

ASSEMBLY HEALTH COMMITTEE

STATEMENT TO

ASSEMBLY, No. 4016

with committee amendments

STATE OF NEW JERSEY

DATED: JANUARY 13, 2021

The Assembly Health Committee reports favorably and with committee amendments Assembly Bill No. 4016.

As amended and reported, this bill establishes a 20-member New Jersey Rare Disease Advisory Council in the Department of Health to advise the Legislature, State departments, agencies, commissions, and authorities, and private agencies providing services for persons diagnosed with a rare disease.

The membership of the advisory council will consist of 20 members as provided for in the bill. 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 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 amendments:

- 1) make technical changes;
- 2) remove the requirement for the advisory council to study cost-effectiveness;
- 3) provide that the Department of Health (department) is to maintain oversight of the advisory council (council) and may delegate the administration thereof to a State research university or institution as provided for in the bill. The department may 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;
- 4) provide that the council organize as soon as practicable after the appointment of a majority of its public members; and
- 5) reduce the council's membership from 30 to 20 members as provided for in the bill.