

2015
ANNUAL REPORT



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





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

February 25, 2016

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 2015 Annual Report. During 2015 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 (NJACE), established in 2012, represents the State's and the Council's commitment to advancing current knowledge of ASD 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.

Enhancing the State's commitment to families affected by autism, on June 25, 2015 First Lady Mary Pat Christie and Former Health Commissioner Mary E. O'Dowd, MPH joined the Governor's Council for Medical Research and Treatment of Autism to announce \$4.4 million in grants to establish Autism Medical Homes and advance research in the understanding, evaluation and treatment of ASD. This funding marks a true commitment to high quality clinical and health services research that will help improve the lives of New Jersey families challenged by ASD.

To spark dialogue and stimulate thought on the newest ideas and hopes in autism research, the NJACE Coordinating Center at Montclair State University hosted the NJACE Statewide Autism Summit on September 18, 2015. The conference, *The Unfolding Story of Autism Research in NJ from Cells to Society*, united families, healthcare providers, educators, researchers from a wide variety of fields and policymakers to discuss breakthroughs in research that shape future understanding of ASD. "This conference highlights the strides New Jersey has made in enriching our understanding of autism and supporting future innovations," Acting Commissioner Bennett said. "Developing intervention and treatment options will improve the lives of children and adults on the autism spectrum."

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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 State of New Jersey is included in the NDAR section of The Interagency Autism Coordinating Committee (IACC) Strategic Plan Update (April 30, 2014) 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.

It is an honor to serve the citizens of New Jersey by being both a member of the Council and the Chairperson. 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,



Caroline Eggerding, M.D.

Chair, Governor's Council for Medical Research and Treatment of Autism

Enclosure

Cc: Acting Commissioner Cathleen Bennett



2015 Annual Report

**THE NJ GOVERNOR'S COUNCIL
FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM
ANNUAL REPORT
JANUARY 1, 2015 - DECEMBER 31, 2015**

The NJ Governor's Council for Medical Research and Treatment of Autism
New Jersey Department of Health
PO Box 360, Trenton, NJ 08625-0360 www.nj.gov/health/autism





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

Executive Summary

The NJ 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, Chapter 174, monies from \$1 dollar 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 former 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 (NJACE), 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 NJACE 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, seven in June 2014 and eight in June 2015. Three Autism Health Needs Medical Homes Pilot Projects, the Council's newest initiative, were also funded in 2015. The NJACE initiative represents the Council's and State's commitment to advancing current knowledge of ASD through clinical research and treatment leading to improvements in interventions that address the physical and behavioral health needs of children, adolescents and adults.

The NJACE initiative represents the Council's and State's commitment to advancing the current knowledge pool through clinical research and treatment leading to improvements in interventions that address 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 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 2015 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.

On September 18, 2015, the NJACE Coordinating Center at Montclair State University convened the first statewide Summit, *The Unfolding Story of Autism Research in NJ: From Cells to Society*, to highlight research being conducted in New Jersey to better understand the nature of ASD. The link between intensive scientific research and clinical research involving children at home and in school were apparent at the conference. The gathering reflected a growing sense

that progress is being made on multiple fronts. It also demonstrated the range of challenges that remain in treating what is increasingly being seen as a range of disorders with different causes and symptoms rather than a single "autism spectrum disorder." The Summit was well received by the more than 200 individuals in attendance, representing families, educators, providers, researchers, and policymakers.

In 2016 the Council's activities will focus on awarding up to \$6 million in grants to the NJACE Clinical and Translational 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 at: <http://nj.gov/health/fhs/eis/index.shtml>.

*** 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.**



Overview of Autism Spectrum Disorder

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.

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 (NJACE)

The NJACE initiative represents the State's and the Council's commitment to advancing current knowledge of ASD through clinical research and treatment. It is anticipated that this 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.

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 NJACE Coordinating Center. The NJACE currently consists of the Coordinating Center, three Clinical Research Program Sites, twenty-two Clinical and Translational Research Pilot Projects and three Autism Health Needs Medical Homes Pilot Projects. Details of the awards are included in the Council's Annual Reports at:

<http://www.state.nj.us/health/autism/report.shtml>.





