

July 3, 2012

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, I am pleased to present the enclosed 2010-2011Biannual Report. During 2010-2011, the Council continued to work with the Department of Health and Senior Services to meet our shared responsibilities to understand autism spectrum disorders (ASD) as well as to ensure best practices for treatment.

The Council awarded funds for 11 grants in basic science and clinical research, primarily in the areas of genetics, fMRI/brain development and neurobiology. The six Clinical Enhancement Centers were funded for a third year. We have released RFAs for the New Jersey Autism Center of Excellence (NJ ACE) Coordinating Center and Program Sites. This five year initiative represents Council's commitment to advancing the current knowledge pool through clinical research leading to improvements in interventions that address the physical and behavioral health needs of children, adolescents and adults with ASD.

The Council also funded a needs assessment for research and treatment of autism in New Jersey. This document will guide future planning for the State. In addition, we have continued to provide ongoing financial support for the NJ Autism Registry that identifies all children with ASD in the State.

It is an honor to serve the citizens of New Jersey by being both a member of the Council and the Chairperson. I have been privileged to work with the highly-dedicated staff at the DHSS. 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, MD

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

Enclosure

Ce: Commissioner Mary E. O'Dowd, MPH

# THE GOVERNOR'S COUNCIL FOR MEDICAL RESEARCH AND TREATMENT OF AUTISM BIANNUAL REPORT JANUARY 1, 2010-DECEMBER 31, 2011

# **TABLE OF CONTENTS**

Executive Summary	3	
Overview of Autism Spectrum Disorders	8	
Grant Activities and Funding Initiative	8	
NJ Autism Center of Excellence	8	
Clinical Enhancement Centers	10	
Basic Science and Clinical Research	11	
NJ Autism Registry	13	
Events and Programmatic Activities	13	
CDC/NJDHSS Autism Conference	13	
Scientific Meeting of Research Grantees	13	
Autism New Jersey 29 <sup>th</sup> Annual Conference	14	
Rutgers University Center for State Health Policy	14	
Council Membership and Meetings	15	
Council's Enhanced Processes	16	
Code of Ethics and Rules of Order	16	
Scientific Advisory Committee	17	
Moving Forward to 2012	18	
Fund Balance Statement	19	

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

# BIANNUAL REPORT JANUARY 1, 2010 – DECEMBER 31, 2011

## **Executive Summary**

The Governor's Council for Medical Research and Treatment of Autism (the Council) was created by State appropriation in 1999 and has been issuing research, clinical and educational enhancement grants since 2000. As per P.L. 2007, 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 mission of the New Jersey Autism Center of Excellence (NJ ACE) is to research, apply and advance best practices in the understanding, prevention, evaluation and treatment of autism spectrum disorders, enhancing the lives of individuals across their lifespans.

# Grant Activities and Funding Initiative

New Jersey Autism Center of Excellence (NJ ACE). The Council announced the Notices of Grant Availability (NOGA) for the NJ ACE Coordinating Center and Program Sites on December 5, 2011 with awards to grantees in June 2012. The Program Sites will conduct clinical research and the Coordinating Center will provide common management and support functions to unify the Program Sites while promoting the sharing of lessons learned and best practices in the conduct of clinical research in autism. This five year \$8 million NJ ACE initiative represents the Council's and State's commitment to advancing the current knowledge pool through clinical research leading to improvements in interventions that address the physical and behavioral health needs of children, adolescents and adults with ASD.

**Clinical Enhancement Centers.** The Council's \$8.55 million Clinical Enhancement Center grant initiative (July 1, 2008-June 30, 2011) enabled six clinical autism centers across New

Jersey to enhance staffing of clinical personnel, improve early detection of ASD and increase the number of multi-disciplinary evaluations provided to children suspected of being on the autism spectrum. This is a patient-centered initiative aimed at establishing more uniform diagnostic, treatment and outreach services to the increasing population of those with or suspected of having autism.

