

# LEGISLATIVE HISTORY CHECKLIST

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## *LAWS of 1999*

**CHAPTER:** 105

**NJSA:** 30:6D-56 to 30:6D-62

("New Jersey Infantile Autism Biomedical Research Act")

**BILL NO:** S1406 (Substituted for A2506 1<sup>st</sup> Reprint)

**SPONSOR(S):** Bassano and Singer

**DATE INTRODUCED:** October 15, 1998

**COMMITTEE:**

**ASSEMBLY:** Health; Appropriations

**SENATE:** Senior Citizens, Veterans' Affairs & Human Services; Budget & Appropriations

**AMENDED DURING PASSAGE:** Yes

**DATE OF PASSAGE:**

**ASSEMBLY:** March 29, 1999

**SENATE:** December 17, 1998

**DATE OF APPROVAL:** May 11, 1999

**THE FOLLOWING ARE ATTACHED IF AVAILABLE:**

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**FINAL TEXT OF BILL:** 1<sup>st</sup> Reprint

(Amendments during passage denoted by superscript numbers)

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## **S1406**

**SPONSORS STATEMENT:** Yes (Begins on page 6 of original bill)

**COMMITTEE STATEMENT:**

**ASSEMBLY:** Yes

**January 21, 1999** Health

**March 4, 1999** Appropriations

**SENATE:** Yes

**October 19, 1998** Senior Citizens, Veterans' Affairs & Human Services

**December 10, 1998** Budget & Appropriations

**FLOOR AMENDMENT STATEMENTS:** *No*

**LEGISLATIVE FISCAL ESTIMATE:** *No*

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## **A2506**

**SPONSORS STATEMENT:** *Yes* (Begins on page 6 of original bill)

Bill and Sponsor's statement identical to S1406

**COMMITTEE STATEMENT:**

**ASSEMBLY:** *Yes*

**January 21, 1999** Health

**March 4, 1999** Appropriations

Identical to Assembly Appropriations Committee Statement of 3-4-99 for S1406

**SENATE:** *No*

**FLOOR AMENDMENT STATEMENTS:** *No*

**LEGISLATIVE FISCAL ESTIMATE:** *No*

**1<sup>st</sup> REPRINT (Final version):** *Yes*

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## **GOVERNOR'S ACTIONS**

**VETO MESSAGE:** *No*

**GOVERNOR'S PRESS RELEASE ON SIGNING:** *Yes*

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## **THE FOLLOWING WERE PRINTED:**

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**REPORTS:** *No*

**HEARINGS:** *No*

**NEWSPAPER ARTICLES:** *No*

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Title 30.  
Chapter 6D.  
Part F. (New)  
Autism Research  
§§1 - 6,8  
C. 30:6D-56  
To 30:6D-62  
§7 Approp.  
§§1 - 8  
Note To 18A:64G-3  
& 18A:64G-11

P.L. 1999, CHAPTER 105, *approved May 11, 1999*  
Senate, No. 1406 (*First Reprint*)

1 **AN ACT** concerning autism, supplementing Title <sup>1</sup>**[26]** 30<sup>1</sup> of the  
2 Revised Statutes and making an appropriation.

3

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

6

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

9

10 2. The Legislature finds and declares that:

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

18 b. With three quarters of those with infantile autism spending their  
19 adult lives in institutions or group homes, and usually entering  
20 institutions by the age of 13, the cost of caring for individuals with  
21 autism and autism spectrum disorder is great, and is estimated to be  
22 \$.5 billion per year in the State, solely for direct costs;

23 c. Best estimates indicate that one in 500 children born in the State  
24 will be diagnosed with an autism spectrum disorder and that 12,000  
25 individuals in the State have autism or an autism spectrum disorder,  
26 but these numbers may be understated because current diagnostic  
27 procedures lack accuracy and sensitivity for those with atypical  
28 symptoms and because there is a need for epidemiological data on  
29 incidence and prevalence of this disorder in the State;

30 d. While infantile autism is the third most common developmental  
31 disorder and is more prevalent than Down's syndrome, childhood  
32 cancer or cystic fibrosis, autism research receives less than 5% of the

**EXPLANATION** - Matter enclosed in bold-faced brackets **[thus]** in the above bill is not enacted and intended to be omitted in the law.

Matter underlined thus is new matter.

Matter enclosed in superscript numerals has been adopted as follows:

<sup>1</sup> Senate SBA committee amendments adopted December 10, 1998.

1 funding of these other diseases from the federal Government and to  
2 date little biomedical research has been done on this disorder, despite  
3 the fact that scientists consider autism to be one of the most heritable  
4 of all the developmental disorders and the most likely to yield to the  
5 latest scientific advancements in genetics and neurology;

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

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

21 g. Other states such as New York, Connecticut and Maryland have  
22 nationally recognized centers for researching and treating autism that  
23 attract significant funding from private sources and the National  
24 Institutes of Health, but since New Jersey lacks such centers, the State  
25 is unable to attract comparable funding, despite the presence of highly  
26 regarded medical facilities in the State such as Robert Wood Johnson  
27 University Hospital and Hackensack University Medical Center, as  
28 well as a higher education medical institution such as the University of  
29 Medicine and Dentistry of New Jersey;

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

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

39

40 3. As used in this act:

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

43 "Center" means <sup>1</sup>[a]the<sup>1</sup> Center of Excellence for Autism  
44 established pursuant to this act.

45 <sup>1</sup>["Commissioner" means the Commissioner of Health and Senior  
46 Services.]<sup>1</sup>

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

3 "President" means the President of the University of Medicine and  
4 Dentistry of New Jersey.<sup>1</sup>

5  
6 4. a. There is established in the <sup>1</sup>~~Department of Health and Senior~~  
7 ~~Services~~University of Medicine and Dentistry of New Jersey<sup>1</sup>, the  
8 "Governor's Council for Medical Research and Treatment of Infantile  
9 Autism." The council shall be composed of <sup>1</sup>~~11~~seven<sup>1</sup> members as  
10 follows: the <sup>1</sup>~~Commissioner of Health and Senior Services~~President  
11 of the University of Medicine and Dentistry of New Jersey<sup>1</sup>, or his  
12 designee, <sup>1</sup>~~and~~<sup>1</sup> the director of <sup>1</sup>~~each~~the<sup>1</sup> center, <sup>1</sup>~~who~~ and the  
13 director of one other treatment center at the University of Medicine  
14 and Dentistry of New Jersey that is devoted to biomedical research on  
15 autism, to be appointed by the president, all of whom<sup>1</sup> shall serve as  
16 ex officio members; and <sup>1</sup>~~eight~~four<sup>1</sup> public members <sup>1</sup>~~to be~~  
17 ~~appointed by the commissioner~~ from autism organizations in New  
18 Jersey<sup>1</sup> as follows: <sup>1</sup>~~four parent representatives, two of whom are~~ ]  
19 one representative<sup>1</sup> designated by New Jersey Cure Autism Now,  
20 <sup>1</sup>~~and two of whom are~~ one representative<sup>1</sup> designated by the  
21 National Alliance for Autism Research <sup>1</sup>~~;~~ two biomedical research  
22 scientists with demonstrated achievements in biomedical research  
23 relating to autism; and two medical clinicians whose practice is  
24 primarily devoted to the treatment of individuals with autism. ] one  
25 representative designated by the Center for Outreach and Services for  
26 the Autism Community, Inc., and one representative designated by the  
27 Autism Autoimmunity Project, Inc.<sup>1</sup>

28 b. The <sup>1</sup>~~commissioner~~president<sup>1</sup> or his designee shall serve as  
29 chairman of the council. Public members of the council shall serve for  
30 three-year terms <sup>1</sup>~~,~~ except that of the members first appointed, the  
31 four parent representatives shall be appointed for a term of three years,  
32 the two biomedical research scientists shall be appointed for a term of  
33 two years and the two medical clinicians shall be appointed for a term  
34 of one year<sup>1</sup>. Each member shall hold office for the term of  
35 appointment and until a successor is appointed and qualified. All  
36 vacancies shall be filled in the same manner as the original  
37 appointment. Members appointed to fill a vacancy occurring for any  
38 reason other than the expiration of the term shall serve for the  
39 unexpired term only. A public member of the council shall be eligible  
40 for reappointment.

41 c. Public members shall serve without compensation, but shall be  
42 reimbursed for necessary expenses incurred in the performance of their  
43 duties.

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

1 e. The council shall meet periodically at the call of the chairman,  
2 but not less than four times in the first year in which <sup>1</sup> ~~['a]~~the<sup>1</sup> center  
3 is established and not less than twice in each subsequent year.

4 f. The <sup>1</sup> ~~['commissioner]~~president<sup>1</sup> shall appoint a salaried  
5 administrator for the council and shall provide the council with  
6 additional administrative staff and support as may be necessary to  
7 enable the council to carry out its functions.

