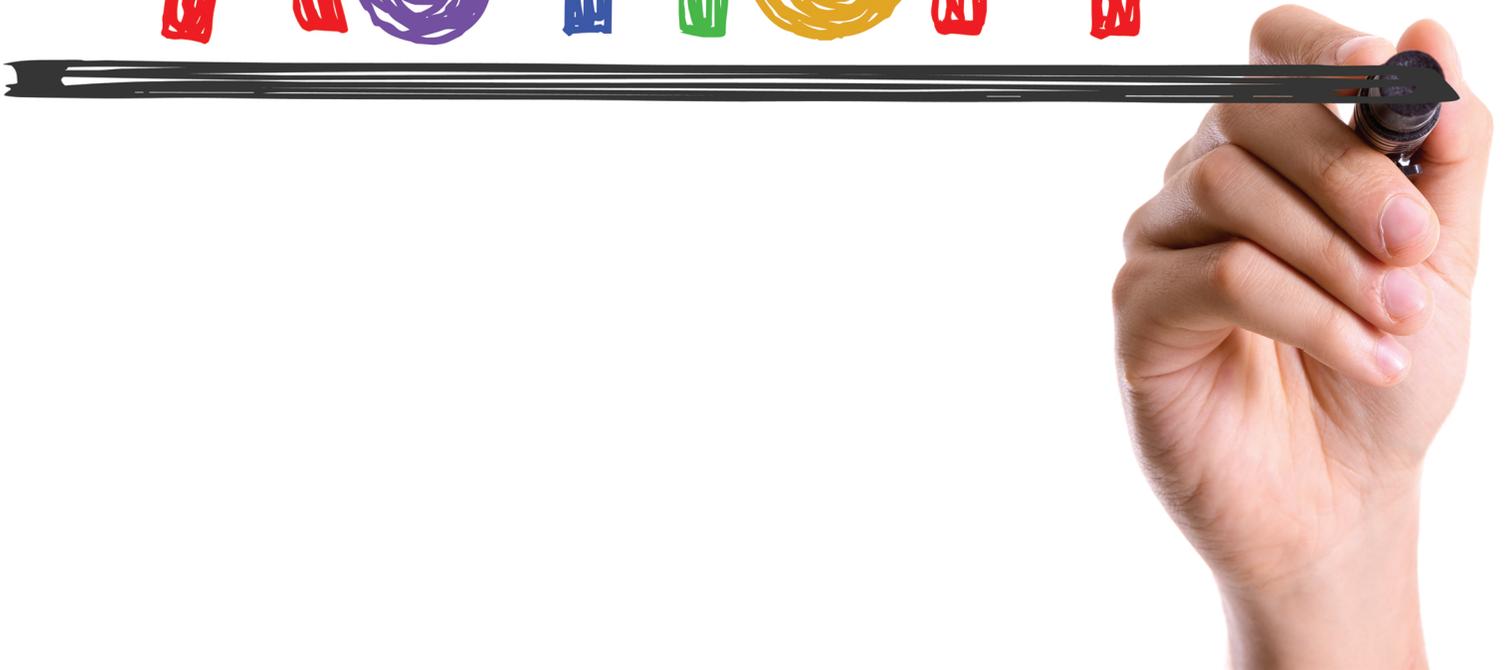


2017  
ANNUAL REPORT



AUTISM



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





April 5, 2018

The Honorable Phil Murphy  
Governor, State of New Jersey

Dear Governor Murphy:

On behalf of the Governor's Council for Medical Research and Treatment of Autism (Council), I am pleased to present the enclosed 2017 Annual Report. During 2017 the Council worked with the Department of Health to meet our shared responsibilities in understanding autism spectrum disorder (ASD) and best practices for treatment.

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. Since 2012 thirty-four clinical and translational research projects, six Autism Health Needs Medical Homes Pilot Projects and three five-year research projects have been funded by the Council for a total of \$27 million.

The Council released a Request for Applications (RFA) for the New Jersey Center of Excellence (NJACE) in June 2017 and anticipates funding the \$4 million five-year NJACE in 2018. The NJACE initiative represents the Council's and State's commitment to advancing the current knowledge pool through research and treatment to improve interventions that meet the physical and behavioral health needs of children, adolescents and adults with ASD.

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 thirteen members who are volunteering their time to serve on the Council, I wish to thank you for your support of our work. We look forward with hope to exciting discoveries that will provide effective treatments and allow those affected by autism to live productive and satisfying lives.

Sincerely,

A handwritten signature in blue ink that reads "Caroline Eggerding".

Caroline Eggerding, M.D.