Basic Science and Clinical Research Grants. In July 2010 the Council awarded 11 two-year Basic Science and Clinical Research grants for a total of \$5 million. The grant program funded research primarily in the areas of genetics, fMRI/brain development, and neurobiology. Accomplishments of the grantees are impressive with significant progress in accomplishing the goals of the projects as evidenced by publications in professional peer reviewed journals. Grantees have also received additional funding through federal agencies and foundations, another indication of the quality of their research.

New Jersey Autism Registry. The Council provided \$500,000 annually to the New Jersey Autism Registry. The State launched the web-based NJ Autism Registry statewide on October 1, 2009. The law establishing the Autism Registry within the Special Child Health Service Registry requires providers to register children diagnosed with autism. The Registry is designed to connect families of children with autism to the appropriate support services in their cities and towns. The Council collaborates with the NJ Autism Registry staff and acknowledges their outstanding accomplishments in providing outreach and education to both providers and families throughout the State.

# **Events and Programmatic Activities**

"Autism Spectrum Disorders: Understanding an Urgent Public Health Concern". This conference, co-sponsored by NJDHSS and The Centers for Disease Control and Prevention (CDC), was held on April 29, 2011 at Children's Specialized Hospital in New Brunswick. The Council staff assisted with plans for the conference and presented a tabletop display highlighting the work of the Council. The conference was well received with New Jersey First Lady Mary Pat Christie and Commissioners O'Dowd and Velez in attendance.

Scientific Meeting of Research Grantees. Planning began in August 2011 for the 2012 Scientific Meeting of Research Grantees. The meeting will provide a unique opportunity for research colleagues to share information and set the stage for possible future collaborations. The intent of the Council is to raise the level of awareness among stakeholders of the impact of New Jersey autism research while positioning grantees to compete for federal funding. This is a new initiative by the Council and the start of what we hope to ultimately be a statewide program to bring all autism researchers together annually for a summit to present and hear about the "State of the State in Autism Research in New Jersey".

**Autism New Jersey 29<sup>th</sup> Annual Conference.** The Basic Science Research and Clinical Enhancement Center Council grantees were invited to participate in a poster session event on October 13, 2011 at Autism New Jersey's 29<sup>th</sup> Annual Conference in Atlantic City. The session was a tremendous success in highlighting the contributions of the Council in supporting autism research and clinical services 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, Executive Vice President of Pediatric and Adolescent Services for Bancroft Neurohealth, served as Chair for the Council. The Council met seven times in 2010 and six times in 2011. Council members, meeting calendar and minutes are posted on the Council's website at www.nj.gov/health/autism.

# Council's Enhanced Processes: Code of Ethics, Rules of Order and Scientific Advisory Committee

Code of Ethics and Rules of Order. The Council's Code of Ethics was approved on May 24, 2011 by the State's Ethics Commission. The Code of Ethics is intended to establish standards of conduct while protecting the Council and the State from accusations of conflict of interest. As Special State Officers, Council members are expected to comply with the Code of Ethics.

The Council's Rules of Order relating to attendance were revised to state that a member can be recommended for removal if the member is absent for more than half of the meetings during a calendar year without prior notification of need for absence.

Scientific Advisory Committee. As part of its enabling legislation, the Executive Director of the Council is responsible for establishing a Scientific Advisory Committee (SAC). After consultation with the Council and a focused recruitment effort, the Executive Director convened the five member SAC in December 2011. Members of the SAC are nationally renowned experts in autism; three biomedical research scientists with demonstrated achievements in biomedical research and two medical clinicians whose practice is primarily devoted to the treatment of individuals with autism. The SAC makes recommendations to the Council, through the Executive Director, on the most promising research studies for biomedical research, diagnosis and treatment for ASD. These recommendations by the SAC are intended as guidance to the deliberations of the Council, which is responsible for decisions on funding of programs and grants.

# Moving Forward to 2012

A majority of the Council's activities will focus on awarding a total of \$8M in grants to the NJ Autism Center of Excellence (NJ ACE) Coordinating Center and Program Sites in June 2012 and periodic review of progress in grantees accomplishing the goals of the grants. These five-year 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 comprehensive progress reports.