8  
9 5. a. The <sup>1</sup> ~~['Department of Health and Senior Services]~~ University  
10 of Medicine and Dentistry of New Jersey<sup>1</sup>, upon the recommendation  
11 of the council, shall make awards of grants and contracts to public and  
12 nonprofit private entities to pay all or part of the cost of planning,  
13 establishing, improving and providing basic operating support for  
14 <sup>1</sup> ~~['two Centers]~~ a Center<sup>1</sup> of Excellence for Autism in the State where  
15 basic and applied biomedical research, diagnosis and treatment for  
16 autism shall take place.

17 b. The council shall define the scope of the programs to be  
18 undertaken at <sup>1</sup> ~~['these centers]~~ the center<sup>1</sup> with the understanding that  
19 <sup>1</sup> ~~['each center]~~ the center<sup>1</sup> shall conduct:

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

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

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

32 c. <sup>1</sup> ~~['A]~~ The<sup>1</sup> center may carry out programs to make individuals  
33 in the State aware of opportunities to participate as subjects in  
34 research conducted by the <sup>1</sup> ~~['centers]~~ center<sup>1</sup>. The program may  
35 provide fees to these subjects. The program may, in accordance with  
36 guidelines established by the council, provide to these subjects health  
37 care, referrals for health and other services and such incidental services  
38 as will facilitate the participation of individuals as subjects.

39 d. <sup>1</sup> ~~['A]~~ The<sup>1</sup> center may provide stipends for health care  
40 professionals enrolled in training programs established under  
41 paragraph (2) of subsection b. of this section.

42 e. The council <sup>1</sup> ~~['shall, as appropriate, provide for the coordination~~  
43 ~~of information between centers and ensure regular communication~~  
44 ~~between centers, and]~~<sup>1</sup> may require the periodic preparation of reports  
45 on the activities of the <sup>1</sup> ~~['centers]~~ center<sup>1</sup> and the submission of the

1 reports to the council.

2 f. <sup>1</sup> ~~Each~~ The<sup>1</sup> center shall use the facilities of a single medical  
3 facility or higher education medical institution, or be formed from a  
4 consortium of cooperating facilities or institutions, and shall meet any  
5 requirements as may be prescribed by the council, with the  
6 understanding that the work carried out at <sup>1</sup> ~~each~~ the<sup>1</sup> center shall be  
7 comprehensive and fully collaborative.

8

9 6. The council shall:

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

13 b. <sup>1</sup> ~~Identify~~ Establish a five member Scientific Advisory  
14 Committee whose members shall serve at the pleasure of the council.  
15 The members of the committee shall include: three biomedical  
16 research scientists with demonstrated achievements in biomedical  
17 research relating to autism; and two medical clinicians whose practice  
18 is primarily devoted to the treatment of individuals with autism. The  
19 committee shall identify<sup>1</sup> and <sup>1</sup> ~~provide~~ make recommendations to  
20 the council regarding<sup>1</sup> grants for the most promising pilot studies for  
21 biomedical research, diagnosis and treatment for autism and autism  
22 spectrum disorders and establish the procedures for soliciting research  
23 proposals and applying for grants for pilot studies.

24 c. <sup>1</sup> Select the final grants for pilot studies based on  
25 recommendations of the Scientific Advisory Committee.

26 d.<sup>1</sup> Establish mechanisms to use the results of biomedical research  
27 on autism and autism spectrum disorders, conducted at the <sup>1</sup> ~~centers~~  
28 center<sup>1</sup> and through the pilot studies in the development of policies  
29 and programs to improve the outcomes of individuals in the State with  
30 these disorders.

31 <sup>1</sup> ~~d.~~ e.<sup>1</sup> Establish a mechanism for the sharing of information  
32 among researchers and clinicians in the State conducting biomedical  
33 research on autism and autism spectrum disorders.

34 <sup>1</sup> ~~e.~~ f.<sup>1</sup> Provide for a mechanism that would permit the public to  
35 obtain information on the existing and planned programs and activities  
36 being conducted through the <sup>1</sup> ~~centers~~ center<sup>1</sup> and the pilot studies,  
37 and the council to receive comments from the public regarding these  
38 programs and activities.

39

40 7. a. There is appropriated <sup>1</sup> to the Department of State<sup>1</sup>  
41 \$1,500,000 from the General Fund <sup>1</sup> for a grant<sup>1</sup> to the <sup>1</sup> ~~Department~~  
42 of Health and Senior Services University of Medicine and Dentistry  
43 of New Jersey<sup>1</sup> for <sup>1</sup> ~~allocation to~~<sup>1</sup> the <sup>1</sup> ~~council~~ Governor's  
44 Council for Medical Research and Treatment of Infantile Autism<sup>1</sup>.

45 b. Of the amount appropriated under subsection a. of this section,

1 the council shall make available: <sup>1</sup> ~~["\$300,000"]~~ \$600,000<sup>1</sup> to <sup>1</sup> ~~["each~~  
2 ~~center"]~~ the Center of Excellence for Autism<sup>1</sup> for the purpose of  
3 conducting basic and clinical research; <sup>1</sup> ~~["\$300,000"]~~ \$600,000<sup>1</sup> to  
4 <sup>1</sup> ~~["each"]~~ the<sup>1</sup> center for the purpose of providing the training,  
5 information and continuing education programs, the participant  
6 research and the stipends for health care professionals; \$200,000 for  
7 the purpose of carrying out the research pilot studies; \$50,000 for the  
8 council administrator's salary; and \$50,000 for carrying out the  
9 initiatives established under subsections a., <sup>1</sup> ~~["c., and"]~~<sup>1</sup> d. <sup>1</sup> and e.<sup>1</sup> of  
10 section 6 of this act.

11

12 8. Authorizations for appropriations under this act are in addition  
13 to any other authorization of appropriations that is available for the  
14 purposes of this act, and shall not supplant any existing or future  
15 funding from the State for the provision of housing, training, education  
16 and general support of individuals with autism and autism spectrum  
17 disorders.

18

19 9. This act shall take effect immediately.

20

21

22

23

24 "New Jersey Infantile Autism Biomedical Research Act;" appropriates  
25 \$1.5 million.



**SENATE, No. 1406**

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**STATE OF NEW JERSEY**  
**208th LEGISLATURE**

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INTRODUCED OCTOBER 15, 1998

**Sponsored by:**

**Senator C. LOUIS BASSANO**

**District 21 (Essex and Union)**

**Senator ROBERT W. SINGER**

**District 30 (Burlington, Monmouth and Ocean)**

**Co-Sponsored by:**

**Senators Rice and Vitale**

**SYNOPSIS**

"New Jersey Infantile Autism Biomedical Research Act;" appropriates \$1.5 million.

**CURRENT VERSION OF TEXT**

As introduced.



**(Sponsorship Updated As Of: 11/24/1998)**

1 AN ACT concerning autism, supplementing Title 26 of the Revised  
2 Statutes and making an appropriation.

3  
4 **BE IT ENACTED** by the Senate and General Assembly of the State  
5 of New Jersey:

6  
7 1. This act shall be known and may be cited as the "New Jersey  
8 Infantile Autism Biomedical Research Act."

9  
10 2. The Legislature finds and declares that:

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

18 b. With three quarters of those with infantile autism spending their  
19 adult lives in institutions or group homes, and usually entering  
20 institutions by the age of 13, the cost of caring for individuals with  
21 autism and autism spectrum disorder is great, and is estimated to be  
22 \$.5 billion per year in the State, solely for direct costs;

23 c. Best estimates indicate that one in 500 children born in the State  
24 will be diagnosed with an autism spectrum disorder and that 12,000  
25 individuals in the State have autism or an autism spectrum disorder,  
26 but these numbers may be understated because current diagnostic  
27 procedures lack accuracy and sensitivity for those with atypical  
28 symptoms and because there is a need for epidemiological data on  
29 incidence and prevalence of this disorder in the State;

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

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

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

7 g. Other states such as New York, Connecticut and Maryland have  
8 nationally recognized centers for researching and treating autism that  
9 attract significant funding from private sources and the National  
10 Institutes of Health, but since New Jersey lacks such centers, the State  
11 is unable to attract comparable funding, despite the presence of highly  
12 regarded medical facilities in the State such as Robert Wood Johnson  
13 University Hospital and Hackensack University Medical Center, as  
14 well as a higher education medical institution such as the University of  
15 Medicine and Dentistry of New Jersey;

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

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

25

26 3. As used in this act:

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

29 "Center" means a Center of Excellence for Autism established  
30 pursuant to this act.

31 "Commissioner" means the Commissioner of Health and Senior  
32 Services.

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

35

36 4. a. There is established in the Department of Health and Senior  
37 Services, the "Governor's Council for Medical Research and Treatment  
38 of Infantile Autism." The council shall be composed of 11 members  
39 as follows: the Commissioner of Health and Senior Services, or his  
40 designee, and the director of each center, who shall serve as ex officio  
41 members; and eight public members to be appointed by the  
42 commissioner as follows: four parent representatives, two of whom  
43 are designated by New Jersey Cure Autism Now, and two of whom are  
44 designated by the National Alliance for Autism Research; two  
45 biomedical research scientists with demonstrated achievements in  
46 biomedical research relating to autism; and two medical clinicians

1 whose practice is primarily devoted to the treatment of individuals  
2 with autism.