Grant Awards – 2015 Enhancing the administration’s firm commitment to funding new and innovative ways to help New Jersey families impacted by autism, First Lady Mary Pat Christie and former Health Commissioner Mary E. O’Dowd, MPH announced, on June 25, 2015, \$4.4 million in grants to establish Autism Medical Homes and advance research in the understanding, evaluation and treatment of the biologically-based disorder. New Jersey is a national leader in early intervention and education of children with autism which affects about 1 in 45 children across the Garden State.

A total of \$1.2 million was awarded for autism medical homes to be established in Children’s Specialized Hospital in Mountainside, Hackensack University Medical Center in Hackensack and Jersey Shore University Medical Center in Neptune. Each of the hospitals will receive approximately \$400,000 over two years.

The goal of the Autism Health Needs Medical Homes Pilot Projects is to improve the overall health outcomes of children with autism, including but not limited to, the physical health of children. The projects focus on reducing the unmet needs for specialty services for children with autism by bringing together primary care providers with sub-specialists and ASD providers to treat the whole person. The Autism Health Needs Medical Homes Pilot Projects’ intent is to improve the quality of and access to services for children and their families, including but not limited to: primary, sub-specialty, diagnostic, behavioral, cognitive, developmental, neurological, psychiatric and prevention/wellness care.

In addition, eight research grants totaling \$3.2 million were awarded to medical schools and universities for clinical and translational research projects including development of early markers of ASD and a study examining how diverse populations with an autism diagnosis link to services.

“The Governor and I have had many opportunities to meet with families throughout New Jersey who are touched by autism.” “Their desire is what all parents want for their children – the best possible outcomes to lead productive and full lives,” said First Lady Mary Pat Christie. “Today marks another milestone in our commitment to these families and their loved ones.” “The \$4.4 million in grants being awarded by the Governor’s Council will help children and adults impacted by autism achieve a better quality of life while giving their families, who experience the challenges of autism every day, hope for the future.”



Autism Health Needs Medical Homes Grant Awards:

\$400,000 to Children’s Specialized Hospital in Mountainside for *Children’s Specialized Hospital Pediatric Primary Care ASD Medical Home*

\$400,000 to Hackensack University Medical Center in Hackensack for *Enhancement of Service and Technology Coordination to Establish a Medical Home for Autism at the Institute for Child Development (ICD), Hackensack University Medical Center (Hackensack UMC)*

\$398,190 to Jersey Shore University Medical Center in Neptune for the *Autism Care Coordination Program*

| 2015 Autism Health Needs Medical Homes Grants | | |
|--|--|----------------------|
| Principal Investigator | Institution | Funding Level |
| Matthew McDonald, MD | Children’s Specialized Hospital | \$400,000 (2 yrs.) |
| Randy Huron, MD | Hackensack University Medical Center | \$400,000 (2 yrs.) |
| Denise Aloisio, MD | Jersey Shore University Medical Center | \$398,190 (2 yrs.) |



Clinical and Translational Autism Research Grant Awards:

- \$398,050 to Rowan University in Glassboro to evaluate Applied Behavior Analysis interventions on communication in preschool children with autism using Sequential Multiple Assignment Randomized Trial (SMART) Treatment Design;
- \$384,382 to Rutgers University, Biomedical and Health Sciences in New Brunswick to research the experiences of diverse families of children newly diagnosed with ASD;
- \$398,319 to Rutgers University, Biomedical and Health Science in New Brunswick for development of early markers of ASD;
- \$385,838 to Rutgers University in Piscataway for bridging the gap between behavior and genetics in individuals with ASD through the detection of micro-movements in social behavior with the potential of leading to earlier diagnosis of ASD;
- \$400,000 to Rutgers University Biomedical and Health Sciences in Piscataway to study human stem cells from individuals with autism to identify neurobiological pathways that contribute to idiopathic autism;
- \$400,000 to Rutgers University, Human Genetics Institute in Piscataway to identify specific genetic changes that increase risk for ASDs by using clinical data and DNA from families affected by ASD;
- \$399,972 to Rowan University-School of Osteopathic Medicine in Stratford to understand how Bisphenol A can affect metabolism in some children with ASD and their mothers; and
- \$400,000 to Rutgers Biomedical and Health Sciences (RBHS) in Piscataway for a treatment trial to confirm phenotypic improvement with sulforaphane treatment in a population of individuals with autism.



