

2018
ANNUAL REPORT



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





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

June 3, 2019

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 2018 Annual Report. During 2018, 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 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. In July 2018 Rutgers University was awarded \$4 million over 5 years to establish the New Jersey Autism Center of Excellence (NJACE). The work carried out by Rutgers, in partnership with the Children's Specialized Hospital, supports the Council's mission by stimulating cutting edge ASD research and improving the clinical care of children, adolescents and adults with ASD. The goal is to make New Jersey a national leader in ASD research 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). 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.

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

PO Box 360, Trenton, NJ 08625-0360

Telephone 609-633-8740

Fax 609-943-4213

www.nj.gov/health/autism/



2018 Annual Report

**THE NEW JERSEY GOVERNOR'S COUNCIL
FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM
ANNUAL REPORT
JANUARY 1, 2018 - DECEMBER 31, 2018**

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 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.

The Council's Scientific Advisory Committee (SAC) includes three biomedical research scientists with demonstrated achievements in biomedical research relating to autism and two medical clinicians whose practice is primarily devoted to the treatment of people with autism. The SAC makes recommendations to the Council regarding grants for the most promising studies for biomedical research, diagnosis and treatment for autism.

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.

In July 2018, Rutgers University was awarded \$4 million over 5 years to establish the New Jersey Autism Center of Excellence (NJACE) with Elizabeth (Liz) Torres, Ph.D. as the Principal Investigator. The work carried out by Rutgers, in partnership with the Children's Specialized Hospital, supports the Council's mission by stimulating cutting edge ASD research and improving the clinical care of children, adolescents and adults with ASD. The goal is to make New Jersey a national leader in ASD research and treatment.

The NJACE is creating an interdisciplinary, collaborative network using existing programs and leveraging the leadership's extensive contacts to build and disseminate innovative initiatives for research, education and service serving individuals with autism across their lifespans. The New Jersey autism community informs the work of the NJACE through a Professional and Community Advisory Board tailored to identify unmet needs in services and research and integrate ASD researchers, service providers, people with ASD, families affected by ASD and related businesses across New Jersey. Open dialogue with relevant stakeholders promotes new cutting-edge concepts to enrich education and diversify clinical care.

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.

The Autism Medical Research and Treatment Fund (Fund) provided \$500,000 in 2018 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. The Fund also provided \$250,000 to Autism New Jersey (ANJ) for the operation of the ANJ Helpline.

In 2019, the Council's activities will focus on awarding up to \$1.5 million for Clinical and Translational Autism Pilot Project grants and Post-doctoral Fellowships while planning for Fiscal Years 2020 through 2022.

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 New Jersey Autism Center of Excellence (NJACE) is a statewide innovative, comprehensive and collaborative network to promote quality research, professional training and build public awareness aimed to improve the lives of individuals with ASD across the lifespan.
<https://njace.us/>



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 disorder is four times more likely to occur in boys than girls.

Autism is a national health issue. The Centers for Disease Control and Prevention (CDC) report (MMWR Surveillance Summaries / April 27, 2018 / 67(6);1–23) estimates an average of one in 59 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 34 children. This reported prevalence rate places New Jersey among 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)

In July 2018, Rutgers University was awarded \$4 million over 5 years to establish the New Jersey Autism Center of Excellence (NJACE) with Elizabeth (Liz) Torres, Ph.D. as the Principal Investigator. The work carried out by Rutgers, in partnership with the Children's Specialized Hospital, supports the Council's mission by stimulating cutting edge ASD research and providing 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 goal is to make New Jersey a national leader in ASD research and treatment.

The NJACE is creating an interdisciplinary, collaborative network using existing programs and leveraging the leadership's extensive contacts to build and disseminate innovative initiatives for research, education and service serving individuals with autism across their lifespans. The New Jersey autism community informs the work of the NJACE through a Professional and Community Advisory Board tailored to identify unmet needs in services and research and integrate ASD researchers, service providers, people with ASD, families affected by ASD and related businesses across New Jersey. Open dialogue with relevant stakeholders promotes new cutting-edge concepts to enrich education and diversify clinical care.

NJACE Goals

- Strengthen Council funded projects by providing administrative and technical support, sharing best practices, and facilitating discussion of progress, lessons learned and challenges.
- Stimulate cutting-edge ASD research in New Jersey by promoting awareness of emerging clinical issues and progress in ASD research and treatment.
- Improve clinical care for individuals with ASD in New Jersey by strengthening knowledge and training of health care professionals in NJ regarding ASD treatment, diagnosis and prevention.
- Position New Jersey as a national leader in autism research and clinical care.