3 b. The commissioner or his designee shall serve as chairman of the  
4 council. Public members of the council shall serve for three-year  
5 terms, except that of the members first appointed, the four parent  
6 representatives shall be appointed for a term of three years, the two  
7 biomedical research scientists shall be appointed for a term of two  
8 years and the two medical clinicians shall be appointed for a term of  
9 one year. Each member shall hold office for the term of appointment  
10 and until a successor is appointed and qualified. All vacancies shall be  
11 filled in the same manner as the original appointment. Members  
12 appointed to fill a vacancy occurring for any reason other than the  
13 expiration of the term shall serve for the unexpired term only. A  
14 public member of the council shall be eligible for reappointment.

15 c. Public members shall serve without compensation, but shall be  
16 reimbursed for necessary expenses incurred in the performance of their  
17 duties.

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

20 e. The council shall meet periodically at the call of the chairman,  
21 but not less than four times in the first year in which a center is  
22 established and not less than twice in each subsequent year.

23 f. The commissioner shall appoint a salaried administrator for the  
24 council and shall provide the council with additional administrative  
25 staff and support as may be necessary to enable the council to carry  
26 out its functions.

27  
28 5. a. The Department of Health and Senior Services, upon the  
29 recommendation of the council, shall make awards of grants and  
30 contracts to public and nonprofit private entities to pay all or part of  
31 the cost of planning, establishing, improving and providing basic  
32 operating support for two Centers of Excellence for Autism in the  
33 State where basic and applied biomedical research, diagnosis and  
34 treatment for autism shall take place.

35 b. The council shall define the scope of the programs to be  
36 undertaken at these centers with the understanding that each center  
37 shall conduct:

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

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

46 (3) information and continuing educational programs on the latest

1 advances in biomedical research on autism for physicians and other  
2 health care and allied health care professionals who provide care for  
3 patients with autism in the State.

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

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

14 e. The council shall, as appropriate, provide for the coordination  
15 of information between centers and ensure regular communication  
16 between centers, and may require the periodic preparation of reports  
17 on the activities of the centers and the submission of the reports to the  
18 council.

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

25

26 6. The council shall:

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

30 b. Identify and provide grants for the most promising pilot studies  
31 for biomedical research, diagnosis and treatment for autism and autism  
32 spectrum disorders and establish the procedures for soliciting research  
33 proposals and applying for grants for pilot studies.

34 c. Establish mechanisms to use the results of biomedical research  
35 on autism and autism spectrum disorders, conducted at the centers and  
36 through the pilot studies in the development of policies and programs  
37 to improve the outcomes of individuals in the State with these  
38 disorders.

39 d. Establish a mechanism for the sharing of information among  
40 researchers and clinicians in the State conducting biomedical research  
41 on autism and autism spectrum disorders.

42 e. Provide for a mechanism that would permit the public to obtain  
43 information on the existing and planned programs and activities being  
44 conducted through the centers and the pilot studies, and the council to  
45 receive comments from the public regarding these programs and  
46 activities.

1 7. a. There is appropriated \$1,500,000 from the General Fund to  
2 the Department of Health and Senior Services for allocation to the  
3 council.

4 b. Of the amount appropriated under subsection a. of this section,  
5 the council shall make available: \$300,000 to each center for the  
6 purpose of conducting basic and clinical research; \$300,000 to each  
7 center for the purpose of providing the training, information and  
8 continuing education programs, the participant research and the  
9 stipends for health care professionals; \$200,000 for the purpose of  
10 carrying out the research pilot studies; \$50,000 for the council  
11 administrator's salary; and \$50,000 for carrying out the initiatives  
12 established under subsections a., c., and d. of section 6 of this act.

13  
14 8. Authorizations for appropriations under this act are in addition  
15 to any other authorization of appropriations that is available for the  
16 purposes of this act, and shall not supplant any existing or future  
17 funding from the State for the provision of housing, training, education  
18 and general support of individuals with autism and autism spectrum  
19 disorders.

20  
21 9. This act shall take effect immediately.  
22  
23

24 STATEMENT  
25

26 This bill establishes an 11-member "Governor's Council for Medical  
27 Research and Treatment of Infantile Autism" in the Department of  
28 Health and Senior Services, which shall make awards of grants and  
29 contracts to public and nonprofit private entities to pay all or part of  
30 the cost of planning, establishing, improving and providing basic  
31 operating support for two Centers of Excellence for Autism in the  
32 State. Basic and applied biomedical research, diagnosis, and treatment  
33 for autism shall be conducted at these centers.

34 The membership of the council shall be as follows: the  
35 Commissioner of Health and Senior Services, or his designee, and the  
36 director of each center, who shall serve as ex officio members; and  
37 eight public members to be appointed by the commissioner as follows:  
38 four parent representatives, two of whom are designed by New Jersey  
39 Cure Autism Now, and two of whom are designated by the National  
40 Alliance for Autism Research; two biomedical research scientists with  
41 demonstrated achievements in biomedical research relating to autism;  
42 and two medical clinicians whose practice is primarily devoted to the  
43 treatment of individuals with autism. The commissioner or his designee  
44 shall serve as chairman of the council.

45 Under the provision of the bill, the council shall make awards of  
46 grants and contracts to public and nonprofit private entities to pay all

1 or part of the cost of planning, establishing, improving and providing  
2 basic operating support for two Centers of Excellence for Autism in  
3 the State where basic and applied biomedical research, diagnosis, and  
4 treatment for autism shall take place. The council shall define the  
5 scope of the programs to be undertaken at these centers with the  
6 understanding that each center shall conduct:

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

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

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

19 In addition, a center may carry out programs to make individuals in  
20 the State aware of opportunities to participate as subjects in research  
21 conducted by the centers, may provide stipends for health care  
22 professionals enrolled in training programs and provide for the  
23 coordination of information between centers. Also, the council may  
24 require the periodic preparation of reports on the activities of the  
25 centers and the submission of the reports to the council.

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

32 With regard to research pilot studies, the council shall identify and  
33 provide grants for the most promising pilot studies for biomedical  
34 research, diagnosis and treatment of autism and autism spectrum  
35 disorders; and establish the procedures for soliciting research  
36 proposals and applying for grants for pilot studies. Also, the council  
37 shall provide for a mechanism that would permit the public to obtain  
38 information, and the council to receive the public's comments,  
39 regarding the existing and planned programs and activities being  
40 conducted through the centers and pilot studies.

41 Lastly, the bill appropriates \$1,500,000 from the General Fund to  
42 the Department of Health and Senior Services for allocation to the  
43 council. The bill specifies that, of this amount, the council shall make  
44 available: \$300,000 to each center for the purpose of conducting basic  
45 and clinical research; \$300,000 to each center for the purpose of  
46 providing the training, information and continuing education programs

**S1406 BASSANO, SINGER**

8

1 as well as the participant research and stipends for health care  
2 professionals; \$200,000 for the purpose of carrying out the research  
3 pilot studies; \$50,000 for the council administrator's salary; and  
4 \$50,000 for carrying out the program to provide information and  
5 education to families, to establish a mechanism to use the results of  
6 research in the development of policies and programs to improve the  
7 outcomes of individuals, and to establish a mechanism to share  
8 information among researchers and clinicians in the State.



# ASSEMBLY HEALTH COMMITTEE

## STATEMENT TO

[First Reprint]

**SENATE, No. 1406**

# STATE OF NEW JERSEY

DATED: JANUARY 21, 1999

The Assembly Health Committee reports favorably Senate Bill No. 1406 (1R).

This bill, which is designated the "New Jersey Infantile Autism Biomedical Research Act," establishes a seven-member "Governor's Council for Medical Research and Treatment of Infantile Autism" in the University of Medicine and Dentistry of New Jersey (UMDNJ). The council is to 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. Basic and applied biomedical research, diagnosis, and treatment for autism shall be conducted at the center.

The membership of the council shall consist of: the President of UMDNJ or his designee, the director of the center, and the director of one other treatment center at UMDNJ devoted to biomedical research on autism who is to be appointed by the President of UMDNJ, all of whom shall serve as ex officio members; and four public members from autism organizations in New Jersey, to be appointed as follows: one representative designated by New Jersey Cure Autism Now, one representative designated by the National Alliance for Autism Research, one representative designated by the Center for Outreach and Services for the Autism Community, Inc., and one representative designated by the Autism Autoimmunity Project, Inc. The President of UMDNJ or his designee shall serve as chairman of the council.

The bill provides that UMDNJ, upon recommendation of 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 the Center of Excellence for Autism. 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 of autism for physicians, scientists, and other 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 professionals who provide care for patients with autism in the State.

