

# SENATE HEALTH, HUMAN SERVICES AND SENIOR CITIZENS COMMITTEE

## STATEMENT TO

### **SENATE, No. 2682**

with committee amendments

# STATE OF NEW JERSEY

DATED: FEBRUARY 9, 2021

The Senate Health, Human Services and Senior Citizens Committee reports favorably and with committee amendments Senate Bill No. 2682.

As amended by the committee, this bill establishes a 20-member New Jersey Rare Disease Advisory Council in the Department of Health.

The purpose of the advisory council will be to: act as the advisory body on rare diseases to the Legislature and State departments, agencies, commissions, authorities, and private agencies that provide services to, or are charged with the care of, persons with rare diseases; conduct a thorough and comprehensive study of all issues relating to the quality of and access to treatment and services provided to persons with rare diseases in this State, including the link between rare diseases and the COVID-19 pandemic, and to develop policy recommendations on those issues; establish and implement a repository of best practice standards to share with health care providers that will ensure they are adequately informed of the most effective strategies for recognizing and treating rare diseases in New Jersey; identify effective research-based strategies that have been developed to help diagnose, treat, and prevent rare diseases; develop effective strategies to raise public awareness of rare diseases in this State; evaluate and make recommendations to improve the State's Newborn Screening Program in the Department of Health and State Medicaid coverage for approved treatments and medications for patients with a rare disease; research and make policy recommendations to the Legislature on access to health insurance specialists and other needed services for patients with a rare disease; and identify, with assistance from the public, additional research topics on rare disease to inform future studies the council may conduct.

Finally, the bill requires the advisory council to report biennially, to the Governor and the Legislature, on its findings and recommendations on issues relating to the quality of, and access to, treatment and services provided to persons with rare diseases in this State.

COMMITTEE AMENDMENTS:

The committee amendments reduce the advisory council's membership to 20 members. Under the current provisions of the bill, the council is comprised of 30 members.

The committee amendments also reduce the number of public members on the advisory council from 20 members, as originally provided in the bill, to 12 members, and provide that the council organize as soon as practicable after the appointment of a majority of its public members.

The committee amended the bill to provide that the Department of Health is to maintain oversight of the advisory council and may delegate the council's administration to a State research university or institution as provided for in the bill.

The committee amended the bill to allow the department to issue a request for proposals for a location for the council to operate and for staff and resources to support operations. The department is to provide staff services to the council if the proposals submitted to the department are insufficient.

The committee amendments remove the requirement for the advisory council to study cost-effectiveness of treatment and services provided to persons with rare diseases in this State.

The committee amendments also make various technical and grammatical changes to the provisions of the bill.