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

Enclosure

Cc: Commissioner, Shereef Elnahal, M.D., MBA

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



# **2017 Annual Report**

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**THE NEW JERSEY GOVERNOR'S COUNCIL  
FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM  
ANNUAL REPORT  
JANUARY 1, 2017-DECEMBER 31, 2017**

The New Jersey 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 NEW JERSEY GOVERNOR'S COUNCIL FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM

## Executive Summary

The New Jersey 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. The Council's Vision is to enhance the lives of individuals with Autism Spectrum Disorder (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.

The Center for Autism and Early Childhood Mental Health at Montclair State University has served as the New Jersey Autism Center of Excellence (NJACE) Coordinating Center since 2012, creating a new coordinated approach to autism research in New Jersey. The NJACE Coordinating Center oversees thirty-four clinical and translational research projects, six Autism Health Needs Medical Homes Pilot Projects and three five-year research projects funded by the Council for a total of \$27 million. The NJACE initiative represents the Council's and State's commitment to advancing the current knowledge pool through clinical research and treatment, resulting in improved interventions that address the physical and behavioral health needs of children, adolescents and adults with ASD.

*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.*

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 to optimize clinical research activities in New Jersey and contribute to the national autism clinical research effort. This effort provides the availability of data to autism researchers in the United States and highlights New Jersey's work. Furthermore, participation in NDAR demonstrates that the funded sites can meet the NIH requirements and 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 2017 to the New Jersey Autism Registry. The law establishing the New Jersey Autism Registry requires all licensed providers to register all children through the age of 21 who are diagnosed with autism. The New Jersey Autism Registry is designed to connect families of children with autism to the appropriate support services in their counties. For information about these services, please visit <http://nj.gov/health/fhs/eis/index.shtml>.



## 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. Autism spectrum disorder 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 one 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 this initiative will lead to the study of outcomes that will have a direct clinical impact, such as earlier diagnosis and improvements in interventions to 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 to establish the NJACE Coordinating Center. The NJACE Coordinating Center oversees thirty-four clinical and translational research pilot projects, six Autism Health Needs Medical Homes Pilot Projects and three five-year research projects funded by the Council for a total of \$27 million. Details of the awards are included in the Council's Annual Reports.

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



## Grant Awards – 2017

Enhancing the administration's firm commitment to finding new and innovative ways is the cornerstone to help New Jersey families impacted by autism. A total of \$2.8 million in grant funds was awarded in 2017 to improve health outcomes for adolescents and young adults with ASD and advance research in the understanding, evaluation and treatment of autism. The funding went to universities and medical centers.

Four-hundred thousand dollars was awarded to Meridian Health Systems at Jersey Shore University Medical Center in Neptune for an autism medical home, to address the needs of adolescents and young adults. Since 2015 a total of \$2.4 million has been awarded to establish autism medical homes for infants, children, adolescents and young adults at Children's Specialized Hospital in Mountainside, Hackensack University Medical Center in Hackensack and Meridian Health Systems (Jersey Shore University Medical Center in Neptune).

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.

Six research grants totaling \$2.4 million were awarded in 2017 to medical schools, universities and a medical center for clinical and translational research projects including a project to study the connection between infections during pregnancy and increased risk for autism and a project to study the characteristics, needs, functions and factors that affect the long-term outcomes and quality of life of adolescents with ASD.