In addition, 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, and may provide stipends for health care professionals enrolled in the training programs. The council may require the periodic preparation of reports on the activities of the center and the submission of the reports to the council.

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.

The bill directs the council to establish a five-member Scientific Advisory Committee, including three biomedical research scientists with demonstrated achievements in autism-related biomedical research, and two medical clinicians whose practice is primarily devoted to the treatment of individuals with autism. Members of the committee are to serve at the pleasure of the council. The committee is to identify and make recommendations to the council regarding grants for the most promising pilot studies for biomedical research, diagnosis and treatment of autism and autism spectrum disorders; and establish the procedures for soliciting research proposals and applying for grants for pilot studies. The council is to select the grants for pilot studies based on the committee's recommendations. Also, the council shall provide for a mechanism that would permit the public to obtain information, and the council to receive the public's comments, regarding the existing and planned programs and activities being conducted through the centers and pilot studies.

The bill appropriates \$1,500,000 from the General Fund to the Department of State for the council. The bill specifies that, of this amount, the council shall make available: \$600,000 to the center for the purpose of conducting basic and clinical research; \$600,000 to the center for the purpose of providing the training, information and continuing education programs as well as the participant research and stipends for health care professionals; \$200,000 for the purpose of carrying out the research pilot studies; \$50,000 for the council administrator's salary; and \$50,000 for carrying out the program to provide information and education to families, to establish a

mechanism to use the results of research in the development of policies and programs to improve the outcomes of individuals, and to establish a mechanism to share information among researchers and clinicians in the State.

This bill is identical to Assembly Bill No. 2506 Aca (Felice/Doria), which the committee also reported on this date.

# ASSEMBLY APPROPRIATIONS COMMITTEE

## STATEMENT TO

[First Reprint]

**SENATE, No. 1406**

# STATE OF NEW JERSEY

DATED: MARCH 4, 1999

The Assembly Appropriations Committee reports favorably Senate Bill No. 1406 (1R).

Assembly Bill No. 1406 (1R), which is designated the "New Jersey Infantile Autism Biomedical Research Act," establishes a seven-member "Governor's Council for Medical Research and Treatment of Infantile Autism" in the University of Medicine and Dentistry of New Jersey (UMDNJ). The council is to 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. Basic and applied biomedical research, diagnosis, and treatment for autism shall be conducted at the center.

The council shall consist of: the President of UMDNJ or his designee, the director of the center, and the director of one other treatment center at UMDNJ devoted to biomedical research on autism appointed by the President of UMDNJ, all of whom shall serve as ex officio members; and four public members from autism organizations in the State, to be appointed as follows: one representative designated by New Jersey Cure Autism Now, one representative designated by the National Alliance for Autism Research, one representative designated by the Center for Outreach and Services for the Autism Community, Inc., and one representative designated by the Autism Autoimmunity Project, Inc. The President of UMDNJ or his designee shall serve as chairman of the council.

As reported by the committee, this bill is identical to Assembly Bill No. 2506 (1R), also reported on this date.

### FISCAL IMPACT:

The bill appropriates \$1,500,000 from the General Fund to the Department of State for the council. The bill specifies that, of this amount, the council shall make available: \$600,000 to the center for basic and clinical research; \$600,000 to the center for training, information and continuing education programs as well as the participant research and stipends for health care professionals;

\$200,000 for research pilot studies; \$50,000 for the council administrator's salary; and \$50,000 to provide information and education to families, to establish a mechanism in the development of policies and programs to improve the outcomes of individuals, and establish a mechanism to share information among researchers and clinicians in the State.

SENATE SENIOR CITIZENS, VETERANS' AFFAIRS AND  
HUMAN SERVICES COMMITTEE

STATEMENT TO

**SENATE, No. 1406**

**STATE OF NEW JERSEY**

DATED: OCTOBER 19, 1998

The Senate Senior Citizens, Veterans' Affairs and Human Services Committee reports favorably Senate Bill No. 1406.

This bill establishes an 11-member "Governor's Council for Medical Research and Treatment of Infantile Autism" in the Department of Health and Senior Services, which 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 two Centers of Excellence for Autism in the State. Basic and applied biomedical research, diagnosis, and treatment for autism shall be conducted at these centers.

The membership of the council shall be as follows: the Commissioner of Health and Senior Services, or his designee, and the director of each center, who shall serve as ex officio members; and eight public members to be appointed by the commissioner as follows: four parent representatives, two of whom are designated by New Jersey Cure Autism Now, and two of whom are designated by the National Alliance for Autism Research; two 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 commissioner or his designee shall serve as chairman of the council.

Under the provision of the bill, 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 two Centers of Excellence for Autism in the State where basic and applied biomedical research, diagnosis, and treatment for autism shall take place. The council shall define the scope of the programs to be undertaken at these centers with the understanding that each 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 of autism for physicians, scientists, and other 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 professionals who provide care for patients with autism in the State.

In addition, a center may carry out programs to make individuals in the State aware of opportunities to participate as subjects in research conducted by the centers, may provide stipends for health care professionals enrolled in training programs and provide for the coordination of information between centers. Also, the council may require the periodic preparation of reports on the activities of the centers and the submission of the reports to the council.

Each 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 each center shall be comprehensive and fully collaborative.

With regard to research pilot studies, the council shall identify and provide grants for the most promising pilot studies for biomedical research, diagnosis and treatment of autism and autism spectrum disorders; and establish the procedures for soliciting research proposals and applying for grants for pilot studies. Also, the council shall provide for a mechanism that would permit the public to obtain information, and the council to receive the public's comments, regarding the existing and planned programs and activities being conducted through the centers and pilot studies.

Lastly, the bill appropriates \$1,500,000 from the General Fund to the Department of Health and Senior Services for allocation to the council. The bill specifies that, of this amount, the council shall make available: \$300,000 to each center for the purpose of conducting basic and clinical research; \$300,000 to each center for the purpose of providing the training, information and continuing education programs as well as the participant research and stipends for health care professionals; \$200,000 for the purpose of carrying out the research pilot studies; \$50,000 for the council administrator's salary; and \$50,000 for carrying out the program to provide information and education to families, to establish a mechanism to use the results of research in the development of policies and programs to improve the outcomes of individuals, and to establish a mechanism to share information among researchers and clinicians in the State.

# SENATE BUDGET AND APPROPRIATIONS COMMITTEE

## STATEMENT TO

### **SENATE, No. 1406**

with committee amendments

# **STATE OF NEW JERSEY**

DATED: DECEMBER 10, 1998

The Senate Budget and Appropriations Committee reports favorably and with committee amendments Senate Bill No. 1406.

This bill, as amended, establishes a seven-member "Governor's Council for Medical Research and Treatment of Infantile Autism" in the University of Medicine and Dentistry of New Jersey (UMDNJ). The council is to 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. Basic and applied biomedical research, diagnosis, and treatment for autism shall be conducted at the center.

The membership of the council shall consist of: the President of UMDNJ or his designee, the director of the center, and the director of one other treatment center at UMDNJ devoted to biomedical research on autism who is to be appointed by the President of UMDNJ, all of whom shall serve as *ex officio* members; and four public members from autism organizations in New Jersey, to be appointed as follows: one representative designated by New Jersey Cure Autism Now, one representative designated by the National Alliance for Autism Research, one representative designated by the Center for Outreach and Services for the Autism Community, Inc., and one representative designated by the Autism Autoimmunity Project, Inc. The President of UMDNJ or his designee shall serve as chairman of the council.

The bill provides that UMDNJ, upon recommendation of 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 the Center of Excellence for Autism. 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 of autism for physicians, scientists, and other 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 professionals who provide care for patients with autism in the State.

In addition, 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, and may provide stipends for health care professionals enrolled in the training programs. The council may require the periodic preparation of reports on the activities of the center and the submission of the reports to the council.

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.

The bill directs the council to establish a five-member Scientific Advisory Committee, including three biomedical research scientists with demonstrated achievements in autism-related biomedical research, and two medical clinicians whose practice is primarily devoted to the treatment of individuals with autism. Members of the committee are to serve at the pleasure of the council. The committee is to identify and make recommendations to the council regarding grants for the most promising pilot studies for biomedical research, diagnosis and treatment of autism and autism spectrum disorders; and establish the procedures for soliciting research proposals and applying for grants for pilot studies. The council is to select the grants for pilot studies based on the committee's recommendations. Also, the council shall provide for a mechanism that would permit the public to obtain information, and the council to receive the public's comments, regarding the existing and planned programs and activities being conducted through the centers and pilot studies.

The bill appropriates \$1,500,000 from the General Fund to the Department of State for the council. The bill specifies that, of this amount, the council shall make available: \$600,000 to the center for the purpose of conducting basic and clinical research; \$600,000 to the center for the purpose of providing the training, information and continuing education programs as well as the participant research and stipends for health care professionals; \$200,000 for the purpose of carrying out the research pilot studies; \$50,000 for the council administrator's salary; and \$50,000 for carrying out the program to provide information and education to families, to establish a mechanism to use the results of research in the development of policies and programs to improve the outcomes of individuals, and to establish

a mechanism to share information among researchers and clinicians in the State.

