



2019 ANNUAL REPORT

THE NEW JERSEY GOVERNOR'S COUNCIL
FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM
ANNUAL REPORT
JANUARY 1, 2019 - DECEMBER 31, 2019





State of New Jersey

DEPARTMENT OF HEALTH

GOVERNOR'S COUNCIL FOR MEDICAL RESEARCH AND
TREATMENT OF AUTISM

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www.nj.gov/health/autism

PHILIP D. MURPHY
Governor

SHEILA Y. OLIVER
Lt. Governor

JUDITH M. PERSICHILLI, RN, BSN, MA
Commissioner

February 28, 2020

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 2019 Annual Report. During 2019 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. During the calendar year 2019, the Council funded four projects that cover the range of our research priorities established at the national level and adopted by the Council in support of their Mission. The Council anticipates funding nine research and fellowship grants in 2020.

The New Jersey Center of Excellence (NJACE) housed within Rutgers University, in partnership with the Children's Specialized Hospital, support the Council's Mission by stimulating cutting edge ASD research and improving the clinical care of children, adolescents and adults with ASD. The NJACE's accomplishments are noted throughout the annual report, including the work of their partner organizations and what they are doing in communities throughout the state to improve the health and well-being of autistic people of all ages and their families.

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 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, Judith Persichilli



2019 Annual Report

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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. Funding for the Council comes from a \$1 surcharge on fines and penalties from traffic violations.

The Council seeks input from its Scientific Advisory Committee (SAC), composed of nationally respected experts in ASD research and treatment, three biomedical researchers and two clinicians. The SAC makes recommendations to the Council regarding grants for the most promising studies for biomedical research, diagnosis and treatment for autism.

Fulfilling its legislative mandate, the Council created a New Jersey Autism Center of Excellence (NJACE) in 2018. This is a statewide organization housed within Rutgers University and, in partnership with the Children's Specialized Hospital, supports the Council's mission by bringing together researchers, health professionals, and families to stimulate cutting edge ASD research and improve the clinical care of children, adolescents and adults with ASD.

The Autism Medical Research and Treatment Fund (Fund) provided \$500,000 in 2019 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 2020 the Council's activities will focus on awarding up to \$2.8 million for Clinical and Basic Science Pilot Project grants and Post-doctoral and Graduate Student Fellowships while planning for Fiscal Years 2021 through 2023.

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 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.



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.



Mission of Council and Scientific Advisory Committee (SAC)

The Governor's Council for Medical Research and Treatment of Autism was created by State appropriation in 1999 and has been issuing clinical and basic research, and educational enhancement grants since 2000. As per P.L.2007, c.174, monies from \$1 surcharges on fines and penalties from traffic violations are deposited by the State Treasurer into the Autism Medical Research and Treatment Fund to sponsor the Council to fund autism research and treatment in the State of New Jersey. As detailed in P.L.2007, c. 168, the Council is to establish an Autism Center of Excellence in the State.

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 seeks expert advice from its Scientific Advisory Committee (SAC). The SAC is composed of three biomedical researchers and two medical clinicians, all nationally recognized experts in research and treatment for people with ASD. The SAC makes recommendations to the Council regarding programs and awards for the most promising studies for biomedical research, diagnosis and treatment for autism.

Since 2012, the Council has issued annual requests for research projects for a variety of programs including NJACE Program Sites and a Coordinating Center, Clinical Research and Basic Science Pilot Projects, Medical Homes Pilot Projects, and Postdoctoral Fellowships. These programs, together with the current NJACE, reflect the Council's commitment to fulfill its legislative mandate and spur research, professional training and community education to improve the lives of children, adolescents, and adults with ASD.