*"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."*



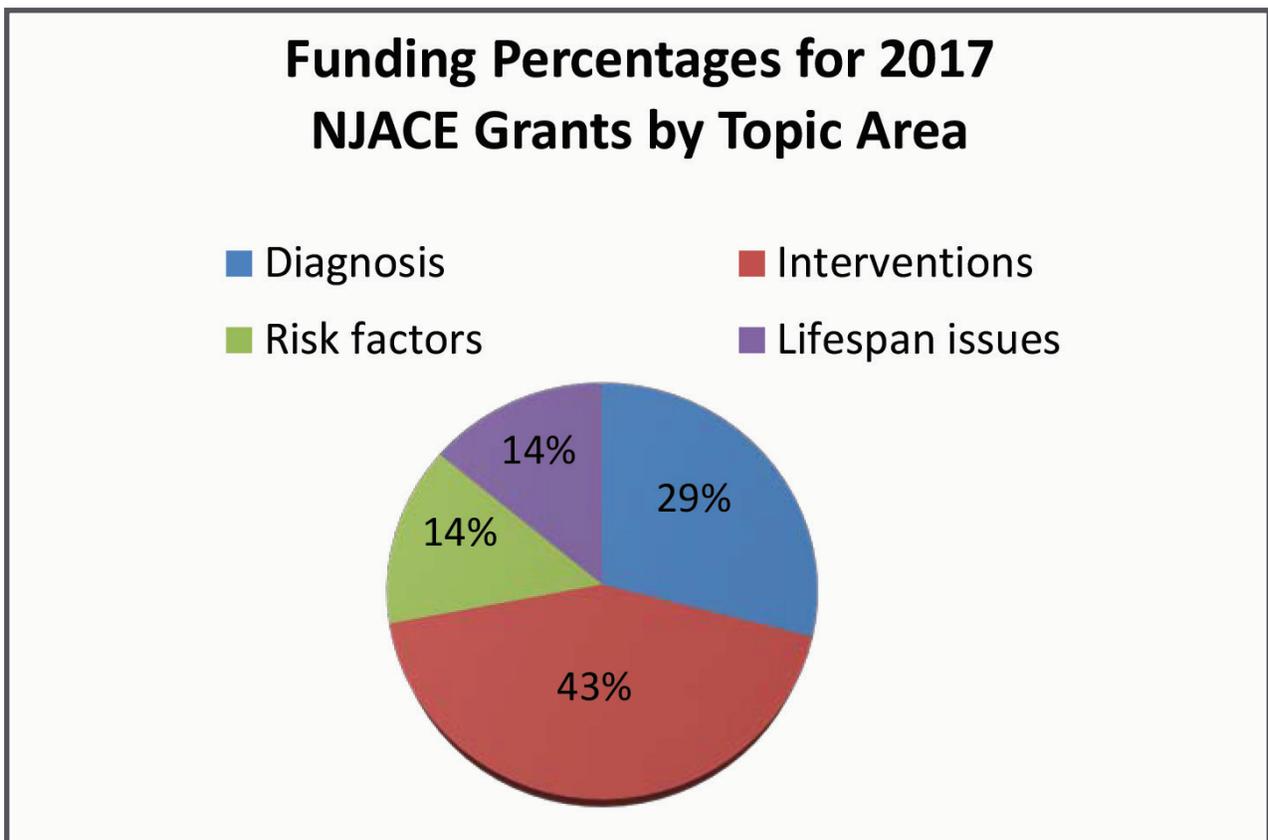
## Grant Awards – 2017

- Funded \$400,000 to Meridian Health Systems at Jersey Shore University Medical Center in Neptune for the Autism Care Coordination Youth Program (ACCYP) to provide a system of comprehensive, coordinated care for adolescents and young adults with ASD. Developmental pediatricians, internists, family practice physicians, neurologists and other specialists participated in the ACCYP.
- Funded \$399,271 to Rutgers University, Biomedical and Health Sciences (RBHS) to study the characteristics, needs, functions and factors that affect the long-term outcomes and quality of life of adolescents with ASD. The primary goal is to establish the knowledge base from which investigators will develop programs and approaches aimed at improving the quality of life of individuals with ASD.
- Funded \$399,230 to Rutgers University, Biomedical and Health Sciences (RBHS) to study the use of high dose propranolol to treat severe and chronic behaviors in adolescents and young adults with ASD that are debilitating to the individual as well as their families. The goal is to confirm the efficacy of treatment with propranolol and offer those with ASD and aggression new treatment options.
- Funded \$400,000 to Rutgers University Biomedical and Health Sciences (RBHS) to study a class of pediatric epilepsy-autism syndromes, interneuronopathies, that can be doubly devastating due to their association with early-life intractable epilepsies. By providing the first integrated genetic, cellular and network-level understanding of the changes in pediatric epilepsy-autism syndromes, this study will develop basic insights needed to pave the way for subsequent targeted therapeutics.
- Funded \$399,538 to Rutgers, The State University to use large data banks to examine hundreds of females with ASD to identify objective criteria with the goal to increase the likelihood of early detection of ASD traits in females. Coping with developmental transitional stages in teenage girls with ASD was a unanimous concern among the parents interviewed by the researchers as was an alarming lack of information for parents.
- Funded \$399,996 to Rutgers University Biomedical and Health Sciences (RBHS) to study the connection between infections during pregnancy and increased risk for autism. By studying the modes through which a key protein (cytokine IL-6) affects brain and gastrointestinal system development the data will lend additional support for the therapeutic neutralization of IL-6 in premature and neonatal infants at risk for developing ASD.
- Funded \$400,000 to Rutgers, The State University to study how specific molecules regulate synaptic structures, called spines, develop in neurons and when they are disrupted lead to altered brain activity and behaviors associated with autism. This project will help to understand why synapses, connections between the cells that make up the brain, are much more abundant in the autistic brain as well as ways to treat it.

