

2016  
**ANNUAL REPORT**



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





February 17, 2017

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 2016 Annual Report. During 2016 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.

New Jersey's Health Commissioner, Cathleen D. Bennett joined the Governor's Council for Medical Research and Treatment of Autism on November 10, 2016 to announce \$3.2 million in grants, furthering the State's and Council's commitment to finding new and innovative ways to help New Jersey families impacted by autism. As a result of the grants, Hackensack University Medical Center (HUMC) and Children's Specialized Hospital (CSH) are establishing autism medical homes for adolescents and young adults and researchers throughout the state will advance current knowledge of ASD through clinical and translational research leading to improvements in interventions.

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

**PO Box 360, Trenton, NJ 08625-0360**

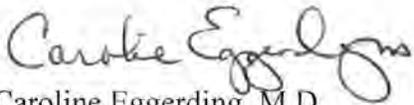
Telephone 609-633-8740

Fax 609-943-4213

[www.nj.gov/health/autism/](http://www.nj.gov/health/autism/)

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 that reads "Caroline Eggerding".

Caroline Eggerding, M.D.

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

Enclosure

cc: Commissioner, Cathleen D. Bennett



# **2016 Annual Report**

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**THE NJ GOVERNOR'S COUNCIL  
FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM  
ANNUAL REPORT  
JANUARY 1, 2016-DECEMBER 31, 2016**

The NJ Governor's Council for Medical Research and Treatment of Autism  
New Jersey Department of Health  
PO Box 360, Trenton, NJ 08625-0360

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

## 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 Autism Spectrum Disorder (ASD) research, clinical and educational enhancement grants since 2000. The Council's vision is to enhance the lives of individuals with ASD across their lifespans. The Mission of the Council is to advance and disseminate the understanding, treatment, and management of ASD by means of a coordinated program of biomedical research, clinical innovation, and professional training in New Jersey.

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 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, eight in June 2015 and six in 2016. Three Autism Health Needs Medical Homes Pilot Projects, the Council's newest initiative, were funded in 2015 and two in 2016.

**The Mission of the Council is to advance and disseminate the understanding, treatment, and management of ASD by means of a coordinated program of biomedical research, clinical innovation, and professional training in New Jersey.**

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 New Jersey data will therefore be made available to autism researchers from around the United States, highlighting the New Jersey effort. Furthermore, participation in NDAR demonstrated 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. The Autism Medical Research and Treatment Fund provided \$500,000 in 2016 to the New Jersey Autism Registry. The law establishing the Autism

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.

In 2017 the Council's activities will focus on awarding up to \$3.0 million in grants to the NJACE Clinical and Translational Research Pilot Projects, Basic Science Pilot Projects on Autism and Autism Health Needs Medical Homes Pilot Projects.

In addition to supporting research and treatment, the New Jersey 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>.

**\* 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 as well as 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 national health issue. The most recent prevalence data from the Centers for Disease Control and Prevention (CDC) report (MMWR Surveillance Summaries, April 1, 2016/ Vol. 65 / No. 3) estimates an average of one 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 41 children, the highest among the eleven states included in the study. 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 the current knowledge pool through clinical and basic science research and treatment. It is anticipated that the initiative will lead to study outcomes that will have a 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-five Clinical and Translational Research Pilot Projects and five Autism Health Needs Medical Homes Pilot Projects. Details of the awards are included in the Council's Annual Reports and can be found at:

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



**Grant Awards – 2016** The administration's firm commitment to finding new and innovative ways is the cornerstone to help New Jersey families impacted by autism. New Jersey's Health Commissioner, Cathleen D. Bennett, announced on November 10, 2016, the awarding of \$3.2 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.

A total of \$800,000 was awarded for two autism medical homes to address the needs of adolescents and young adults. The medical homes are to be established in Children's Specialized Hospital in Mountainside and Hackensack University Medical Center in Hackensack. Both of these institutions were awarded medical homes grants in 2015 to address the needs of infants and children. Jersey Shore University Medical Center in Neptune was also awarded a medical homes grant in 2015.