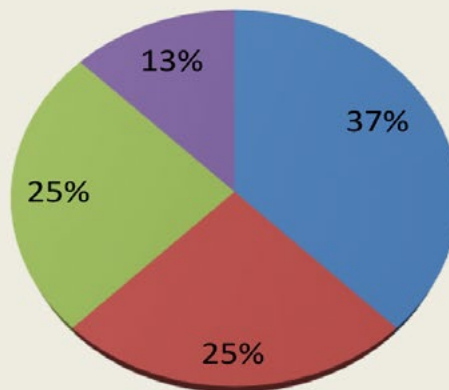
Clinical and Translational Autism Research Grant Awards

| Principal Investigator | Institution | Funding Level |
|---------------------------|--|--------------------|
| Mary Louise Kerwin, Ph.D. | Rowan University, Glassboro | \$398,050 (2 yrs.) |
| Deborah Spitalnik, Ph.D. | Rutgers University, New Brunswick | \$384,382 (2 yrs.) |
| Michael Lewis, Ph.D. | Rutgers University, New Brunswick | \$398,319 (2 yrs.) |
| Elizabeth Torres, Ph.D. | Rutgers University, Piscataway | \$385,838 (2 yrs.) |
| Emanuel DiCicco-Bloom, MD | Rutgers University, Piscataway | \$400,000 (2 yrs.) |
| Linda Brzustowicz, MD | Rutgers University, Piscataway | \$400,000 (2 yrs.) |
| T. Peter Stein, Ph.D. | Rowan University-School of Osteopathic Medicine, Stratford | \$399,972 (2 yrs.) |
| William Johnson, Ph.D. | Rutgers University, Piscataway | \$400,000 (2 yrs.) |

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.

Funding Percentages for NJACE Clinical and Translational Research Grants by Topic Area

■ Diagnosis
 ■ Interventions
 ■ Risk factors
 ■ Lifespan issues



2015 Clinical and Translational Research Grants

To advance the goal of widespread data sharing among ASD researchers, investigators funded under the NJACE 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 New Jersey 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 researchers 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 2015 to the New Jersey Autism Registry. The law that created the 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 Autism Registry staff and acknowledges their outstanding accomplishments in providing outreach and education to both providers and families throughout the State.

As of December 2015, 20,225 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 2,200 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 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 state fiscal year (SFY) 2015, 3,917 were registered and a similar number is anticipated by the end of state fiscal year 2016.

NJACE Summit To spark dialogue and provoke thought on the newest ideas and hopes in autism research, the NJACE Coordinating Center at Montclair State University hosted the NJACE Statewide Autism Summit on September 18, 2015. The conference, *The Unfolding Story of Autism Research in NJ from Cells to Society*, united families, health-care providers, educators, researchers from a wide variety of fields and policymakers to discuss breakthroughs in research that shape future understanding of autism spectrum disorder (ASD).

"This conference highlights the strides New Jersey has made in enriching our understanding of autism and supporting future innovations," Acting Commissioner Bennett said. "Developing intervention and treatment options will improve the lives of children and adults on the autism spectrum."

The Keynote Address *Research Begins with Questions and Implicit Assumptions: How May this Impact Autism Research?* was presented by Willis F. Overton, Ph.D., and Thaddeus L. Bolton Professor of Psychology, Emeritus, Temple University. Two panels of talented researchers then discussed projects that are transforming our understanding of ASD and offering glimpses of how we can improve identification and care in the future. This broad array of ASD research looked at all aspects of life from genetics and perinatal risk factors to education, technology, and transportation. Studies included new approaches to using videos to reach children with autism; compared the effectiveness of different approaches for treating autism earlier, including among low income and minority children who have tended to be diagnosed later; examined the role that infections during pregnancy may play in autism; and assessed the needs and barriers to providing transportation to adults with autism.