In addition, the Council intends to provide, based on the availability of funds, \$2M for autism research in FY 13. An ad hoc committee of the Council has been charged with recommending, based on the legislation (P.L. 2007, Chapter 168), the categories of grants to be funded in June 2013.

It is anticipated that the Council will continue to participate in events throughout 2012, such as Autism New Jersey's annual conference, and sponsor a summit to bring all autism researchers

statewide together to present and hear about the "State of the State in Autism Res Jersey".	earch in New

# BIANNUAL REPORT JANUARY 1, 2010 – DECEMBER 31, 2011

# Overview of Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) is a group of Neurodevelopmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual or restricted behaviors and interests. The thinking and learning abilities of individuals with ASD can vary from gifted to severely challenged. ASD begins before the age of three and lasts throughout a person's life. They occur in all racial, ethnic, and socioeconomic groups. The disorders are four times more likely to occur in boys than girls, and the often devastating emotional and financial tolls on the family of an autistic child have been well-documented. The Centers for Disease Control and Prevention (CDC) estimates that an average of 1 in 88 children in the United States has an ASD. As part of the same CDC study, the prevalence rate for the New Jersey sites was established at 1 in 49 children\*. This reported prevalence rate places New Jersey among the states with the highest rates of autism in the country.

### Grant Activities and Funding Initiative

#### **New Jersey Autism Center of Excellence (NJ ACE)**

As detailed in P.L.2007, Chapter 168, the Council is to establish an Autism Center of Excellence in the State. The mission of the New Jersey Autism Center of Excellence (NJ ACE) is to research, apply and advance best practices in the understanding, prevention, evaluation and treatment of autism spectrum disorders, enhancing the lives of individuals across their lifespans.

The Council announced the Notices of Grant Availability (NOGA) for the NJ ACE Coordinating Center and Program Sites released on December 5, 2011 with awards to grantees proposed in early June 2012. Applications will be reviewed through a process designed to emulate the National Institutes of Health (NIH) standards and procedures to provide an impartial and rigorous review.

<sup>\*</sup>Reported in the MMWR Surveillance Summaries, March 30, 2012/61 (SS03; 1-19).

This five year \$8M NJ ACE initiative represents the Council's and State's commitment to advancing the current knowledge pool through clinical research leading to improvements in interventions that address the physical and behavioral health needs of children, adolescents and adults with ASD.

The Program Sites' grant awardees will conduct clinical research projects that address the national priorities described in the Interagency Autism Coordinating Committee (IACC) Strategic Plan and, as such, have the potential to improve the physical and/or behavioral health and well-being of individuals with ASDs. If applicable, applicants will also reference the Healthy People 2020 autism-related objective addressed by the research project. The designated NJ ACE Coordinating Center will provide common management and support functions to unify the NJ ACE Program Sites by serving as the voice of the NJ ACE and promoting the sharing of lessons learned and best practices in the conduct of clinical research.

To advance the goal of widespread data sharing among ASD researchers, investigators funded under the NJ ACE Program Sites grant program will share those data via the NIH National Database for Autism Research (NDAR). 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. This is the first time the Council grantees will have their clinical research data submitted to the National Database.

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 demonstrates that the funded sites are capable of meeting the National Institutes of Health (NIH) requirements and will help them develop stronger proposals for submission to the NIH and biomedical research foundations.

#### **The Clinical Enhancement Centers**

The Clinical Enhancement Center (CEC) grant initiative enabled six clinical autism centers across New Jersey to enhance staffing of clinical personnel, improve early identification of ASD and increase the number of multi-disciplinary evaluations provided to children suspected of being on the autism spectrum. The third year of a three-year cycle ended on June 30, 2011 with three of the six Centers continuing with no cost extensions through June 30, 2012.

