

## LEGISLATIVE HISTORY CHECKLIST

NJSA: 26: 2D-1

(Cystic fibrosis--  
provide  
nutritional &  
pharmaceutical  
assistance)

LAWS OF: 1989

CHAPTER: 270

Bill No: S133

Sponsor(s): Russo

Date Introduced: Pre-filed

Committee: Assembly: -----

Senate: Revenue, Finance & Appropriations; Institutions, Health &  
WelfareAmended during passage: Yes Senate Committee Substitute (1R)  
enacted

Date of Passage: Assembly: December 11, 1989

Senate: October 24, 1988

Date of Approval: January 8, 1990

## Following statements are attached if available:

Sponsor statement: Yes

Committee Statement: Assembly: Yes

Senate: Yes 9-29-88 &amp; 2-29-88

Fiscal Note: Yes

Veto Message: No

Message on signing: No

## Following were printed:

Reports: No

Hearings: No

SENATE COMMITTEE SUBSTITUTE FOR  
SENATE, No. 133 [1R]

STATE OF NEW JERSEY

ADOPTED SEPTEMBER 29, 1988

Sponsored by Senator RUSSO

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1 AN ACT concerning financial assistance for adults with cystic  
fibrosis, supplementing Title 26 of the Revised Statutes,  
3 repealing P.L.1981, c.289 and making an appropriation therefor.

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

7 1. The Legislature finds and declares that:

a. It is estimated that about 5% of the population carries the  
9 cystic fibrosis gene, which currently cannot be detected by any  
test, and that the number of persons born with cystic fibrosis who  
11 are living to adulthood is increasing;

b. The New Jersey State Organization of Cystic Fibrosis has  
13 identified at least 60 adults with cystic fibrosis living in New  
Jersey; however, there are estimates of as many as 150 to 200;

15 c. These adults, who are afflicted with a chronic hereditary  
disorder that affects the lungs and digestive system and causes  
17 difficulty in breathing and an inability to digest foods, have  
special needs for nutritional and pharmaceutical assistance that  
19 have not been met by previous or existing State programs which  
serve children with cystic fibrosis;

21 d. The program of medical care and treatment established  
pursuant to P.L.1981, c.289 (C.26:2-118), which provided  
23 pharmaceutical assistance to adults with cystic fibrosis became  
inoperative because of a lack of funding and was limited in its  
25 effectiveness because many potential service recipients were  
unaware of the program due to a lack of publicity;

27 e. The State should meet the special needs of adults with cystic  
fibrosis by helping them to purchase the supplemental foods that  
29 they need and the drugs and medical supplies and equipment that  
they require; and

31 f. A Statewide nutritional and pharmaceutical assistance  
program for adults with cystic fibrosis will enable these persons  
33 to stay in the workforce and continue to be productive members  
of the community.

1       2. The Commissioner of Health shall establish a program of  
2 financial assistance for persons with cystic fibrosis to meet the  
3 expenses of: supplemental, nutritious foods; prescription drugs  
4 and medical supplies and equipment that are necessary for the  
5 treatment of cystic fibrosis; and certain health insurance costs.

6       The commissioner shall contract with a nonprofit organization  
7 in New Jersey which has experience in providing financial  
8 assistance and direct services to persons with cystic fibrosis, to  
9 administer the program.

10       3. a. A person with cystic fibrosis is eligible for assistance  
11 under this act for the purchase of supplemental, nutritious foods  
12 and prescription drugs and medical supplies and equipment that  
13 are necessary for the treatment of cystic fibrosis, if the person is  
14 18 years of age or older and (1) the person's annual income is less  
15 than \$25,000; or (2) the person's annual income is \$25,000 or  
16 greater, but the person has incurred, within the last 12 months,  
17 prescription drug and medical supplies and equipment costs  
18 related to the treatment of cystic fibrosis, the total cost of  
19 which, when deducted from the person's income, reduces the  
20 person's income to under \$25,000.

21       b. A person with cystic fibrosis who is 18 years of age or older  
22 who has health insurance is eligible for financial assistance under  
23 this act of up to \$500 per year to help meet the cost of the  
24 deductible on the insurance policy. This financial assistance may  
25 be provided in addition to assistance for the purchase of  
26 supplemental, nutritious foods and pharmaceutical drugs and  
27 medical supplies and equipment and shall be provided without  
28 consideration of the person's annual income.