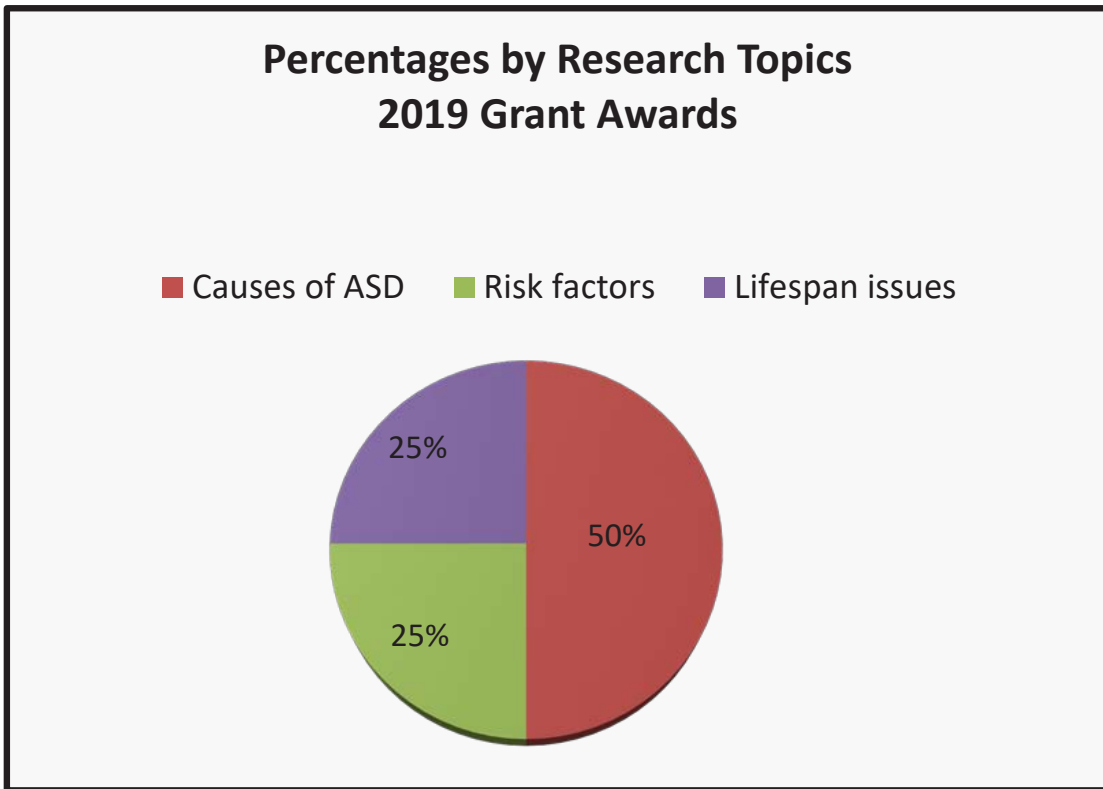
Grant Awards in 2019

- Awarded \$400,000 to the Kessler Foundation for the project Utilization of a Virtual-Reality Based Job Training Tool in Adolescents with Autism Spectrum Disorder, led by Dr. Helen Genova. This project will test whether a virtual reality training program can help adolescents with ASD interview for a job.
- Awarded \$400,000 to Virtua Health, Inc. for the project Building a streamlined birth cohort to study autism risk factors and biomarkers, led by Dr. Ronald Librizzi. This will explore the feasibility of enrolling pregnant women, collecting various biological samples at birth, and following the children as they grow. Such a study could identify some of the complex interacting factors that contribute to ASD and could serve as diagnosis or treatment target.
- Awarded \$200,000 to Rutgers, The State University for the project Elucidating Genetic Components of Autism and Co-occurring Attention Deficit Hyperactivity Disorder (ADHD) using Whole Genome Sequencing, led by Dr. Jinchuan Xing. The identification of the gene(s) involved in both ASD and ADHD would inform the development of treatments for individuals with ASD and ADHD.
- Awarded \$400,000 to Rutgers University, Biomedical and Health Sciences (RBHS) for the project Defining the signaling pathways that lead to hyperproliferation of neural progenitor cells in 16p11.2 Deletion Syndrome, led by Dr. James Millonig. Exploring the genes and pathways in cells from individuals with a genetic condition that leads to autism could inform the development of treatments for individuals with this and other causes of ASD.

2019 GRANT AWARDS

Principal Investigator	Institution	Amount
Helen Genova, Ph.D.	Kessler Foundation	\$400,000 (2 yrs.)
Ronald Librizzi, M.D.	Virtua Health, Inc.	\$400,000 (2 yrs.)
James Millonig, Ph.D.	Rutgers University RBHS	\$400,000 (2 yrs.)
Jinchuan Xing, Ph.D.	Rutgers, The State University	\$200,000 (2 yrs.)

The chart illustrates the three research topics represented by the 2019 grants as defined by the NIH's Interagency Autism Coordinating Committee (IACC). Seven topic areas are represented in the IACC Strategic Plan Update (<https://iacc.hhs.gov/publications/strategic-plan/2017/>).



