier M.D.	Saint Peter's University Hospital	\$399,846, (2 yrs.)

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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 with no cost extensions for ten of the grantees through 2013. The grant program funded research primarily in the areas of genetics, fMRI/brain development, neurobiology and clinical science. 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. Please refer to http://www.state.nj.us/health/autism/grant_ini.shtml for grant abstracts.



2010 – 2012 Basic Science and Clinical Research Grantees

*no cost extensions through 2013

Principal Investigator	Institution	Funding Level
Bharat Biswal, Ph.D.	*UMDNJ-NJMS** (now Rutgers University)	\$469,550
Gabriella D’Arcangelo, Ph.D.	*Rutgers University	\$381,700
Bonnie Firestein, Ph.D.	*Rutgers University	\$469,550
Emanuel DiCicco-Bloom, M.D.	*UMDNJ-RWJMS** (now Rutgers University)	\$469,550
Yvette Janvier, M.D.	Children’s Specialized Hospital	\$469,550
G. Miller Jonakait, Ph.D.	*New Jersey Institute of Technology (NJIT)	\$392,162
Michael Lewis, Ph.D.	*UMDNJ-RWJMS** (now Rutgers University)	\$469,550
James Millonig, Ph.D.	*UMDNJ-RWJMS** (now Rutgers University)	\$469,550
Maggie Shiffrar, Ph.D.	*Rutgers University	\$469,550
Gleb Shumyatsky, Ph.D.	*Rutgers University	\$469,550
Harvey Weiss, Ph.D.	*UMDNJ-RWJMS (now Rutgers University)	\$469,550

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New Jersey Autism Registry. The Autism Medical Research and Treatment Fund provided \$500,000 in 2013 to the New Jersey Autism Registry. The State launched the 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 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 2013, 12,264 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 2,400 newly diagnosed children per birth year cohort will be diagnosed and registered. Registry staff continue 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. Once the previously diagnosed children have been registered, staff expect that most children registered will be those who are newly diagnosed. In 2013, 1,873 children were entered into the Registry.

Events

Autism New Jersey 31th Annual Conference. The NJ ACE Coordinating Center staff represented the Council at the October 8, 2013 Autism New Jersey's 31st 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, served as Chair for the Council. The Council met three times in 2013. Council members, meeting calendar and minutes are posted on the Council's website at www.nj.gov/health/autism.

Moving Forward to 2014

With a goal to build capacity for the NJ ACE, Council announced a \$4 million Notice of Grant Availability (NOGA) on December 5, 2013 with awards to grantees in June 2014. The NOGA calls for applicants for translational research pilot projects and clinical research 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 awards will be posted on the Council's website at http://www.state.nj.us/health/autism/grant_ini.shtml in July 2014. 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. An ad hoc committee of the Council has been charged with recommending the categories of grants to be funded in FY15 and FY16. In addition, the Council intends to sponsor a scientific conference in April 2014 entitled "Translational Research in Autism" for Council funded researchers and their colleagues.

Fund Balance Statement

	SFY 2013 <i>Projected</i>	SFY 2013 Actual	SFY 2014 <i>Projected</i>
Opening Fund Balance (July 1)	\$9,474,522	\$7,017,174	\$3,862,442
Revenues			
Assessments ¹	\$3,600,000	\$4,034,472	\$3,600,000
State Appropriated Funds	\$500,000	\$500,000	\$500,000
Total Revenue:	\$4,100,000	\$4,534,472	\$4,100,000
Total Funds Available	\$13,574,522	\$11,551,646	\$7,962,442
Disbursements and Expenses			
Disbursements to Grantees	\$6,030,000	\$6,689,204	\$4,020,000
Total disbursements	\$6,030,000	\$6,689,204	\$4,020,000
Expenses			
Administrative & Office expense	\$400,000	\$400,000	\$400,000
Professional Review Panel	\$100,000	\$100,000	\$100,000
Autism Registry	\$500,000	\$500,000	\$750,000
Total expenses	\$1,000,000	\$1,000,000	\$1,250,000
Total Disbursements and Expenses	\$7,030,000	\$7,689,204	\$5,270,000
Closing Fund Balance (June 30)	\$6,544,522	\$3,862,442	\$2,692,442

¹Net revenue variance

²Funds plus interest deposited annually in Jan.