29       4. The Commissioner of Health, pursuant to the  
30 "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et  
31 seq.), shall adopt rules and regulations to effectuate the purposes  
32 of this act.

33       5. P.L.1981, c.289 (C.26:2-118) is repealed.

34       6. There is appropriated \$600,000 from the General Fund to the  
35 Department of Health to carry out the purposes of this act, of  
36 which sum no more than \$37,500 shall be used for administrative  
37 purposes.

      7. This act shall take effect immediately.

1

HEALTH

Handicapped

3

5

Provides financial assistance to persons with cystic fibrosis and appropriates \$600,000.

# SENATE, No. 133

## STATE OF NEW JERSEY

PRE-FILED FOR INTRODUCTION IN THE 1988 SESSION

By Senator RUSSO

2     **AN ACT** concerning nutritional and pharmaceutical assistance for  
adults with cystic fibrosis, amending P.L. 1975, c. 194,  
supplementing Titles 26 and 48 of the Revised Statutes,  
4     repealing P.L. 1981, c. 289, and making an appropriation  
therefor.

6  
8     **BE IT ENACTED** *by the Senate and General Assembly of the  
State of New Jersey:*

1. (New section) The Legislature finds and declares that:

10     a. It is estimated that about 5% of the population carry the  
cystic fibrosis gene, which currently cannot be detected by any  
12     test, and that the number of persons born with cystic fibrosis who  
are living to adulthood is increasing;

14     b. The Cystic Fibrosis Foundation and the New Jersey State  
Organization of Cystic Fibrosis have identified at least 60 adults  
16     with cystic fibrosis living in New Jersey; however, there are  
estimates of as many as 150 to 200;

18     c. These adults, who are afflicted with a chronic hereditary  
disorder that affects the lungs and digestive system and causes  
20     difficulty in breathing and an inability to digest foods, have  
**special needs** for nutritional and pharmaceutical assistance that  
22     **have not been met** by previous or existing State programs which  
served children with cystic fibrosis;

24     d. The program of medical care and treatment established  
pursuant to P.L. 1981, c. 289 (C. 26:2-118), which provided  
26     pharmaceutical assistance to adults with cystic fibrosis became  
inoperative because of a lack of funding and was limited in its  
28     effectiveness because many potential service recipients were  
unaware of the program due to a lack of publicity; and

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

Matter underlined thus is new matter.

2 e. The State should meet the special nutritional and  
pharmaceutical needs of adults with cystic fibrosis by helping  
4 them to purchase the additional foods that they need, over and  
above the nutritional requirements of the average person, in  
6 order to obtain their required daily intake of between 4,000 and  
6,000 calories, which can cost between \$40.00 and \$60.00 a  
8 person each week, and by helping them to purchase the drugs and  
medical equipment that they require, which can cost an average  
of between \$300.00 and \$500.00 a person each month.

10 2. (New section) The Commissioner of Health shall establish a  
program of nutritional assistance for persons with cystic fibrosis  
12 who are 18 years of age and over.

The program shall provide supplemental, nutritious foods, or  
14 assistance in the purchase of these foods, to those persons who  
are determined to be at special nutritional risk because of cystic  
16 fibrosis, according to standards established by the Commissioner  
of Health in consultation with the Cystic Fibrosis Foundation and  
18 the New Jersey State Organization of Cystic Fibrosis. A person  
who receives assistance under this program may be required to  
20 contribute towards the cost of the assistance based upon the  
person's income, according to a sliding fee scale to be developed  
22 by the Commissioner of Health.

The Commissioner of Health shall seek to ensure maximum  
24 publicity for the nutritional assistance program in order to serve  
as many eligible persons as possible, within the limits of funds  
26 made available for this program.

28 3. Section 2 of P.L. 1975, c. 194 (C. 30:4D-21) is amended to  
read as follows:

2. Any resident of this State who is either a recipient of  
30 disability insurance benefits under Title II of the federal Social  
Security Act (42 U.S.C. § 401 et seq.) or 65 years of age and over  
32 and whose annual income is less than \$13,650.00 if single or, if  
married, whose annual income combined with that of his spouse is  
34 less than \$16,750.00, or who is certified by a physician to have  
cystic fibrosis and is 18 years of age and over, shall be eligible  
36 for "Pharmaceutical Assistance to the Aged and Disabled" if he  
is not otherwise qualified for assistance under P.L. 1968, c. 413  
38 (C. 30:4D-1 et seq.).