“Collaboration among great minds throughout New Jersey can help identify the best way to support those affected by autism and unravel the complex questions that the study of autism deserves,” said Dr. Gerard Costa, Director of the NJACE Coordinating Center at Montclair State University.

Note: Summit Proceeding are available at:
<http://njace-cc.montclair.edu/home>

Autism New Jersey 33rd Annual Conference. The NJACE Coordinating Center staff represented the Council at the October 15-16, 2015 Autism New Jersey’s 33rd Annual Conference in Atlantic City. The staff distributed materials from several of the NJACE research sites while responding to inquiries from conference attendees including family members, providers, service systems administrators and other researchers. The table display with NJACE information including the names of grantees and

their research projects was well received. 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 health-care 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 three times in 2015. Council members, meeting calendar and minutes are posted on the Council’s website at: www.nj.gov/health/autism.



Moving Forward to 2016

With a goal to build capacity for the NJACE, the Council announced a \$6 million Notice of Grant Availability (NOGA) on November 5, 2015 with awards to grantees anticipated in June 2016. 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 will be 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 2015 <i>Projected</i> | SFY 2015 Actual | SFY 2016 <i>Projected</i> |
|---|------------------------------|---------------------------|------------------------------|
| Opening Fund Balance (July 1) | \$3,561,976 | \$4,682,834 | \$3,561,976 |
| Revenues | | | |
| Assessments ¹ | \$3,600,000 | \$3,993,893 | \$3,800,000 |
| State Appropriated Funds | \$500,000 | \$500,000 | \$500,000 |
| Total Revenue: | \$4,100,000 | \$4,493,893 | \$4,300,000 |
| Total Funds Available | \$7,661,976 | \$9,176,727 | \$7,861,976 |
| Disbursements and Expenses | | | |
| Disbursements to Grantees | \$6,000,000 | \$4,364,751 | \$6,000,000 |
| Total Disbursements | \$6,000,000 | \$4,364,751 | \$6,000,000 |
| Expenses | | | |
| Administrative & Office expense | \$400,000 | \$342,169 | \$450,000 |
| State Appropriated Funds ² | | \$111,831 | |
| Professional Review Panel | \$100,000 | \$46,000 | \$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) | \$411,976 | \$3,561,976 | \$611,976 |

1 Net revenue variance

2 Unexpended funds



Council Membership

Michael Aquino, MD, F.A.C.G., Senate President Appointee; Partner, Shore Gastroenterology Associates, Cofounder, VP of Operations, Pathology Solutions

Elizabeth K. Bell, BS, Public Member - Individual or Family Member with Autism Representative; Volunteer and Independent Contractor with Autism Speaks

Cheryl F. Dreyfus, Ph.D., Academic Institution Representative; Professor and Chair, Department of Neuroscience and Cell Biology, Rutgers University, Robert Wood Johnson Medical School

***Caroline Eggerding, MD**, Healthcare Organization Representative; Division Head, Department of Pediatric Neurology and Development, Cooper Children's Regional Hospital

Susan P. Evans, Ed.D., Commissioner of Health Appointee; Education Program Specialist for Early Intervention Program, NJ Department of Health

Wilma Judith Friedman, Ph.D., Academic Institution Representative; Professor, Department of Biological Sciences Rutgers University

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

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

Thomas V. Macchiaverna, MA, Public Member representative; Special Education Teacher

Dana E. Spett, MSW, Autism Organization Representative; Founder/Executive Director, Pony Power Therapies

Samuel Sheng-Hung Wang, Ph.D., Academic Institution Representative; Associate Professor, Department of Molecular Biology and Princeton Neuroscience Institute, Princeton University

Gary Weitzen, BA, Autism Organization Representative; Executive Director of POAC (Parents of Autistic Children)

* *Denotes Council Chair*





Council and Staff Membership

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