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 subspecialists 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, six research grants in total \$2.4 million were awarded to medical schools, universities and a medical center for clinical and translational research projects including a project using innovative genetic and molecular technologies to develop clinical interventions to help improve the cognitive abilities and quality of life for patients with autism and a project to study biomarkers of autism risk in early development leading to a better understanding of impacts and how to individualize treatment.

**"These grants enhance the state's commitment to find new and innovative ways to help New Jersey families affected by autism," Commissioner Bennett said. "These grants will help us better understand Autism Spectrum Disorder (ASD) and allow our families with special needs children to benefit from the best research and services New Jersey has to offer."**



## Autism Health Needs Medical Homes Grant Awards:

\$400,000 to Children’s Specialized Hospital in Mountainside for *The Autism Medical Home Transition Collaborative Partnership Pediatric and Adult Care*.

\$400,000 to Hackensack University Medical Center in Hackensack for *Medical Home for Autism at the Institute for Child Development (ICD), Hackensack University Medical Center (Hackensack UMC)-Comprehensive Service Provision and Care Coordination for Adolescents and Young Adults with Autism Spectrum Disorder*.

| 2016 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.) |

## Clinical and Translational Autism Research Grant Awards:

- \$399,875 to the New Jersey Institute of Technology to use neuroimaging to study the brains of children with autism to answer why this disorder is more prevalent in boys and to identify key brain properties that may be helpful for early diagnosis of autism.
- \$400,000 to Rutgers Biomedical and Health Sciences to conduct a study using innovative genetic and molecular technologies to provide novel insights into the development of clinical interventions to help improve the cognitive ability and quality of life for patients with autism.
- An additional \$399,751 to Rutgers Biomedical and Health Sciences to study markers of autism risk using sophisticated medical testing in early development leading to a better understanding of impacts and how to individualize treatment.
- \$400,000 to Children’s Hospital of Philadelphia for research that focuses on creating low-cost, efficient tools for the measurement of motor behavior (including motor delays, instability in standing or walking, and poor handwriting), developing automatic ways to assess ASD risk, studying individual variations between different people with ASD, and measuring individual responses to treatment.
- \$400,000 to Saint Peter’s University Hospital to study children with ASD who also have additional medical conditions that affect other organs, not just the brain. Symptoms involving multiple organs may serve as a biomarker that can hold the key to understanding the complex medical conditions found in these children. The study aims to show how the biomarkers are useful for assessing clinical outcomes and responses to first line interventions and may also lead to new treatment measures.
- \$392,304 to Rutgers, the State University for a study that focuses on identifying the potential barriers in pedestrian infrastructure design for individuals with ASD. Pedestrian skills are the prerequisite skills needed for community integration and for using fixed route public transportation services. Through identifying the potential barriers in pedestrian infrastructure design, modifications can be made to the designs that are more conducive to those with autism and other developmental disabilities.

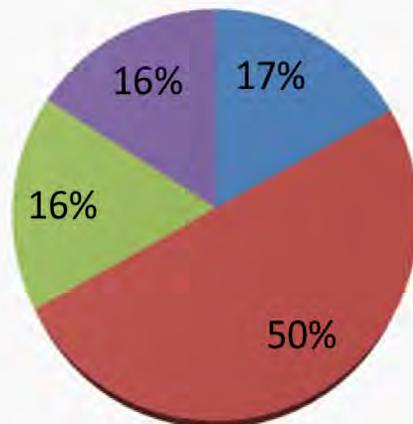
## Clinical and Translational Autism Research Grant Awards

| Principal Investigator    | Institution                         | Funding Level      |
|---------------------------|-------------------------------------|--------------------|
| Xin Di, Ph.D.             | New Jersey Institute of Technology  | \$399,875 (2 yrs.) |
| Zhiping Pang, Ph.D.       | Rutgers University, New Brunswick   | \$400,000 (2 yrs.) |
| Barbie Zimmerman-Bier, MD | Rutgers University, New Brunswick   | \$399,751 (2 yrs.) |
| Elizabeth S. Kim, Ph.D.   | Children's Hospital of Philadelphia | \$400,000 (2 yrs.) |
| Harumi Jyonouchi, MD      | Saint Peter's University Hospital   | \$400,000 (2 yrs.) |
| Cecelia Feeley, Ph.D.     | Rutgers University, Piscataway      | \$392,304 (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



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 2016 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 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 2016, 24,129 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 41 children), it is expected that at least 2400 newly diagnosed children per birth year cohort will be diagnosed, with even more children being 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 going forward most children registered will be those who are newly diagnosed. In state fiscal year (SFY) 2016, 4,285 were registered, an increase of 345 compared to state fiscal year (SFY 2015). A similar number is anticipated by the end of state fiscal year 2017.