To leverage and highlight the efforts of New Jersey researchers, Program Sites grantees are required to share their data via the NIMH Data Archive (NDA). Pilot project grantees are encouraged to share data via NDA if compatible with the study design. NDA houses research data of all types (genetic, imaging, clinical assessment, etc.) from human subjects

involved in ASD studies. It enables the cross-linking of information across studies and further analysis of the data by qualified researchers while ensuring participants' privacy. Submitting data to NDA reflects the Council's priority to maximize the effect of clinical research activities in New Jersey and contribute to the national research effort.



New Jersey Autism Center of Excellence (NJACE)

The NJACE is a statewide organization funded by the NJDOH Governor's Council for Medical Research and Treatment of Autism. The Center is located at Rutgers University and, 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. In addition, the NJACE supports twenty-two clinical and basic science research projects, including the four funded in 2019.

More specifically, the goals of the NJACE, are to:

- 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 regarding ASD treatment, diagnosis and prevention.
- Position New Jersey as a national leader in autism research and clinical care.

The interdisciplinary, collaborative network created by the NJACE builds on existing programs and leverages the leadership's extensive contacts to launch 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 and statewide outreach to communities through focus groups, brain storming sessions, community education and events for families with autistic children. The goal is 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 stakeholders promotes new cutting-edge concepts to enrich education and clinical care.

The NJACE staff has been working in communities throughout the state to continue to build relationships vital to their mission, bringing together families, schools, vocational training programs, sports teams, care providers from many health professions and researchers from many fields. This collaborative approach aims to address some of the fundamental issues affecting the well-being of people with ASD and to facilitate the life and work of their families, clinicians, teachers, and care providers. Such broad and diverse community engagement should enable the NJACE and its partners to bring about change in the community in New Jersey to improve the health and well-being of autistic people of all ages and their families.

The NJACE's many accomplishments in 2019 include (1) a symposium for families on sports and scientific research; (2) conferences for researchers on emerging technologies and communicating research to the public; (3) webinars for families and clinicians on adult issues in ASD and "Transition to Adult Health Care for Youth with ASD"; (4) parent, provider and researcher focus groups; (5) a workshop on "Vocational Training and Autism"; (6) brain storming sessions on transition and employment for people with autism and on introducing technology for use in autism interventions. Please see www.njace.us for details on the NJACE educational, research and collaborative activities.

The New Jersey Autism Center of Excellence (NJACE) initiative represents the State's and the Council's commitment to advancing current knowledge through clinical and basic science research and treatment. The goal is to realize outcomes that will have direct clinical impact, such as improvements in interventions that address the physical and behavioral health needs of children, adolescents and adults with ASD.

New Jersey Autism Registry

The Autism Medical Research and Treatment Fund provided \$500,000 in 2019 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 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 2019, over 35,000 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.

The Autism Medical Research and Treatment Fund provided \$250,000 to Autism New Jersey (ANJ) for the operation of the ANJ Helpline <https://www.autismnj.org/information-services/help-line/>. 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 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 three times in 2019. The meeting calendar, meeting minutes and a list of Council members are posted on the Council's website at www.nj.gov/health/autism.

Moving Forward to 2020

In 2020 the Council's activities will focus on awarding up to \$2.8 million for Clinical and Basic Science Pilot Project grants and Post-doctoral and Graduate Student Fellowships while planning for Fiscal Years 2021 through 2023.



Fund Balance Statement

	SFY 2019 <i>Projected</i>	SFY 2019 Actual	SFY 2020 <i>Projected</i>
Opening Fund Balance (July 1)	\$188,648	\$549,008	\$897,957
Revenues			
Assessments ¹	\$3,720,000	\$3,870,532	\$3,720,000
State Appropriated Funds	\$500,000	\$500,000	\$500,000
Total Revenue:	\$4,220,000	\$4,370,532	\$4,220,000
Total Funds Available	\$4,408,648	\$4,919,540	\$5,117,957
Disbursements and Expenses			
Spending Plan Reduction			
Disbursements to Grantees	\$3,000,000	\$2,771,583	\$3,600,000
Total disbursements	\$3,000,000	\$2,771,583	\$3,600,000
Expenses			
Administrative & Office expense	\$400,000	\$421,963	\$400,000
Professional Review Panel	\$100,000	\$78,037	\$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	\$4,021,583	\$4,850,000
Closing Fund Balance (June 30)	\$158,648	\$897,957	\$267,957

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, COO, A2Z Diagnostics

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

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