(cf: P.L. 1987, c. 221, s. 1)

2 4. Section 3 of P.L. 1975, c. 194 (C. 30:4D-22) is amended to  
read as follows:

4 3. The program of "Pharmaceutical Assistance to the Aged and  
Disabled" shall consist of payments to pharmacies for the  
reasonable cost of prescription drugs of eligible persons which  
6 exceed a \$2.00 copayment. Said copayment shall be paid in full  
by each eligible person to the pharmacist at the time of each  
8 purchase of prescription drugs, and shall not be waived,  
discounted or rebated in whole or in part.

10 The commissioner may restrict the day supply of initial  
prescriptions to less than a 30 day supply in order to reduce waste  
and reduce inappropriate drug utilization. Subsequently, the  
12 commissioner may limit prescription drugs used in the treatment  
of acute care medical conditions to an amount not to exceed a 30  
14 day supply. The commissioner may allow up to a 60 day supply or  
16 100 unit doses, whichever is greater, of prescription drugs used in  
the treatment of chronic maintenance conditions.

18 Whenever any interchangeable drug product contained in the  
latest list approved and published by the Drug Utilization Review  
20 Council is available for the prescription written, an eligible  
person shall either:

22 (1) Purchase an interchangeable drug product which is equal to  
or less than the maximum allowable cost, at the \$2.00  
24 copayment; or

26 (2) Purchase the prescribed drug product which is higher in  
cost than the maximum allowable cost and pay the difference  
between the two, in addition to the \$2.00 copayment, unless the  
28 prescriber specifically indicates that substitution is not  
permissible, in which case an eligible person may purchase the  
30 prescribed drug product at the \$2.00 copayment.

For purposes of this act:

32 a. "Prescription drugs" means all legend drugs, including any  
interchangeable drug products contained in the latest list  
34 approved and published by the Drug Utilization Review Council in  
conformance with the provisions of the "Prescription Drug Price  
36 and Quality Stabilization Act" (P.L.1977, c. 240; C. 24:6E-1 et  
seq.), diabetic testing materials, medical equipment for use by a  
38 person with cystic fibrosis which is certified by a physician as  
being medically necessary for the treatment of the disorder for  
40 that person, and insulin, insulin syringes and insulin needles;

b. "Reasonable cost" means the maximum allowable cost of prescription drugs and a dispensing fee, as determined by the commissioner. In the case of diabetic testing materials or medical equipment for use by a person with cystic fibrosis, the maximum allowable cost is the manufacturer's suggested retail selling price or the pharmacy's usual over-the-counter price charged to other persons in the community, whichever is less;

c. "Resident" means one legally domiciled within the State for a period of 30 days immediately preceding the date of application for inclusion in the program. Mere seasonal or temporary residence within the State, of whatever duration, does not constitute domicile. Absence from this State for a period of 12 months is prima facie evidence of abandonment of domicile. The burden of establishing legal domicile within the State is upon the applicant;

d. "Diabetic testing materials" means blood glucose reagent strips which can be visually read, urine monitoring strips, tapes and tablets and bloodletting devices and lancets, but shall not include electronically monitored devices.

(cf: P.L. 1985, c. 291, s. 2)

5. (New section) Notwithstanding the provisions of P.L. 1979, c. 197 (C. 48:2-29.15 et seq.) or P.L. 1981, c. 210 (C. 48:2-29.30 et seq.) to the contrary, a person who is eligible for the program of pharmaceutical assistance to the aged and disabled established pursuant to P.L. 1975, c. 194 (C. 30:4D-20 et seq.) solely by virtue of being certified by a physician as having cystic fibrosis and who is not otherwise eligible for the Lifeline Credit Program established pursuant to P.L. 1979, c. 197 (C. 48:2-29.15 et seq.) or the Tenants' Lifeline Assistance Program established pursuant to P.L. 1981, c. 210 (C. 48:2-29.30 et seq.), shall not be entitled to receive benefits under the Lifeline Credit Program or the Tenants' Lifeline Assistance Program.

6. The Commissioner of Health, pursuant to the "Administrative Procedure Act," P.L. 1968, c. 410 (C. 52:14B-1 et seq.), shall adopt rules and regulations to effectuate the purposes of section 2 of this act.