Funding totaled \$8.55M for the three year period (July 1, 2008 – June 30, 2011). The Council funding resulted in increased accessibility to diagnostic and treatment services through the addition of new clinical programs and specialized medical personnel and expanded hours of operation. In the third year of funding 5,414 patients received care at the six Clinical Enhancement Centers with a total of 15,370 patient visits. Diagnostic autism evaluations were conducted for 2,570 patients, resulting in 1,131 diagnoses of ASD. The six Centers also conducted extensive outreach and education programs to primary care physicians to improve screening and early identification efforts across the State. In addition, the Centers provided outreach to pediatric residency programs, nurse practitioners, daycare providers and preschool teachers. The Centers also developed education and information resources such as a regional autism telephone answer line and a website listing autism services and provider information. Clinical Enhancement Center summary reports are posted on the Council's website at <a href="https://www.nj.gov/health/autism">www.nj.gov/health/autism</a> under "Current Initiatives".

2008-2011 Clinical Enhancement Centers

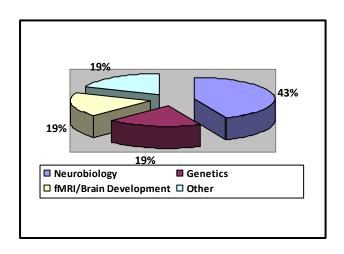
Principal Investigator	Institution	<b>Total Funding (3 Years)</b>
Mark Mintz, MD	The Center for Neurological and Neurodevelopmental Health, Gibbsboro, New Jersey	\$ 1,500,000
Yvette M. Janvier, MD	Children's Specialized Hospital – Toms River, New Jersey	\$ 1,500,000
Randye Huron, MD	Hackensack University Medical Center - Institute for Child Development, Hackensack, New Jersey	\$ 1,500,000

Audrey Mars, MD	Hunterdon Medical Center – Child Development Center, Flemington, New Jersey	\$ 1,050,000
Denise Aloisio, MD	Jersey Shore University Medical Center, Neptune, New Jersey	\$ 1,500,000
Tyrone Bentley, MD	University of Medicine and Dentistry, New Jersey Medical School - Newark, New Jersey	\$ 1,500,000

#### **Basic Science and Clinical Research Grants**

In July 2010 the Council awarded 11 two-year Basic Science and Clinical Research grants for a total of \$5M. The grant program funded research primarily in the areas of genetics, fMRI/brain development, and neurobiology. Accomplishments of the grantees are impressive with significant progress in accomplishing the goals of the projects as evidenced by publications in professional peer reviewed journals. Grantees have also received additional funding through federal agencies and foundations, another indication of the quality of their research. Grantees' progress reports, including accomplishments, are posted at <a href="www.nj/gov/health/autism">www.nj/gov/health/autism</a> under "Current Initiatives".

The following chart illustrates the percentage that each of these disciplines was funded during this grant cycle:



2010 – 2012 Basic and Clinical Science Grantees

Principal Investigator	Title	Institution	Type of Study	Funding Level
Bharat Biswal	Altered brain connectivity in Autism Spectrum Disorder patients	UMDNJ-NJMS	Basic Science	\$469,550
Gabriella D'Arcangelo	Reelin abnormalities in synaptogenesis and ASD	Rutgers University	Basic Science	\$381,700
Emmanuel DiCicco-Bloom	En2 Regulates Forebrain Monoamines and Behavior	UMDNJ-RWJMS	Basic Science	\$469,550
Bonnie Firestein	Regulation of synaptogenesis by Cypin and Neuroligin- 1	Rutgers University	Basic Science	\$469,550
Yvette Janvier	Autism outreach /screening in under- served areas	Children's Specialized Hospital	Clinical Research	\$469,550
G. Miller "Mill" Jonakait	Mediators of maternal inflammation	NJIT	Basic Science	\$392,162
Michael Lewis	Self representation and brain Development in Autism	UMDNJ-RWJMS	Clinical Research	\$469,550
James Millonig	Genetic and epigenetic Engrailed- 2 ASD risk factors	UMDNJ-RWJMS	Basic Science	\$469,550
Maggie Shiffrar	Perceptual-motor anticipation in individuals with Autism Spectrum Disorder	Rutgers University	Clinical Research	\$469,550
Gleb Shumyatsky	Amygdala-enriched genes in behaviors Related to ASD	Rutgers University	Basic Science	\$469,550
Harvey Weiss	Autism and control of cerebral metabolism	UMDNJ-RWJMS	Basic Science	\$469,550