## 2017 Grant Awards

Principal Investigator	Institution	Funding Level
Denise Aloisio, MD	Meridian Health Systems, Jersey Shore University Medical Center	\$400,000 (2 yrs.)
Walter Zahorodny, Ph.D.	Rutgers University, RBHS	\$399,271 (2 yrs.)
Barbie Zimmerman-Bier, MD	Rutgers University, New Brunswick, RBHS	\$399,230 (2 yrs.)
Tracy Tran , Ph.D.	Rutgers The State University	\$400,000 (2 yrs.)
Elizabeth B. Torres Ph.D.	Rutgers The State University	\$399,538 (2 yrs.)
Steven W. Levison Ph.D.	Rutgers University, RBHS	\$399,996 (2 yrs.)
Vijayalakshmi Santhakumar, Ph.D.	Rutgers University, RBHS	\$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.



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 percent 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 contributes to the national autism clinical research effort.

The New Jersey data will be made available to autism researchers in the United States and highlights New Jersey's effort. 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 able to meet the NIH requirements as well as help researchers develop stronger proposals for submission to the NIH and biomedical research foundations.

## **Autism Summit 2017**

Autism Summit 2017: Meeting of the Minds and Honoring Diversity in Research, Part I was held on April 19th and 20th, 2017, at the Princeton Marriott at Forrestal in Princeton, New Jersey. The 2017 summit convened the NJACE community and a select group of state, national and world leaders in the field of autism. The purpose was to profile the ASD research talents within New Jersey, and to engage in an interdisciplinary discourse seeking an integrated understanding of the nature of autism. Part II of the Autism Summit 2017: Meeting of the Minds and Honoring Diversity in Research: Continuing the Conversation was held on October 6, 2017, at Montclair State University. The purpose of Part II was to share the outcomes of Autism Summit 2017 Part I and to engage in dialogue with the larger community of researchers, educators, self-advocates and families, policymakers and the range of

multidisciplinary providers. The Autism Summit Parts I and II were well received by the 140 participants. The Summit was funded by the Council with the NJACE Coordinating Center responsible for planning and implementing the two-day Summit.

## **New Jersey Autism Registry**

The Autism Medical Research and Treatment Fund provided \$500,000 in 2017 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 Autism 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 2017, over 26,000 children with ASD were registered. These figures include newly diagnosed and previously diagnosed children. Based on the number of children within one birth cohort and the current autism prevalence rates for New Jersey (1 out of 41 children), estimates predict that at least 3400 children per birth year cohort will be newly diagnosed, with even more children being registered. The Autism Registry staff continue to educate health care providers about their responsibilities to register both previously and newly diagnosed children.

## **Autism New Jersey 35<sup>th</sup> Annual Conference**

The NJACE Coordinating Center staff represented the Council at the Autism New Jersey 35th Annual Conference held in Atlantic City, New Jersey, on October 19-20, 2017. 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. 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 public, and an individual with autism, or family member of someone 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 2017. 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 2018

In 2018 the Council's activities will focus on awarding up to \$4.0 million for a New Jersey Autism Center of Excellence (NJACE) and planning for SFY19 funding initiatives. The NJACE will support and stimulate research into the causes, diagnosis and treatment of ASD in New Jersey and provide a statewide system of training and continuing education programs for health care professionals to improve the clinical care of children, adolescents and adults with ASD. The award will be posted on the Council's website at <http://www.nj.gov/health/autism/report.shtml>. This five-year award is 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. The NJACE Coordinating Center grant awarded to Montclair State University in 2012 will end on June 30, 2018.



## Fund Balance Statement

	SFY 2017 <i>Projected</i>	SFY 2017 <b>Actual</b>	SFY 2018 <i>Projected</i>
<b>Opening Fund Balance (July 1)</b>	<b>\$3,862,442</b>	<b>\$4,658,238</b>	<b>\$712,330</b>
<b>Revenues</b>			
Assessments <sup>1</sup>	\$3,600,000	\$3,789,342	\$3,600,000
State Appropriated Funds	\$500,000	\$500,000	\$500,000
Total Revenue:	\$4,100,000	\$4,289,342	\$4,100,000
<b>Total Funds Available</b>	<b>\$7,962,442</b>	<b>\$8,947,580</b>	<b>\$4,812,330</b>
<b>Disbursements and Expenses</b>			
Spending Plan Reduction		\$4,000,000	
Disbursements to Grantees	\$4,020,000	\$2,985,250	\$3,000,000
Total disbursements	\$4,020,000	\$6,985,250	\$3,000,000
<b>Expenses</b>			
Administrative & Office expense	\$400,000	\$443,800	\$400,00
Professional Review Panel	\$100,000	\$56,200	\$100,000
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>\$8,235,250</b>	<b>\$4,250,000</b>
<b>Closing Fund Balance (June 30)</b>	<b>\$2,692,442</b>	<b>\$712,330</b>	<b>\$562,330</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

**Michele Sorvino, RDMS**, Speaker of the General Assembly Appointee; Executive Director Golden Door International Film Festival of Jersey City; Sonographer

**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

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