

CHAPTER 168

AN ACT concerning medical research and treatment of autism, amending and supplementing P.L.1999, c.105 and amending P.L.2001, c.338 and P.L.2003, c.144.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. Section 1 of P.L.1999, c.105 (C.30:6D-56) is amended to read as follows:

C.30:6D-56 Short title.

1. This act shall be known and may be cited as the "New Jersey Autism Biomedical Research Act."

2. Section 2 of P.L.1999, c.105 (C.30:6D-57) is amended to read as follows:

C.30:6D-57 Findings, declarations relative to autism.

2. The Legislature finds and declares that:

- a. Autism and autism spectrum disorders are biologically-based developmental disorders which cause severe impairments in language and communication and generally manifest in young children sometime during the first two years of life, and the devastation caused by autism lasts a lifetime due to the emotional and financial distress that families experience from the intense support which most individuals with autism require throughout their lives;

- b. With three quarters of those with autism spending their adult lives in institutions or group homes, and usually entering institutions by the age of 13, the cost of caring for individuals with autism and autism spectrum disorders is great, and is estimated to be \$.5 billion per year in the State, solely for direct costs;

- c. According to the federal Centers for Disease Control and Prevention, or CDC, one of every 94 children in this State has autism, which is the highest rate among the states examined by the CDC in the most comprehensive study of the prevalence of autism to date;

- d. While autism is the third most common developmental disorder and is more prevalent than Down's syndrome, childhood cancer or cystic fibrosis, autism research receives less than 5% of the funding of these other diseases from the federal government and to date little biomedical research has been done on this disorder, despite the fact that scientists consider autism to be one of the most heritable of all the developmental disorders and the most likely to yield to the latest scientific advancements in genetics and neurology;

- e. The lack of research was due to 40 years of neglect of autism by the scientific community, arising from the formerly widespread but now discredited belief that autism was an emotional disorder caused by faulty parenting, and thus, few dollars were allocated to researchers, leaving an entire generation of children to be overlooked; however, the rapid advancements in biomedical science suggest that effective treatment and a cure for autism are attainable, if sufficient dollars are allocated to research so that another generation of children in the State is not lost to this disorder;

- f. While promising findings in the field of autism research have been made in recent years, the diverse symptoms and etiology of autism require a high level of activity in the widest variety of scientific fields, from genetics and neurology to neuroimaging, immunology and gastroenterology, if effective treatments and a cure are to be found quickly;

- g. Other states such as New York, Connecticut and Maryland have nationally recognized centers for researching and treating autism that attract significant funding from private sources and the National Institutes of Health, but since New Jersey lacks such centers, the State is unable to attract comparable funding, despite the presence of highly regarded

medical facilities in the State such as Robert Wood Johnson University Hospital and Hackensack University Medical Center, as well as a higher education medical institution such as the University of Medicine and Dentistry of New Jersey;

h. The State's substantial pharmaceutical industry would benefit from having medical centers dedicated to autism research and treatment by gaining access to families for clinical trials and by enabling easy collaboration between public and private scientists; and

i. Legislation has been introduced in the United States Congress which, if passed, will increase the level of federal funding for biomedical research on autism; however, in order for State researchers to be eligible for these dollars, funding must be made available for State researchers to carry out preliminary pilot studies.

3. Section 3 of P.L.1999, c.105 (C.30:6D-58) is amended to read as follows:

C.30:6D-58 Definitions relative to autism.

3. As used in this act:

"Autism" includes autism spectrum disorders to the extent determined by the council to be appropriate.

"Center" means the Center of Excellence for Autism established pursuant to this act.

"Council" means the "Governor's Council for Medical Research and Treatment of Autism" established pursuant to this act.

4. Section 4 of P.L.1999, c.105 (C.30:6D-59) is amended to read as follows:

C.30:6D-59 "Governor's Council for Medical Research and Treatment of Autism."

4. a. There is established in the Department of Health and Senior Services, the "Governor's Council for Medical Research and Treatment of Autism." The council shall be composed of 14 members as follows: seven persons to be appointed by the Governor, two of whom shall be members of the public who do not occupy a leadership position in any of the organizations represented on the council, of which two members one shall be a person with a diagnosis of autism or autism spectrum disorder or the family member of such a person, four of whom shall be appointed in consultation with the presidents of academic institutions in this State that are engaged in autism research, and one of whom shall be a representative of a health care organization with demonstrated clinical expertise in the evaluation and treatment of autism spectrum disorders; one person to be appointed by the President of the Senate and one person to be appointed by the Speaker of the General Assembly; one person to be appointed by the Commissioner of Health and Senior Services; and four persons, also to be appointed by the Governor, who represent autism organizations in New Jersey each of whom shall represent no more than one such organization.

b. At its first meeting of each calendar year, the council shall select, by a simple majority of the members present, a chairperson from among its members, who shall serve as the chairperson until the first meeting held in the next calendar year, at which time the same person may be selected as chairperson or a new chairperson may be selected in the same manner. The members of the council shall serve for three-year terms. Each member shall hold office for the term of appointment and until a successor is appointed and qualified. All vacancies shall be filled in the same manner as the original appointment. Members appointed to fill a vacancy occurring for any reason other than the expiration of the term shall serve for the unexpired term only. The members of the council shall be eligible for reappointment.

c. The members of the council shall serve without compensation, but shall be reimbursed for necessary expenses incurred in the performance of their duties.

d. A majority of the members of the council shall constitute a quorum, but a lesser number may hold hearings.

e. The council shall meet periodically at the call of the chairperson, but not less than four times in each calendar year.

f. The Commissioner of Health and Senior Services, in consultation with the council, shall appoint a director of the council. The director shall be a person qualified by training and experience to perform the duties of that position. The director at the direction of the council, may call upon the commissioner for additional staff assistance and resources as appropriate.