**COMMITTEE AMENDMENTS:**

Amendments to the bill (1) remove the Governor's Council from the Department of Health and Senior Services (DHSS) and allocate it instead to UMDNJ, designating the President of the University rather than the Commissioner of DHSS as council chairman and revising the language of the appropriation provision in accordance with the change in allocation; (2) reduce the size of the council from 11 to seven members by eliminating from membership four public members with scientific or clinical backgrounds; (3) provide for designation of one each of the remaining public members by the Center for Outreach and Services and the Autism Autoimmunity Project; (4) reduce from two to one the number of centers for autism research, diagnosis and treatment to be established under the bill; and (5) establish the Scientific Advisory Committee to recommend pilot studies for grant funding by the council.

**FISCAL IMPACT:**

This bill appropriates from the General Fund to the Department of State for the Governor's Council for Medical Research and Treatment of Infantile Autism \$1.5 million to effectuate the purposes of the legislation.

# ASSEMBLY, No. 2506

## STATE OF NEW JERSEY 208th LEGISLATURE

INTRODUCED OCTOBER 5, 1998

**Sponsored by:**

**Assemblyman NICHOLAS R. FELICE**

**District 40 (Bergen and Passaic)**

**Assemblyman JOSEPH V. DORIA, JR.**

**District 31 (Hudson)**

**Co-Sponsored by:**

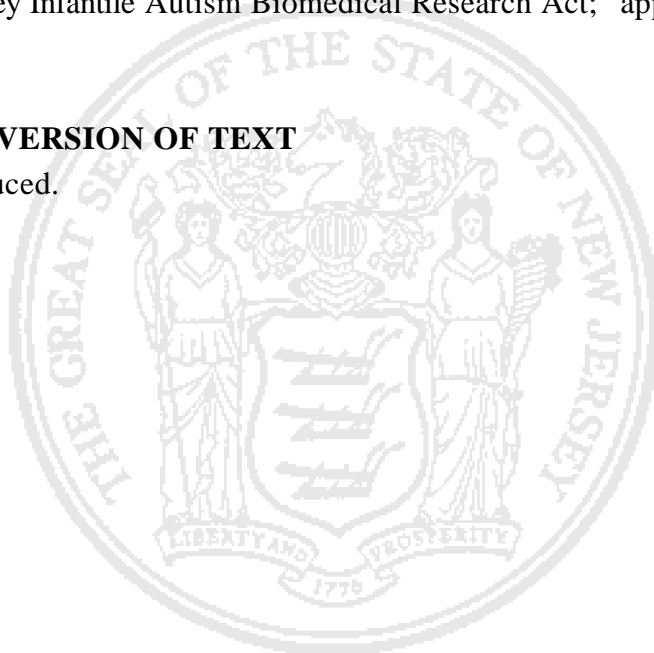
**Assemblymen LeFevre, Bagger, Barnes, Assemblywoman Buono,  
Assemblyman Greenwald, Assemblywoman Previte, Assemblymen  
Wisniewski, Cottrell, Holzapfel, Wolfe, Augustine, Conaway and  
Assemblywoman Weinberg**

**SYNOPSIS**

"New Jersey Infantile Autism Biomedical Research Act;" appropriates \$1.5 million.

**CURRENT VERSION OF TEXT**

As introduced.



**(Sponsorship Updated As Of: 1/22/1999)**

1 AN ACT concerning autism, supplementing Title 26 of the Revised  
2 Statutes and making an appropriation.

3  
4 **BE IT ENACTED** by the Senate and General Assembly of the State  
5 of New Jersey:

6  
7 1. This act shall be known and may be cited as the "New Jersey  
8 Infantile Autism Biomedical Research Act."

9  
10 2. The Legislature finds and declares that:

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

18 b. With three quarters of those with infantile autism spending their  
19 adult lives in institutions or group homes, and usually entering  
20 institutions by the age of 13, the cost of caring for individuals with  
21 autism and autism spectrum disorder is great, and is estimated to be  
22 \$.5 billion per year in the State, solely for direct costs;

23 c. Best estimates indicate that one in 500 children born in the State  
24 will be diagnosed with an autism spectrum disorder and that 12,000  
25 individuals in the State have autism or an autism spectrum disorder,  
26 but these numbers may be understated because current diagnostic  
27 procedures lack accuracy and sensitivity for those with atypical  
28 symptoms and because there is a need for epidemiological data on  
29 incidence and prevalence of this disorder in the State;

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

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

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

7 g. Other states such as New York, Connecticut and Maryland have  
8 nationally recognized centers for researching and treating autism that  
9 attract significant funding from private sources and the National  
10 Institutes of Health, but since New Jersey lacks such centers, the State  
11 is unable to attract comparable funding, despite the presence of highly  
12 regarded medical facilities in the State such as Robert Wood Johnson  
13 University Hospital and Hackensack University Medical Center, as  
14 well as a higher education medical institution such as the University of  
15 Medicine and Dentistry of New Jersey;

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

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

25  
26 3. As used in this act:

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

29 "Center" means a Center of Excellence for Autism established  
30 pursuant to this act.

31 "Commissioner" means the Commissioner of Health and Senior  
32 Services.

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

35  
36 4. a. There is established in the Department of Health and Senior  
37 Services, the "Governor's Council for Medical Research and Treatment  
38 of Infantile Autism." The council shall be composed of 11 members  
39 as follows: the Commissioner of Health and Senior Services, or his  
40 designee, and the director of each center, who shall serve as ex officio  
41 members; and eight public members to be appointed by the  
42 commissioner as follows: four parent representatives, two of whom  
43 are designed by New Jersey Cure Autism Now, and two of whom are  
44 designated by the National Alliance for Autism Research; two  
45 biomedical research scientists with demonstrated achievements in  
46 biomedical research relating to autism; and two medical clinicians

1 whose practice is primarily devoted to the treatment of individuals  
2 with autism.

3 b. The commissioner or his designee shall serve as chairman of the  
4 council. Public members of the council shall serve for three-year  
5 terms, except that of the members first appointed, the four parent  
6 representatives shall be appointed for a term of three years, the two  
7 biomedical research scientists shall be appointed for a term of two  
8 years and the two medical clinicians shall be appointed for a term of  
9 one year. Each member shall hold office for the term of appointment  
10 and until a successor is appointed and qualified. All vacancies shall be  
11 filled in the same manner as the original appointment. Members  
12 appointed to fill a vacancy occurring for any reason other than the  
13 expiration of the term shall serve for the unexpired term only. A  
14 public member of the council shall be eligible for reappointment.

15 c. Public members shall serve without compensation, but shall be  
16 reimbursed for necessary expenses incurred in the performance of their  
17 duties.

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

20 e. The council shall meet periodically at the call of the chairman,  
21 but not less than four times in the first year in which a center is  
22 established and not less than twice in each subsequent year.

23 f. The commissioner shall appoint a salaried administrator for the  
24 council and shall provide the council with additional administrative  
25 staff and support as may be necessary to enable the council to carry  
26 out its functions.

27  
28 5. a. The Department of Health and Senior Services, upon the  
29 recommendation of the council, shall make awards of grants and  
30 contracts to public and nonprofit private entities to pay all or part of  
31 the cost of planning, establishing, improving and providing basic  
32 operating support for two Centers of Excellence for Autism in the  
33 State where basic and applied biomedical research, diagnosis and  
34 treatment for autism shall take place.

35 b. The council shall define the scope of the programs to be  
36 undertaken at these centers with the understanding that each center  
37 shall conduct:

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

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

46 (3) information and continuing educational programs on the latest

1 advances in biomedical research on autism for physicians and other  
2 health care and allied health care professionals who provide care for  
3 patients with autism in the State.

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

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

14 e. The council shall, as appropriate, provide for the coordination  
15 of information between centers and ensure regular communication  
16 between centers, and may require the periodic preparation of reports  
17 on the activities of the centers and the submission of the reports to the  
18 council.

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

25

26 6. The council shall:

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

30 b. Identify and provide grants for the most promising pilot studies  
31 for biomedical research, diagnosis and treatment for autism and autism  
32 spectrum disorders and establish the procedures for soliciting research  
33 proposals and applying for grants for pilot studies.

34 c. Establish mechanisms to use the results of biomedical research  
35 on autism and autism spectrum disorders, conducted at the centers and  
36 through the pilot studies in the development of policies and programs  
37 to improve the outcomes of individuals in the State with these  
38 disorders.

39 d. Establish a mechanism for the sharing of information among  
40 researchers and clinicians in the State conducting biomedical research  
41 on autism and autism spectrum disorders.

42 e. Provide for a mechanism that would permit the public to obtain  
43 information on the existing and planned programs and activities being  
44 conducted through the centers and the pilot studies, and the council to  
45 receive comments from the public regarding these programs and  
46 activities.