7. P.L. 1981, c. 289 (C. 26:2-118) is repealed.

8. There is appropriated \$100,000.00 from the General Fund to the Department of Health to carry out the provisions of section 2 of this act.



9. This act shall take effect on the 90th day after enactment.

2

#### STATEMENT

4

6 This bill establishes a nutritional assistance program in the  
Department of Health for persons 18 years of age and older who  
8 have cystic fibrosis and provides an appropriation of \$100,000 to  
implement the program. The bill also makes these persons eligible  
for the Pharmaceutical Assistance to the Aged and Disabled  
10 (PAAD) Program established pursuant to P.L. 1975, c. 194 (C.  
30:4D-20 et seq.).

12 This bill is intended to meet the special needs of the growing  
number of persons with cystic fibrosis living to adulthood, who  
14 must incur substantial expenditures in order to meet their dietary  
requirements and to obtain the drugs and medical equipment that  
16 they need to survive. The assistance provided in this bill will  
enable these persons to stay in the workforce and continue to be  
18 productive members of the community.

The bill repeals P.L. 1981, c. 289 (C. 26:2-118), since the  
20 program of pharmaceutical assistance for adults with cystic  
fibrosis which was established by the Department of Health  
22 pursuant to that act has been defunct for several years, and  
would, in any event, be obviated by the expansion of the PAAD  
24 program under this bill to include adults with cystic fibrosis.

26

#### HEALTH

##### Handicapped

28

Provides nutritional and pharmaceutical assistance to persons  
30 with cystic fibrosis and appropriates \$100,000.

SENATE REVENUE, FINANCE AND APPROPRIATIONS  
COMMITTEE

STATEMENT TO

SENATE COMMITTEE SUBSTITUTE FOR

**SENATE, No. 133 [1R]**

**STATE OF NEW JERSEY**

DATED: SEPTEMBER 29, 1988

The Senate Revenue, Finance and Appropriations Committee reported Senate Committee Substitute for Senate Bill No. 133 [1R] favorably.

Senate Committee Substitute for Senate Bill No. 133 [1R] establishes a financial assistance program in the Department of Health for persons with cystic fibrosis and appropriates \$600,000 to the department to fund the program for the remainder of the fiscal year.

Financial assistance shall be available under this program to meet the expenses of: supplemental, nutritious foods; prescription drugs and medical supplies and equipment necessary for the treatment of cystic fibrosis; and certain health insurance costs.

The substitute provides that a person with cystic fibrosis is eligible for assistance if the person is 18 years of age or older and (1) the person's annual income is less than \$25,000; or (2) the person's annual income is \$25,000 or greater, but the person has incurred, within the last 12 months, costs related to the treatment of cystic fibrosis which effectively reduce the person's income to under \$25,000.

The substitute further provides that a person with cystic fibrosis who is 18 years of age or older who has health insurance is eligible for additional financial assistance under this act of up to \$500 per year to help meet the cost of the deductible on the insurance policy, regardless of the person's annual income.

The substitute requires the Commissioner of Health to contract with a nonprofit organization in this State which has experience in providing financial assistance and direct services to persons with cystic fibrosis, to administer the program.

The substitute also repeals P.L.1981, c.289 (C.26:2-118), which established a program of pharmaceutical assistance for adults with cystic fibrosis. That act is not in operation due to a lack of funding.

This substitute is identical to Assembly Bill No. 1635 (ACS 1R).

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COMMITTEE SUBSTITUTE

The bill, as received by the Committee, appropriated \$100,000 to the Department of Health for a nutrition program for persons with cystic fibrosis. The bill also appropriated \$1,000,000 to the Department of Human Services for the costs associated with having persons with cystic fibrosis become eligible for Pharmaceutical Assistance to the Aged and Disabled (PAAD).

The Committee Substitute appropriates \$600,000 to the Department of Health to establish a financial assistance program for the remaining months of the fiscal year for persons with cystic fibrosis.

FISCAL IMPACT

This substitute appropriates \$600,000 from the General Fund to the Department of Health to provide financial assistance to persons with cystic fibrosis. No more than \$37,500 of the appropriation may be used for administrative purposes.

SENATE INSTITUTIONS, HEALTH AND WELFARE COMMITTEE

STATEMENT TO

SENATE, No. 133

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with Senate committee amendments

STATE OF NEW JERSEY

DATED: FEBRUARY 29, 1988

The Senate Institutions, Health and Welfare Committee favorably reports Senate Bill No. 133 with committee amendments.