#### The NJ Autism Registry

The Council provided \$500,000 annually to the New Jersey Autism Registry. The State launched the web-based NJ Autism Registry statewide on October 1, 2009. The law establishing the Autism Registry within the Special Child Health Service Registry mandates providers to register those children with a diagnosis of autism. The Registry is designed to connect families of children with autism to the appropriate support services in their cities and towns. The Council collaborates with the NJ Autism Registry staff and acknowledges their outstanding accomplishments in providing outreach and education to both providers and families throughout the State.

Over 8,000 children with ASD were registered as of December 2011. These figures include newly diagnosed and previously diagnosed children and are expected to increase as more health care providers report previously and currently diagnosed children to the Autism Registry. Based on the number of children within one birth cohort and the current autism prevalence rates, it is expected that approximately 1200 newly diagnosed children will be entered into the Registry each year.

# **Events and Programmatic Activities**

"Autism Spectrum Disorders: Understanding an Urgent Public Health Concern". This conference, co-sponsored by the New Jersey Department of Health and Senior Services (NJDHSS) and the Centers for Disease Control and Prevention (CDC), was held on April 29, 2011 at Children's Specialized Hospital in New Brunswick. The Council staff assisted with plans for the conference and presented a tabletop display highlighting the work of the Council. The conference was well received with New Jersey First Lady Mary Pat Christie and Commissioners O'Dowd and Velez in attendance.

Scientific Meeting of Research Grantees. Planning began in August 2011 for the 2012 Scientific Meeting of Research Grantees. Researchers completed interest surveys and suggested topics for the meeting agenda. The meeting will provide a unique opportunity for research colleagues to share information and set the stage for possible future collaborations. The intent of

the Council is to raise the level of awareness among stakeholders of the impact of New Jersey autism research while positioning grantees to compete for federal funding. This is a new initiative by the Council and the start of what we hope to ultimately be a statewide program to bring all autism researchers together annually for a summit to present and hear about the "State of the State in Autism Research in New Jersey".

Autism New Jersey 29<sup>th</sup> Annual Conference. The Basic Science Research and Clinical Enhancement Center grantees were invited to participate in a poster session event on October 13-14, 2011 at Autism New Jersey's 29<sup>th</sup> Annual Conference in Atlantic City. The session was a tremendous success in highlighting the contributions of the Council in supporting autism research and clinical services statewide. Nine grantees presented a total of 16 posters. Presenters were Dr. Randye Huron (Hackensack University Medical Center), Dr. Mark Mintz (Center for Neurological and Neurodevelopmental Health (CNNH)), Dr. Denise Aloisio (Jersey Shore University Medical Center), Dr. Audrey Mars (Hunterdon Medical Center), Dr. Gleb Shumyatsky (Rutgers), Dr. Walter Zahorodny (UMDNJ), Drs. Yvette Janvier and Jill Harris (Children's Specialized Hospital), Drs. Dicicco-Bloom and Matthieu Genestine (UMDNJ) and Drs. Dennis Carmody & Michael Lewis (Rutgers University).

Rutgers University Center for State Health Policy. To fully meet the charge of the establishing legislation in a coordinated manner, the Council contracted with the Rutgers University Center for State Health Policy (CSHP) to conduct a needs assessment. The CSHP catalogued the existing autism research and medical services in the State and are synthesizing the results of interviews with key stakeholders in the New Jersey autism community with the response to autism by other states. The results will be used to develop a strategic plan for the Governor's Council for Medical Research and Treatment of Autism. This plan will guide the Governor's Council with its funding priorities and strategy, including the type and structure of grant-funded programs and activities that are supported. A report on Phases 1 of the study was presented to Council in December 2011 with Phase 2 and the final report to be presented in early to mid-2012.