5. Section 5 of P.L.1999, c.105 (C.30:6D-60) is amended to read as follows:

C.30:6D-60 Center of Excellence for Autism.

5. a. The council shall make awards of grants and contracts to public and nonprofit private entities to pay all or part of the cost of planning, establishing, improving and providing basic operating support for a Center of Excellence for Autism in the State where basic and applied biomedical research, diagnosis and treatment for autism shall take place.

b. The council shall define the scope of the programs to be undertaken at the center with the understanding that the center shall conduct:

(1) basic and clinical research into the cause, diagnosis, early detection, prevention, control and treatment of autism, including research in the fields of developmental neurobiology, genetics, psychopharmacology, neuroimaging, immunology, infectious diseases, gastroenterology and endocrinology;

(2) training programs on biomedical treatments, diagnosis and prevention for autism for physicians, scientists and other health care and allied health care professionals in the State; and

(3) information and continuing educational programs on the latest advances in biomedical research on autism for physicians and other health care and allied health care professionals who provide care for patients with autism in the State.

c. The center may carry out programs to make individuals in the State aware of opportunities to participate as subjects in research conducted by the center. The program may provide fees to these subjects. The program may, in accordance with guidelines established by the council, provide to these subjects health care, referrals for health and other services and such incidental services as will facilitate the participation of individuals as subjects.

d. The center may provide stipends for health care professionals enrolled in training programs established under paragraph (2) of subsection b. of this section.

e. The council may require the periodic preparation of reports on the activities of the center and the submission of the reports to the council.

f. The center shall use the facilities of a single medical facility or higher education medical institution, or be formed from a consortium of cooperating facilities or institutions, and shall meet any requirements as may be prescribed by the council, with the understanding that the work carried out at the center shall be comprehensive and fully collaborative.

6. Section 6 of P.L.1999, c.105 (C.30:6D-61) is amended to read as follows:

C.30:6D-61 Duties of council, director.

6. The council shall provide guidance and direction to the director of the council, who shall be responsible for the following duties:

a. Carry out a program to provide information and education on advances in the diagnosis and biomedical treatment of autism to families in the State with autistic members and to the general public;

b. Establish a five-member Scientific Advisory Committee whose members shall serve at the pleasure of the council. The members of the committee shall include: 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 individuals with autism. The committee shall identify and make recommendations to the council regarding grants for the most promising pilot studies for biomedical research, diagnosis and treatment for autism and autism spectrum disorders;

c. Present the recommendations of the Scientific Advisory Committee to the council, which shall select the final grants for pilot studies;

d. Establish mechanisms to use the results of biomedical research on autism and autism spectrum disorders, conducted at the center and through the pilot studies in the development of policies and programs to improve the outcomes of individuals in the State with these disorders;

e. Establish a mechanism for the sharing of information among researchers and clinicians in the State conducting biomedical research on autism and autism spectrum disorders;

f. Provide for a mechanism that would permit the public to obtain information on the existing and planned programs and activities being conducted through the center and the pilot studies, and the council to receive comments from the public regarding these programs and activities;

g. Continually seek and apply for funding to supplement and eventually replace the moneys provided pursuant to subsection f. of R.S.39:5-41; and

h. Report not later than March 1 of each year to the Governor and, pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), to the Legislature on the status of the Center of Excellence for Autism and other activities of the council.

C.30:6D-58.1 References to Council.

7. Whenever the term "Governor's Council for Medical Research and Treatment of Infantile Autism" occurs or any reference is made thereto in any law, contract or document, the same shall be deemed to mean or refer to the "Governor's Council for Medical Research and Treatment of Autism."

8. Section 1 of P.L.2001, c.338 (C.30:6D-62.1) is amended to read as follows:

C.30:6D-62.1 Annual appropriation to Governor's Council for Medical Research and Treatment of Autism.

1. Beginning in Fiscal Year 2001 and in each fiscal year thereafter, the Governor shall recommend and the Legislature shall appropriate \$1,500,000 from the General Fund to the Governor's Council for Medical Research and Treatment of Autism established pursuant to P.L.1999, c.105 (C.30:6D-56 et seq.).

9. Section 1 of P.L.2003, c.144 (C.30:6D-62.2) is amended to read as follows:

C.30:6D-62.2 "Autism Medical Research and Treatment Fund" established.

1. a. There is established in the Department of the Treasury a nonlapsing fund to be known as the "Autism Medical Research and Treatment Fund." This fund shall be the repository for moneys provided pursuant to subsection f. of R.S.39:5-41. Moneys deposited in the fund, and any interest earned thereon, shall be allocated to the Governor's Council for Medical Research and Treatment of Autism established pursuant to P.L.1999, c.105 (C.30:6D-56 et seq.), to support grants and contracts awarded under subsection a. of section 5 of P.L.1999, c.105 (C.30:6D-60), and any grants for pilot studies selected under subsection c. of section 6 of P.L.1999, c.105 (C.30:6D-61), provided that, if federal funds are available for the purpose, the grantee or contractor shall, as a condition of receiving any such grant or contract from the fund, apply for an amount of federal funds in support of that grant or contract.

b. Any costs incurred by the department in the collection or administration of the fund may be deducted from the funds deposited therein, as determined by the Director of the Division of Budget and Accounting.

10. This act shall take effect immediately.

Approved September 12, 2007.