Website

The NJACE website (<https://njace.us/>) is a dynamically interactive one stop shopping site providing researchers, clinicians and the public important information about new and ongoing activities. Videos posted on the site explain research results in layman terms and highlight research participants, celebrating their contribution to research (<https://njace.us/research/current-studies/>). The website is complemented by Social Media (Facebook, Twitter, LinkedIn and YouTube) to announce events, opportunities and successes. The website also includes a variety of resources for people with ASD and their families.

Advisory Board

The NJACE Professional and Community Advisory Board (<https://njace.us/about-us/advisory-board/>) is composed of varied stakeholders including leaders in autism research, training and service, people with ASD, families affected by ASD, and businesses involved with technology. The Board provides input to the NJACE to help identify research and training gaps and to provide guidance regarding priorities and activities.

Training Events

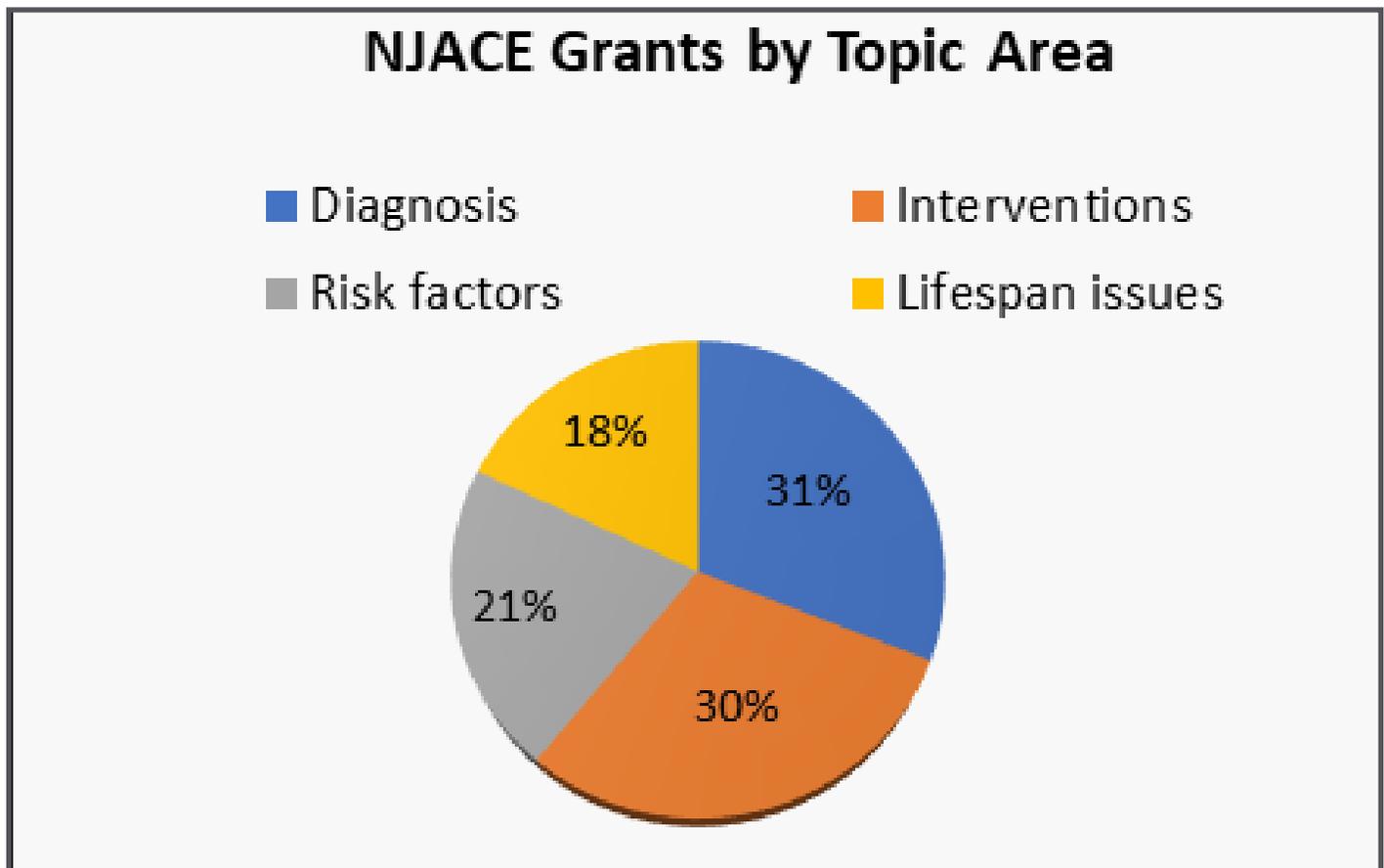
The NJACE promotes statewide training for professionals, pre-professionals, parents and guardians, self-advocates, and all other community members to better enhance the lives of those with ASD (<https://njace.us/resources/training-opportunities/>). Additional NJACE training events (see examples on <https://njace.us/news/njace-news/>) include Grand Rounds, conferences, brainstorming events and presentations by the NJACE leadership.