# 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, Executive Vice President of Pediatric and Adolescent Services for Bancroft Neurohealth, served as Chair for the Council. The Council met seven times in 2010 and six times in 2011. Council members, meeting calendar and minutes are posted on the Council's website at <a href="https://www.nj.gov/health/autism">www.nj.gov/health/autism</a>.

#### **Current Council Members**

**Elizabeth K. Bell, BS**, Autism Organization Representative; Volunteer and Independent Contractor with Autism Speaks.

**Matthew Cortland, BA,** Public Member; Co-founder and Program Director, BrosUnited (BUD), a mentorship program pairing fraternity brothers with teenage boys with autism.

\*Caroline Eggerding, MD, Healthcare Organization Representative; Executive Vice President of Pediatric and Adolescent Services for Bancroft NeuroHealth.

**Susan P. Evans, EdD,** Commissioner of Health and Senior Services Appointee, and the Education Program Specialist for Early Intervention program in the DHSS.

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

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

**Linda S. Meyer, MPA, EdD, BCBA-D,** Autism Organization Representative; Executive Director of Autism New Jersey.

**Barbara J. Morvay, MA,** Academic Institution Representative; Member, The Richard Stockton College of New Jersey and author of "My Brother is Different – A Siblings Guide to Coping with Autism".

**Grace M. Reilly, RN, MSN, APN-C,** Individual with Autism or Family Member Representative; Adult Nurse Practitioner for Riverview Medical Center.

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

\*Denotes Council Chair

## Past Council Members (2010-2011)

Michele Adubato, MSW, MA, Deputy Executive Director, The North Ward Center, Inc.

Jessica C. Guberman, PhD, Executive Director for Community Options, Inc.

Yvette Janvier, MD, FAAP, Medical Director, Children's Specialized Hospital, Toms River

Kendell R. Sprott, MD, JD, Acting Director of Pediatrics, UMDNJ-New Jersey Medical School

**Barbie Zimmerman-Bier, MD,** Appointment at Rutgers University, clinician at St. Peter's University

# Council's Enhanced Processes: Code of Ethics, Rules of Order and Scientific Advisory Committee

#### Code of Ethics and Rules of Order

The Council's Code of Ethics that was approved on May 24, 2011 by the State's Ethics Commission. The Code of Ethics is intended to establish standards of conduct while protecting the Council and the State from accusations of conflict of interest. The Council's Code of Ethics is a based on the Codes of Ethics for the Commission on Brain Injury Research and the Commission on Spinal Cord Injury Research and addresses several of the provisions of the New Jersey Conflicts of Interest Law and the Uniform Ethics Code. Of the fourteen issues addressed in the Code of Ethics, the following four are particularly relevant to the Council:

#7: An Autism Council Member cannot write a letter of support for a grant application for funding by the Autism Council.

#8: An Autism Council Member cannot sign a grant application on behalf of his/her institution/employer when the institution/employer is applying to the Autism Council for funding.

#9: Autism Council Members are not permitted to be primary investigators, co-investigator, subgrantees or collaborators on grant applications submitted to the Autism Council.

#11; An Autism Council Member whose institution/employer applies for an Autism Council grant is barred from any official involvement with that grant application.

As Special State Officers, the Council members are expected to comply with the Code of Ethics. Members signed documents certifying receipt of State ethics policies and training provided by the State Ethics Officer and the NJDHSS Ethics Liaison Office. Ethics training must be renewed annually and is accessed through the States on-line training portal.

The Council's Rules of Order relating to attendance were revised to address the difficulty in achieving a quorum on a regular basis. The following statement was approved by the Council "...a member can be recommended for removal if the member is absent for more than half of the meetings during a calendar year without prior notification of need for absence."