As amended by committee, this bill provides for nutritional and pharmaceutical assistance for adults with cystic fibrosis. Specifically, the bill establishes a nutritional assistance program in the Department of Health for persons 18 years of age and older who have cystic fibrosis. The bill provides an appropriation of \$100,000 to the Department of Health for the nutrition program. The bill also makes these persons eligible for the Pharmaceutical Assistance to the Aged and Disabled (PAAD) program and provides, in the PAAD program, for the coverage of medical supplies and equipment (as well as prescription drugs) that a physician has certified as being medically necessary for the treatment of cystic fibrosis. The bill appropriates \$1,000,000 to the Department of Human Services for the expansion of the PAAD program.

The bill repeals P.L. 1981, c. 289 (C. 26:2-118), since the program of pharmaceutical assistance for adults with cystic fibrosis which was established by the Department of Health pursuant to that act has been defunct for several years, and would, in any event, be obviated by the expansion of the PAAD program to include adults with cystic fibrosis, as provided in this bill.

This bill is intended to meet the special needs of the growing number of persons with cystic fibrosis living to adulthood, who must incur substantial expenditures in order to meet their dietary requirements and to obtain the drugs and medical equipment that they need to survive. The assistance provided in this bill will enable these persons to stay in the workforce and continue to be productive members of the community.

The committee amended the bill to add an appropriation of \$1,000,000 to the Department of Human Services for the added costs to the PAAD program. Other amendments clarify that medical supplies, as well as equipment, would be covered under the PAAD program for persons with cystic fibrosis and conform the determination of "maximum allowable cost" for medical supplies and equipment with the procedures used by the State Medicaid program. Finally, the amendments clarify that a person who is eligible for PAAD solely on the basis of having cystic fibrosis (who does not meet the income eligibility limits of the PAAD program), shall not receive benefits under any other program of assistance to which a person may be entitled based on eligibility for PAAD.

LEGISLATIVE FISCAL ESTIMATE TO

[FIRST REPRINT]

SENATE, No. 133

STATE OF NEW JERSEY

DATED: October 5, 1988

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Senate Bill No. 133 (1R) establishes a nutritional and pharmaceutical assistance program for persons with cystic fibrosis who are 18 years of age and older. The bill appropriates \$100,000 to the Department of Health to carry out the program of nutritional assistance and \$1,000,000 to the Department of Human Services to implement the drugs/medical supplies/equipment program.

The Department of Health and the Office of Management and Budget (OMB) have estimated the cost of the nutritional program at \$100,000, \$200,000 and \$400,000, in each of the next three fiscal years, respectively. The Department of Human Services has not submitted information concerning the drugs/medical supplies/equipment provisions of the bill.

The findings and declaration section of the bill indicates that the New Jersey State Organization of Cystic Fibrosis has identified at least 60 adults with cystic fibrosis and that there may be 200 such adults. The organization has now identified 85 persons over age 18. Assuming that it costs between \$40.00 and \$60.00 per week to meet the "special" nutritional requirements of adults with cystic fibrosis the annual cost of meeting the special nutritional requirements is \$221,000, though assuming a gradual phase-in during the first year, the \$100,000 estimate for the first year is reasonable.

The \$1,000,000 appropriation to the Department of Human Services appears excessive in the absence of any data by the department in support of the appropriation. Though the bill extends eligibility to the Pharmaceutical Assistance to the Aged and Disabled (PAAD) to any person 18 years of age and over "who is certified by a physician to have cystic fibrosis," persons with "cystic fibrosis" may already qualify for Social Security disability benefits. Social Security disability data indicate that persons with the ICD code for cystic fibrosis (270) receive disability benefits. Even if persons with cystic fibrosis do not receive PAAD benefits, the cost to support the 85 persons with cystic fibrosis would approximate \$408,000 (85 x \$400 average cost of drugs/medical supplies/equipment per month x 12 months). Thus, total first year costs for both the nutritional and the pharmaceutical programs may be \$600,000 as opposed to the legislation's \$1,100,000 appropriation.

This legislative fiscal estimate has been produced by the Office of Legislative Services due to the failure of the Executive Branch to respond to our request for a fiscal note.

This fiscal estimate has been prepared pursuant to P.L. 1980, c.67.