1 7. a. There is appropriated \$1,500,000 from the General Fund to  
2 the Department of Health and Senior Services for allocation to the  
3 council.

4 b. Of the amount appropriated under subsection a. of this section,  
5 the council shall make available: \$300,000 to each center for the  
6 purpose of conducting basic and clinical research; \$300,000 to each  
7 center for the purpose of providing the training, information and  
8 continuing education programs, the participant research and the  
9 stipends for health care professionals; \$200,000 for the purpose of  
10 carrying out the research pilot studies; \$50,000 for the council  
11 administrator's salary; and \$50,000 for carrying out the initiatives  
12 established under subsections a., c., and d. of section 6 of this act.  
13

14 8. Authorizations for appropriations under this act are in addition  
15 to any other authorization of appropriations that is available for the  
16 purposes of this act, and shall not supplant any existing or future  
17 funding from the State for the provision of housing, training, education  
18 and general support of individuals with autism and autism spectrum  
19 disorders.  
20

21 9. This act shall take effect immediately.  
22  
23

24 STATEMENT  
25

26 This bill establishes an 11-member "Governor's Council for Medical  
27 Research and Treatment of Infantile Autism" in the Department of  
28 Health and Senior Services, which shall make awards of grants and  
29 contracts to public and nonprofit private entities to pay all or part of  
30 the cost of planning, establishing, improving and providing basic  
31 operating support for two Centers of Excellence for Autism in the  
32 State. Basic and applied biomedical research, diagnosis, and treatment  
33 for autism shall be conducted at these centers.

34 The membership of the council shall be as follows: the  
35 Commissioner of Health and Senior Services, or his designee, and the  
36 director of each center, who shall serve as ex officio members; and  
37 eight public members to be appointed by the commissioner as follows:  
38 four parent representatives, two of whom are designed by New Jersey  
39 Cure Autism Now, and two of whom are designated by the National  
40 Alliance for Autism Research; two biomedical research scientists with  
41 demonstrated achievements in biomedical research relating to autism;  
42 and two medical clinicians whose practice is primarily devoted to the  
43 treatment of individuals with autism. The commissioner or his designee  
44 shall serve as chairman of the council.

45 Under the provision of the bill, the council shall make awards of  
46 grants and contracts to public and nonprofit private entities to pay all



1 or part of the cost of planning, establishing, improving and providing  
2 basic operating support for two Centers of Excellence for Autism in  
3 the State where basic and applied biomedical research, diagnosis, and  
4 treatment for autism shall take place. The council shall define the  
5 scope of the programs to be undertaken at these centers with the  
6 understanding that each center shall conduct:

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

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

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

19 In addition, a center may carry out programs to make individuals in  
20 the State aware of opportunities to participate as subjects in research  
21 conducted by the centers, may provide stipends for health care  
22 professionals enrolled in training programs and provide for the  
23 coordination of information between centers. Also, the council may  
24 require the periodic preparation of reports on the activities of the  
25 centers and the submission of the reports to the council.

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

32 With regard to research pilot studies, the council shall identify and  
33 provide grants for the most promising pilot studies for biomedical  
34 research, diagnosis and treatment of autism and autism spectrum  
35 disorders; and establish the procedures for soliciting research  
36 proposals and applying for grants for pilot studies. Also, the council  
37 shall provide for a mechanism that would permit the public to obtain  
38 information, and the council to receive the public's comments,  
39 regarding the existing and planned programs and activities being  
40 conducted through the centers and pilot studies.

41 Lastly, the bill appropriates \$1,500,000 from the General Fund to  
42 the Department of Health and Senior Services for allocation to the  
43 council. The bill specifies that, of this amount, the council shall make  
44 available: \$300,000 to each center for the purpose of conducting basic  
45 and clinical research; \$300,000 to each center for the purpose of  
46 providing the training, information and continuing education programs

**A2506 FELICE, DORIA**

8

1 as well as the participant research and stipends for health care  
2 professionals; \$200,000 for the purpose of carrying out the research  
3 pilot studies; \$50,000 for the council administrator's salary; and  
4 \$50,000 for carrying out the program to provide information and  
5 education to families, to establish a mechanism to use the results of  
6 research in the development of policies and programs to improve the  
7 outcomes of individuals, and to establish a mechanism to share  
8 information among researchers and clinicians in the State.

# ASSEMBLY HEALTH COMMITTEE

## STATEMENT TO

### **ASSEMBLY, No. 2506**

with committee amendments

# **STATE OF NEW JERSEY**

DATED: JANUARY 21, 1999

The Assembly Health Committee reports favorably and with committee amendments Assembly Bill No. 2506.

As amended by the committee, this bill, which is designated the "New Jersey Infantile Autism Biomedical Research Act," establishes a seven-member "Governor's Council for Medical Research and Treatment of Infantile Autism" in the University of Medicine and Dentistry of New Jersey (UMDNJ). The council is to 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. Basic and applied biomedical research, diagnosis, and treatment for autism shall be conducted at the center.

The membership of the council shall consist of: the President of UMDNJ or his designee, the director of the center, and the director of one other treatment center at UMDNJ devoted to biomedical research on autism who is to be appointed by the President of UMDNJ, all of whom shall serve as ex officio members; and four public members from autism organizations in New Jersey, to be appointed as follows: one representative designated by New Jersey Cure Autism Now, one representative designated by the National Alliance for Autism Research, one representative designated by the Center for Outreach and Services for the Autism Community, Inc., and one representative designated by the Autism Autoimmunity Project, Inc. The President of UMDNJ or his designee shall serve as chairman of the council.

The bill provides that UMDNJ, upon recommendation of 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 the Center of Excellence for Autism. 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 of autism for physicians, scientists, and other 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 professionals who provide care for patients with autism in the State.

In addition, 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, and may provide stipends for health care professionals enrolled in the training programs. The council may require the periodic preparation of reports on the activities of the center and the submission of the reports to the council.

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.

The bill directs the council to establish a five-member Scientific Advisory Committee, including three biomedical research scientists with demonstrated achievements in autism-related biomedical research, and two medical clinicians whose practice is primarily devoted to the treatment of individuals with autism. Members of the committee are to serve at the pleasure of the council. The committee is to identify and make recommendations to the council regarding grants for the most promising pilot studies for biomedical research, diagnosis and treatment of autism and autism spectrum disorders; and establish the procedures for soliciting research proposals and applying for grants for pilot studies. The council is to select the grants for pilot studies based on the committee's recommendations. Also, the council shall provide for a mechanism that would permit the public to obtain information, and the council to receive the public's comments, regarding the existing and planned programs and activities being conducted through the centers and pilot studies.

The bill appropriates \$1,500,000 from the General Fund to the Department of State for the council. The bill specifies that, of this amount, the council shall make available: \$600,000 to the center for the purpose of conducting basic and clinical research; \$600,000 to the center for the purpose of providing the training, information and continuing education programs as well as the participant research and stipends for health care professionals; \$200,000 for the purpose of carrying out the research pilot studies; \$50,000 for the council administrator's salary; and \$50,000 for carrying out the program to provide information and education to families, to establish a

mechanism to use the results of research in the development of policies and programs to improve the outcomes of individuals, and to establish a mechanism to share information among researchers and clinicians in the State.

The committee amendments:

- remove the Governor's Council from the Department of Health and Senior Services (DHSS) and allocate it instead to UMDNJ, designating the President of UMDNJ rather than the Commissioner of DHSS as council chairman and revising the language of the appropriation provision in accordance with the change in allocation;
- reduce the size of the council from 11 to seven members by eliminating from membership four public members with scientific or clinical backgrounds;
- provide for the designation of one each of the remaining public members by the Center for Outreach and Services and the Autism Autoimmunity Project;
- reduce from two to one the number of centers for autism research, diagnosis and treatment to be established under the bill; and
- establish the Scientific Advisory Committee to recommend pilot studies for grant funding by the council.

As reported by the committee, this bill is identical to Senate Bill No. 1406 (1R) (Bassano/Singer), which the committee also reported on this date.

# ASSEMBLY APPROPRIATIONS COMMITTEE

## STATEMENT TO

[First Reprint]

**ASSEMBLY, No. 2506**

# STATE OF NEW JERSEY

DATED: MARCH 4, 1999

The Assembly Appropriations Committee reports favorably Assembly Bill No. 2506 (1R).

Assembly Bill No. 2506 (1R), which is designated the "New Jersey Infantile Autism Biomedical Research Act," establishes a seven-member "Governor's Council for Medical Research and Treatment of Infantile Autism" in the University of Medicine and Dentistry of New Jersey (UMDNJ). The council is to 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. Basic and applied biomedical research, diagnosis, and treatment for autism shall be conducted at the center.