The 21 NJACE research grants (<https://njace.us/research>) represent a wide range of topics each addressing one of key questions identified by the National Institute of Health (NIH) Interagency Autism Coordinating Committee (IACC). Examples of research include studies:

- Identifying factors that affect the long-term outcomes and quality of life of adolescents with ASD, with the goal of developing approaches to improve their quality of life.
- Exploring whether high dose propranolol can treat severe and chronic behavioral issues in adolescents and young adults with ASD, issues that are debilitating to both the individuals and their families.
- Analyzing data from hundreds of females with ASD to identify objective criteria that could facilitate early detection of ASD traits in females.
- Examining synapses, connections between brain cells, to understand why synapses are much more abundant in the autistic brain.
- Testing the link between infections during pregnancy and increased risk for autism.

The following chart illustrates the distribution of funding by research topics for the NJACE 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. 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.

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 2018 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 2018, over 31,000 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 34 children), it is expected that at least 3400 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.

Autism New Jersey (ANJ)

The Autism Medical Research and Treatment Fund provided \$250,000 in 2018 to Autism New Jersey (ANJ) for the operation of the ANJ Helpline <https://www.autismnj.org/information-services/helpline/>. The Helpline is a source for referrals and services and provides access to an on-line referral database and consultation with a Helpline Specialist.

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 four times in 2018. Council members, meeting calendar and minutes are posted on the Council's website at www.nj.gov/health/autism.

Moving Forward to 2019

In 2019, the Council's activities will focus on awarding up to \$1.5 million for Clinical and Translational Autism Pilot Project grants and Post-doctoral Fellowships while planning for Fiscal Years 2020 through 2022.

Grant 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 2018 <i>Projected</i>	SFY 2018 <i>Actual</i>	SFY 2019 <i>Projected</i>
Opening Fund Balance (July 1)	\$712,330	\$729,722	\$188,648
Revenues			
Assessments ¹	\$3,600,000	\$3,833,462	\$3,720,000
State Appropriated Funds	\$500,000	\$500,000	\$500,000
Total Revenue:	\$4,100,000	\$4,333,462	\$4,220,000
Total Funds Available	\$4,812,330	\$5,063,184	\$4,408,648
Disbursements and Expenses			
Spending Plan Reduction		\$1,000,000	
Disbursements to Grantees	\$3,000,000	\$2,624,536	\$3,000,000
Total disbursements	\$3,000,000	\$3,624,536	\$3,000,000
Expenses			
Administrative & Office expense	\$400,000	\$496,000	\$400,000
Professional Review Panel	\$100,000	\$4,000	\$100,000
Autism Registry	\$750,000	\$750,000	\$750,000
Total expenses	\$1,250,000	\$1,250,000	\$1,250,000
Total Disbursements and Expenses	\$4,250,000	\$4,874,536	\$4,250,000
Closing Fund Balance (June 30)	\$562,330	\$188,648	\$158,648

¹ Net revenue variance

² Funds plus interest deposited annually in Jan

Council Membership

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

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, Morristown Memorial Hospital

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
NJGCA@doh.nj.gov

Martin T. Zanna, MD, MPH*

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

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

Mary Ray

Contract Administrator 1
NJ Governor's Council for Medical Research and
Treatment of Autism
(609) 943-5405
Mary.Ray@doh.nj.gov

*Sadly, Dr. Zanna passed away on February 5, 2019 having served for over 40 years in NJ State government as a public health physician and administrator and as Acting Executive Director for the Governor's Council for Medical Research and Treatment of Autism (Council) since 2011. He was responsible for the research and policy agendas necessary to fulfill the mission of the Council. His work at the national level included the establishment of a Scientific Advisory Committee of scientists and clinicians known nationally for their accomplishments in autism research and service and his work with the National Institutes of Health (NIH) in advancing the Council's goal of widespread data sharing among ASD researchers. The members of the Council are grateful for Dr. Zanna's years of service.

