

SENATE HEALTH COMMITTEE

STATEMENT TO

SENATE, No. 1585

with committee amendments

STATE OF NEW JERSEY

DATED: MARCH 15, 1999

The Senate Health Committee reports favorably and with committee amendments Senate Bill No. 1585.

As amended by committee, this bill, designated the "Spinal Cord Research Act," establishes a New Jersey Commission on Spinal Cord Research. The commission's responsibility would be to design and administer a grant program to fund approved medical and scientific research projects that focus on the treatment of spinal cord injuries and diseases that damage the spinal cord.

The moneys for these grants would be generated by a \$1 surcharge on all motor vehicle fines. These moneys are to be deposited in a special nonlapsing fund, known as the "New Jersey Spinal Cord Research Fund."

The commission will consist of 11 members, including the Commissioner of Health and Senior Services, or his designee, as an ex officio member. The other 10 members shall include: one representative of the University of Medicine and Dentistry of New Jersey; one representative of Rutgers, The State University; one representative of a federally designated Spinal Cord Injury Model System; one representative from the American Paralysis Association; and six public members who are residents of the State knowledgeable about spinal cord injuries and who include at least one physician licensed in this State and at least one person with a spinal cord injury. The members shall be appointed by the Governor with the advice and consent of the Senate.

The commission is directed to:

- a. Review and authorize approved research projects, for which purpose the commission may establish an independent scientific advisory panel composed of scientists and clinicians who are not members of the commission to review proposals submitted to the commission and make funding recommendations to the commission;
- b. Apportion all available funds to qualifying research institutions to finance approved research projects and necessary institutional support services;
- c. Ensure that funds so apportioned to approved research projects

are not diverted to any other use;

d. Take steps necessary to encourage the development within the State of spinal cord research projects;

e. Compile a directory of all spinal cord research projects being conducted in the State; and

f. Provide the Governor and the Legislature with a report by January 30 of each year describing the status of the commission's activities and the results of its funded research efforts.

In addition, the commission is directed to establish and maintain, in conjunction with the Department of Health and Senior Services, a central registry of persons who sustain spinal cord injuries other than through disease, whether or not the injury results in a permanent disability, in order to provide a database that indicates the incidence and prevalence of spinal cord injuries and which will serve as a resource for research, evaluation and information on spinal cord injuries and available services.

The bill requires that health care facilities and health care providers report all cases of spinal cord injuries, except those caused through disease, and submit specified additional information on reported cases, to the commission. The commission shall, by regulation, specify the health care facilities and providers required to make the report, information that shall be included in the report, the method for making the report and the time period in which the report shall be made.

The reports made to the registry are to be used only by the commission and the Department of Health and Senior Services and such other agencies as may be designated by the commission or the department and shall not otherwise be divulged or made public so as to disclose the identity of any person to whom they relate. To ensure that the required reports are made to the commission, the bill establishes a penalty of up to \$100 per unreported spinal cord injury case.

Finally, the bill specifies that its provisions shall not preclude a qualifying research institution or any other research facility in the State from directly applying for or receiving funds from any public or private agency to conduct spinal cord research.

The committee amended the bill to include in the definition of "qualifying research institution" the Coriell Institute for Medical Research and to delete the requirement that a qualifying research institution be a nonprofit institution. Other amendments revise the composition of the New Jersey Commission on Spinal Cord Research to delete the Commissioner of Human Services and add one additional public member who will be appointed by the Governor with the advice and consent of the Senate. Other amendments update the provisions of R.S.39:5-41 to reflect changes made in the law pursuant to P.L.1998, c.149.

As amended, this bill is identical to the Senate Committee Substitute for Assembly Bill No. 2419(2R) (Felice/Impoveduto) which the committee also reported on this date.