#### **Scientific Advisory Committee**

As part of its enabling legislation, the Executive Director of the Council is responsible for establishing a Scientific Advisory Committee (SAC). After consultation with the Council and a focused recruitment effort, the Executive Director convened the five member SAC in 2011. Members of the SAC are nationally renowned experts in autism; three biomedical research scientists with demonstrated achievements in biomedical research and two medical clinicians whose practice is primarily devoted to the treatment of individuals with autism. They as follows: Catherine Rice, Ph.D., CDC (and affiliated with the Marcus Autism Center at Emory). Dr. Rice is a member of the CDC's Autism Surveillance/monitoring Unit (ADDM); Ted Abel, Ph.D., Director of the Biological Basis of Behavior Program at the University of Pennsylvania; Susan Hyman, MD (University of Rochester and Chair of the Autism sub-committee of the American Academy of Pediatrics); Stewart Mostofsky MD, Medical Director of the Center for Autism and Related Disorders at the Kennedy Krieger Institute; and Joseph Buxbaum Ph.D. Professor of Genetics and Genomic Sciences at The Mt. Sinai Medical Center.

The SAC makes recommendations to the Council, through the Executive Director, on the most promising research studies for biomedical research, diagnosis and treatment for ASD. These

recommendations by the SAC are intended as guidance to the deliberations of the Council, which is responsible for decisions on funding of programs and grants.

# Moving Forward to 2012

A majority of the Council's activities will focus on awarding a total of \$8M in grants to the NJ Autism Center of Excellence (NJ ACE) Coordinating Center and Program Sites in June 2012 and periodic review of progress in grantees accomplishing the goals of the grants. After scoring of the applications by an Independent Scientific Merit Review Panel, the Council will review the grants, the reviewers' critiques and a brief synopsis of the Panel's deliberations. In May 2012 the Council will meet to vote on funding one Coordinating Center and up to three Program Sites. Twice during the first year and yearly thereafter, the Coordinating Center will provide progress reports to Council, through the Executive Director, on its activities and its evaluation of the Program Sites. Multi-year awards are made through one-year contracts. Each funding award within the multi-year period will be contingent upon the availability of funds. Support for the continuing years of all grants is contingent upon submission and approval of annual comprehensive progress reports.

In addition, the Council intends to provide, based on the availability of funds, \$2M for autism research in FY 13. An ad hoc committee of the Council has been charged with recommending, based on the legislation (P.L.2007, Chapter 168), the categories of grants to be funded in June 2013.

It is anticipated that the Council will continue to participate in events throughout 2012, such as Autism New Jersey's annual conference, and sponsor a summit to bring all autism researchers statewide together to present and hear about the "State of the State in Autism Research in New Jersey".

# FUND BALANCE STATEMENT

	SFY 2011	SFY 2011	SFY 2012
	Projected	Actual	Projected
Opening Fund Balance (July 1)	\$9,562,980	\$9,562,980	\$9,474,627
Revenues			
Assessments <sup>1</sup>	\$3,600,000	\$3,976,973	\$3,600,000
State Appropriated Funds			\$500,000
Total Revenue:	\$3,600,000	\$3,976,973	\$4,100,000
<b>Total Funds Available</b>	\$13,162,980	\$13,539,953	\$13,574,627
Disbursements and Expenses			
Disbursements to Grantees	\$2,500,000	\$3,065,000	\$10,526,301
Total disbursements	\$2,500,000	\$	\$10,526,301
		3,065,000	
Expenses			
Administrative & Office	\$411,031	\$498,300	\$476,000
expense			
Professional Review Panel	\$3,000	\$1,700	\$24,000
Autism Registry	\$500,000	\$500,000	\$500,000
Total expenses	\$914,031	\$1,000,000	\$1,000,000
Total Disbursements and	\$3,414,031	\$4,065,000	\$11,526,301
Expenses			
Closing Fund Balance (June 30)	\$9,748,949	\$9,474,953	\$2,048,326

<sup>&</sup>lt;sup>1</sup>Net revenue variance