The council shall consist of: the President of UMDNJ or his designee, the director of the center, and the director of one other treatment center at UMDNJ devoted to biomedical research on autism appointed by the President of UMDNJ, all of whom shall serve as ex officio members; and four public members from autism organizations in the State, to be appointed as follows: one representative designated by New Jersey Cure Autism Now, one representative designated by the National Alliance for Autism Research, one representative designated by the Center for Outreach and Services for the Autism Community, Inc., and one representative designated by the Autism Autoimmunity Project, Inc. The President of UMDNJ or his designee shall serve as chairman of the council.

As reported by the committee, this bill is identical to Senate Bill No. 1406 (1R), also reported on this date.

### FISCAL IMPACT:

The bill appropriates \$1,500,000 from the General Fund to the Department of State for the council. The bill specifies that, of this amount, the council shall make available: \$600,000 to the center for basic and clinical research; \$600,000 to the center for training, information and continuing education programs as well as the participant research and stipends for health care professionals;

\$200,000 for research pilot studies; \$50,000 for the council administrator's salary; and \$50,000 to provide information and education to families, to establish a mechanism in the development of policies and programs to improve the outcomes of individuals, and establish a mechanism to share information among researchers and clinicians in the State.

[First Reprint]

**ASSEMBLY, No. 2506**

**STATE OF NEW JERSEY**  
**208th LEGISLATURE**

INTRODUCED OCTOBER 5, 1998

**Sponsored by:**

**Assemblyman NICHOLAS R. FELICE**

**District 40 (Bergen and Passaic)**

**Assemblyman JOSEPH V. DORIA, JR.**

**District 31 (Hudson)**

**Co-Sponsored by:**

**Assemblymen LeFevre, Bagger, Barnes, Assemblywoman Buono, Assemblyman Greenwald, Assemblywoman Previte, Assemblymen Wisniewski, Cottrell, Holzapfel, Wolfe, Augustine, Conaway, Assemblywomen Weinberg, Crecco, Assemblyman Conners, Assemblywoman Quigley and Assemblyman Azzolina**

**SYNOPSIS**

"New Jersey Infantile Autism Biomedical Research Act;" appropriates \$1.5 million.

**CURRENT VERSION OF TEXT**

As reported by the Assembly Health Committee on January 21, 1999, with amendments.

(Sponsorship Updated As Of: 3/5/1999)



1 AN ACT concerning autism, supplementing Title <sup>1</sup>[26] 30<sup>1</sup> of the  
2 Revised Statutes and making an appropriation.

3  
4 **BE IT ENACTED** by the Senate and General Assembly of the State  
5 of New Jersey:

6  
7 1. This act shall be known and may be cited as the "New Jersey  
8 Infantile Autism Biomedical Research Act."

9  
10 2. The Legislature finds and declares that:

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

18 b. With three quarters of those with infantile autism spending their  
19 adult lives in institutions or group homes, and usually entering  
20 institutions by the age of 13, the cost of caring for individuals with  
21 autism and autism spectrum disorder is great, and is estimated to be  
22 \$.5 billion per year in the State, solely for direct costs;

23 c. Best estimates indicate that one in 500 children born in the State  
24 will be diagnosed with an autism spectrum disorder and that 12,000  
25 individuals in the State have autism or an autism spectrum disorder,  
26 but these numbers may be understated because current diagnostic  
27 procedures lack accuracy and sensitivity for those with atypical  
28 symptoms and because there is a need for epidemiological data on  
29 incidence and prevalence of this disorder in the State;

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

38 e. The lack of research was due to 40 years of neglect of autism by  
39 the scientific community, arising from the formerly widespread but  
40 now discredited belief that autism was an emotional disorder caused  
41 by faulty parenting, and thus, few dollars were allocated to

**EXPLANATION - Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and intended to be omitted in the law.**

**Matter underlined thus is new matter.**

**Matter enclosed in superscript numerals has been adopted as follows:**

**<sup>1</sup> Assembly AHL committee amendments adopted January 21, 1999.**

1 researchers, leaving an entire generation of children to be overlooked;  
2 however, the rapid advancements in biomedical science suggest that  
3 effective treatment and a cure for autism are attainable, if sufficient  
4 dollars are allocated to research so that another generation of children  
5 in the State is not lost to this disorder;

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

12 g. Other states such as New York, Connecticut and Maryland have  
13 nationally recognized centers for researching and treating autism that  
14 attract significant funding from private sources and the National  
15 Institutes of Health, but since New Jersey lacks such centers, the State  
16 is unable to attract comparable funding, despite the presence of highly  
17 regarded medical facilities in the State such as Robert Wood Johnson  
18 University Hospital and Hackensack University Medical Center, as  
19 well as a higher education medical institution such as the University of  
20 Medicine and Dentistry of New Jersey;

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

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

30

31 3. As used in this act:

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

34 "Center" means <sup>1</sup>[a]the<sup>1</sup> Center of Excellence for Autism  
35 established pursuant to this act.

36 <sup>1</sup>["Commissioner" means the Commissioner of Health and Senior  
37 Services.]<sup>1</sup>

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

40 <sup>1</sup>"President" means the President of the University of Medicine and  
41 Dentistry of New Jersey.<sup>1</sup>

42

43 4. a. There is established in the <sup>1</sup>[Department of Health and  
44 Senior Services] University of Medicine and Dentistry of New  
45 Jersey<sup>1</sup>, the "Governor's Council for Medical Research and Treatment  
46 of Infantile Autism." The council shall be composed of <sup>1</sup>[11] seven<sup>1</sup>

1 members as follows: the <sup>1</sup>~~Commissioner of Health and Senior~~  
2 ~~Services~~President of the University of Medicine and Dentistry of New  
3 Jersey<sup>1</sup>, or his designee, <sup>1</sup>~~and~~<sup>1</sup> the director of <sup>1</sup>~~each~~the<sup>1</sup> center,  
4 <sup>1</sup>~~who~~ and the director of one other treatment center at the  
5 University of Medicine and Dentistry of New Jersey that is devoted to  
6 biomedical research on autism, to be appointed by the president, all of  
7 whom<sup>1</sup> shall serve as ex officio members; and <sup>1</sup>~~eight~~four<sup>1</sup> public  
8 members <sup>1</sup>~~to be appointed by the commissioner~~ from autism  
9 organizations in New Jersey<sup>1</sup> as follows: <sup>1</sup>~~four parent representatives,~~  
10 ~~two of whom are designed~~ one representative designated<sup>1</sup> by New  
11 Jersey Cure Autism Now, <sup>1</sup>~~and two of whom are~~ one representative<sup>1</sup>  
12 designated by the National Alliance for Autism Research<sup>1</sup>; two  
13 biomedical research scientists with demonstrated achievements in  
14 biomedical research relating to autism; and two medical clinicians  
15 whose practice is primarily devoted to the treatment of individuals  
16 with autism.], one representative designated by the Center for  
17 Outreach and Services for the Autism Community, Inc., and one  
18 representative designated by the Autism Autoimmunity Project, Inc.<sup>1</sup>

19 b. The <sup>1</sup>~~commissioner~~president<sup>1</sup> or his designee shall serve as  
20 chairman of the council. Public members of the council shall serve for  
21 three-year terms<sup>1</sup>, except that of the members first appointed, the  
22 four parent representatives shall be appointed for a term of three years,  
23 the two biomedical research scientists shall be appointed for a term of  
24 two years and the two medical clinicians shall be appointed for a term  
25 of one year<sup>1</sup>. Each member shall hold office for the term of  
26 appointment and until a successor is appointed and qualified. All  
27 vacancies shall be filled in the same manner as the original  
28 appointment. Members appointed to fill a vacancy occurring for any  
29 reason other than the expiration of the term shall serve for the  
30 unexpired term only. A public member of the council shall be eligible  
31 for reappointment.

32 c. Public members shall serve without compensation, but shall be  
33 reimbursed for necessary expenses incurred in the performance of their  
34 duties.

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

37 e. The council shall meet periodically at the call of the chairman,  
38 but not less than four times in the first year in which <sup>1</sup>~~a~~the<sup>1</sup> center  
39 is established and not less than twice in each subsequent year.

40 f. The <sup>1</sup>~~commissioner~~president<sup>1</sup> shall appoint a salaried  
41 administrator for the council and shall provide the council with  
42 additional administrative staff and support as may be necessary to  
43 enable the council to carry out its functions.

44

45 5. a. The <sup>1</sup>~~Department of Health and Senior Services~~ University

1 of Medicine and Dentistry of New Jersey<sup>1</sup>, upon the recommendation  
2 of the council, shall make awards of grants and contracts to public and  
3 nonprofit private entities to pay all or part of the cost of planning,  
4 establishing, improving and providing basic operating support for  
5 <sup>1</sup>~~two Centers~~ a Center<sup>1</sup> of Excellence for Autism in the State where  
6 basic and applied biomedical research, diagnosis and treatment for  
7 autism shall take place.