## Autism New Jersey 34th Annual Conference

The NJACE Coordinating Center staff represented the Council at the Autism New Jersey's 34th Annual Conference held in Atlantic City on October 27-28, 2016. 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, their research projects and publications 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 four times in 2016. Council members, meeting calendar and minutes are posted on the Council's website at: [www.nj.gov/health/autism](http://www.nj.gov/health/autism).

## Moving Forward to 2017

With a goal to build capacity for the NJACE, the Council announced a \$3.0 million Notice of Grant Availability (NOGA) on July 26, 2016 with awards to grantees in June 2017. The NOGA calls for applicants for clinical and translational research pilot projects, basic science on autism 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](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 2016<br><i>Projected</i> | SFY 2016<br><b>Actual</b> | SFY 2017<br><i>Projected</i> |
|---|------------------------------|---------------------------|------------------------------|
| <b>Opening Fund Balance (July 1)</b>    | \$3,561,976                  | \$3,961,976               | \$4,137,641                  |
| <b>Revenues</b>                         |                              |                           |                              |
| Assessments <sup>1</sup>                | \$3,800,000                  | \$3,717,595               | \$3,700,000                  |
| State Appropriated Funds                | \$500,000                    | \$500,000                 | \$500,000                    |
| Total Revenue:                          | \$4,300,000                  | \$4,217,595               | \$4,200,000                  |
| <b>Total Funds Available</b>            | <b>\$7,861,976</b>           | <b>\$8,179,571</b>        | <b>\$8,337,641</b>           |
| <b>Disbursements and Expenses</b>       |                              |                           |                              |
| Disbursements to Grantees               | \$6,000,000                  | \$2,791,930               | \$6,000,000                  |
| Total disbursements                     | \$6,000,000                  | \$2,791,930               | \$6,000,000                  |
| <b>Expenses</b>                         |                              |                           |                              |
| Administrative & Office expense         | \$450,000                    | \$245,262                 | \$450,000                    |
| State Appropriated Funds <sup>2</sup>   |                              | \$222,738                 |                              |
| Professional Review Panel               | \$50,000                     | \$32,000                  | \$50,000                     |
| Autism Registry                         | \$750,000                    | \$750,000                 | \$750,000                    |
| Total expenses                          | \$1,250,000                  | \$1,250,000               | \$1,250,000                  |
| <b>Total Disbursements and Expenses</b> | <b>\$5,270,000</b>           | <b>\$4,041,930</b>        | <b>\$7,250,000</b>           |
| <b>Closing Fund Balance (June 30)</b>   | <b>\$611,976</b>             | <b>\$4,137,641</b>        | <b>\$1,087,641</b>           |

<sup>1</sup> Net revenue variance

<sup>2</sup> 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; 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 Staff

### 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](http://www.nj.gov/health/autism)

[NJGCA@doh.nj.gov](mailto:NJGCA@doh.nj.gov)

**Martin T. Zanna, MD, MPH**

Acting Executive Director

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

(609) 633-8740

[Martin.Zanna@dhs.state.nj.us](mailto:Martin.Zanna@dhs.state.nj.us)

**Linda N. Bocclair, M.Ed., MBA**

Executive Assistant

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

(609) 633-8740

[Linda.Bocclair@doh.nj.gov](mailto:Linda.Bocclair@doh.nj.gov)

**Mary Ray**

Contract Administrator II

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

(609) 943-5405

[Mary.Ray@doh.nj.gov](mailto:Mary.Ray@doh.nj.gov)