8 b. The council shall define the scope of the programs to be  
9 undertaken at <sup>1</sup>~~these centers~~ the center<sup>1</sup> with the understanding that  
10 <sup>1</sup>~~each center~~ the center<sup>1</sup> shall conduct:

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

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

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

23 c. <sup>1</sup>~~A~~ The<sup>1</sup> center may carry out programs to make individuals  
24 in the State aware of opportunities to participate as subjects in  
25 research conducted by the <sup>1</sup>~~centers~~ center<sup>1</sup>. The program may  
26 provide fees to these subjects. The program may, in accordance with  
27 guidelines established by the council, provide to these subjects health  
28 care, referrals for health and other services and such incidental services  
29 as will facilitate the participation of individuals as subjects.

30 d. <sup>1</sup>~~A~~ The<sup>1</sup> center may provide stipends for health care  
31 professionals enrolled in training programs established under  
32 paragraph (2) of subsection b. of this section.

33 e. The council <sup>1</sup>~~shall, as appropriate, provide for the coordination~~  
34 ~~of information between centers and ensure regular communication~~  
35 ~~between centers, and]~~<sup>1</sup> may require the periodic preparation of reports  
36 on the activities of the <sup>1</sup>~~centers~~ center<sup>1</sup> and the submission of the  
37 reports to the council.

38 f. <sup>1</sup>~~Each~~ The<sup>1</sup> center shall use the facilities of a single medical  
39 facility or higher education medical institution, or be formed from a  
40 consortium of cooperating facilities or institutions, and shall meet any  
41 requirements as may be prescribed by the council, with the  
42 understanding that the work carried out at <sup>1</sup>~~each~~ the<sup>1</sup> center shall be  
43 comprehensive and fully collaborative.

1 6. The council shall:

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

5 b. <sup>1</sup>~~Identify~~ Establish a five member Scientific Advisory  
6 Committee whose members shall serve at the pleasure of the council.  
7 The members of the committee shall include: three biomedical  
8 research scientists with demonstrated achievements in biomedical  
9 research relating to autism; and two medical clinicians whose practice  
10 is primarily devoted to the treatment of individuals with autism. The  
11 committee shall identify<sup>1</sup> and <sup>1</sup>~~provide~~ make recommendations to  
12 the council regarding<sup>1</sup> grants for the most promising pilot studies for  
13 biomedical research, diagnosis and treatment for autism and autism  
14 spectrum disorders and establish the procedures for soliciting research  
15 proposals and applying for grants for pilot studies.

16 c. <sup>1</sup>Select the final grants for pilot studies based on  
17 recommendations of the Scientific Advisory Committee.

18 d.<sup>1</sup> Establish mechanisms to use the results of biomedical research  
19 on autism and autism spectrum disorders, conducted at the <sup>1</sup>~~centers~~  
20 center<sup>1</sup> and through the pilot studies in the development of policies  
21 and programs to improve the outcomes of individuals in the State with  
22 these disorders.

23 <sup>1</sup>~~d.~~ e.<sup>1</sup> Establish a mechanism for the sharing of information  
24 among researchers and clinicians in the State conducting biomedical  
25 research on autism and autism spectrum disorders.

26 <sup>1</sup>~~e.~~ f.<sup>1</sup> Provide for a mechanism that would permit the public to  
27 obtain information on the existing and planned programs and activities  
28 being conducted through the <sup>1</sup>~~centers~~ center<sup>1</sup> and the pilot studies,  
29 and the council to receive comments from the public regarding these  
30 programs and activities.

31

32 7. a. There is appropriated <sup>1</sup>to the Department of State<sup>1</sup>  
33 \$1,500,000 from the General Fund <sup>1</sup>for a grant<sup>1</sup> to the <sup>1</sup>~~Department~~  
34 of Health and Senior Services University of Medicine and Dentistry  
35 of New Jersey<sup>1</sup> for <sup>1</sup>~~allocation to~~<sup>1</sup> the <sup>1</sup>~~council~~ Governor's  
36 Council for Medical Research and Treatment of Infantile Autism<sup>1</sup>.

37 b. Of the amount appropriated under subsection a. of this section,  
38 the council shall make available: <sup>1</sup>~~[\$300,000]~~ \$600,000<sup>1</sup> to <sup>1</sup>~~each~~  
39 center the Center of Excellence for Autism<sup>1</sup> for the purpose of  
40 conducting basic and clinical research; <sup>1</sup>~~[\$300,000]~~ \$600,000<sup>1</sup> to  
41 <sup>1</sup>~~each~~ the<sup>1</sup> center for the purpose of providing the training,  
42 information and continuing education programs, the participant  
43 research and the stipends for health care professionals; \$200,000 for  
44 the purpose of carrying out the research pilot studies; \$50,000 for the  
45 council administrator's salary; and \$50,000 for carrying out the

1 initiatives established under subsections a., **1** **[c., and]** **1** d. **1** and e. **1** of  
2 section 6 of this act.

3

4 8. Authorizations for appropriations under this act are in addition  
5 to any other authorization of appropriations that is available for the  
6 purposes of this act, and shall not supplant any existing or future  
7 funding from the State for the provision of housing, training, education  
8 and general support of individuals with autism and autism spectrum  
9 disorders.

10

11 9. This act shall take effect immediately.

*Office of the Governor*  
**NEWS RELEASE**

PO BOX 004  
TRENTON, NJ 08625

CONTACT: Jayne O'Connor  
Gene Herman  
609-777-2600

RELEASE: May 11, 1999

**GOVERNOR SIGNS INFANTILE AUTISM RESEARCH ACT  
TO PROMOTE RESEARCH INTO AUTISM DIAGNOSIS AND TREATMENT**

Gov. Christie Whitman today signed into law the New Jersey Infantile Autism Biomedical Research Act, which will establish the Governor's Council for Medical Research and Treatment of Infantile Autism in the University of Medicine and Dentistry of New Jersey.

"The council will be comprised of experts devoted to autism research and includes four members designated by autism organizations with our state," the Governor said. "The council will work to establish New Jersey's own Center of Excellence for Autism. This center will be an important new resource not only for researchers, but for those with autism and their families and caregivers as well."

"Our Center of Excellence for Autism will fund research into the diagnosis and treatment of autism and also provide information to families and individuals coping with this disease," she said.

"Infantile autism is the third most common developmental disorder in children," Gov. Whitman said. "It is more prevalent than Down's syndrome, childhood cancer, or cystic fibrosis. In New Jersey alone, it is estimated that 12,000 people have autism or an autism spectrum disorder."

"Little biomedical research has been done on autism, despite that fact that scientists consider autism to be one of the developmental disorders most likely to benefit from the latest scientific advancements," the Governor said. "Today's legislation will help get that critical research under way."

Gov. Whitman said to ensure that the most promising studies are funded, the council will rely on a Scientific Advisory Committee made up of scientists with demonstrated achievement in autism-related research.

Under the legislation, the UMDNJ, upon recommendation of the Governor's Council for Medical Research and Treatment of Infantile Autism, will 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 the Center of Excellence for Autism where basic and applied biomedical research, diagnosis and treatment for autism will be

conducted.

The center will 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 meet any requirements as may be prescribed by the council.

The Governor's Council for Medical Research and Treatment of Infantile Autism will consist of the president of UMDNJ or his designee; the director of the center, and the director of one other treatment center at UMDNJ devoted to biomedical research on autism appointed by the president of UMDNJ. These three members will serve in an ex-officio capacity. The council will also include four public members from autism organizations in the state, to be appointed as follows: one representative designated by New Jersey Cure Autism Now, one representative designated by the National Alliance for Autism Research, one representative designated by the Center for Outreach and Services for the Autism Community, Inc., and one representative designated by the Autism Autoimmunity Project, Inc. The president of UMDNJ or his designee shall serve as chairman of the council.

The Scientific Advisory Committee, to be established by the council, will include three biomedical research scientists with demonstrated achievements in autism-related biomedical research and two medical clinicians whose practice is primarily devoted to the treatment of individuals with autism. The committee will identify and make recommendations to the council regarding grants for the most promising pilot studies for biomedical research, diagnosis and treatment of autism and autism spectrum disorders and establish the procedures for soliciting research proposals and applying for grants for pilot studies.

The council will also provide a mechanism that would permit the public to obtain information, and the council to receive the public's comments, regarding the existing and planned programs and activities being conducted through the centers and pilot studies.

The bill appropriates \$1.5 million from the General Fund to the Department of State for a grant to UMDNJ for the establishment of the council. Of this amount, the council will provide \$600,000 for the center for basic and clinical research; \$600,000 to the center for training, information and continuing education programs as well as the participant research and stipends for health care professionals; \$200,000 for research pilot studies; \$50,000 for the council administrator's salary and \$50,000 to provide information and education to families, to establish a mechanism in the development of policies and programs to improve the outcomes of individuals, and establish a mechanism to share information among researchers and clinicians in the state.

The bill, S-1406, was sponsored by Senators C. Louis Bassano (R-Essex/Union) and Robert W. Singer (R- Burlington/Monmouth/Ocean) and Assembly



Members Nicholas R. Felice (R-Bergen/Passaic) and Joseph V. Doria, Jr. (D-Hudson).