

ASSEMBLY HEALTH COMMITTEE

STATEMENT TO

ASSEMBLY, No. 1878

STATE OF NEW JERSEY

DATED: DECEMBER 16, 2024

The Assembly Health Committee reports favorably Assembly Bill No. 1878.

This bill makes a supplemental appropriation of \$500,000 to Division of Community Health in the Department of Health (DOH) for the Huntington's Disease Grant Program. The amount appropriated under the bill, in addition to any other State or federal funds allocated for the same purposes, is to be allocated to support grants to institutions of higher education, non-profit organizations, or New Jersey based and operated research organizations for the provision of pre-symptomatic testing, neurology and psychiatry services, neurophysiological evaluations, treatment, disease management, and counseling for people living with or at risk for Huntington's disease. According to the department's Notice of Fund Availability, the Huntington's Disease Grant Program is currently estimated to distribute \$ 201,000 in FY 2025. This supplemental appropriation would increase that amount to \$ 701,000.

Huntington's disease is a fatal rare, inherited disease that causes the progressive breakdown of nerve cells in the brain. It deteriorates a person's physical and mental abilities during their prime working years and has no cure. Huntington's disease has a wide impact on a person's functional abilities and usually results in movement, cognitive, and psychiatric disorders. Many describe the symptoms as similar to having amyotrophic lateral sclerosis (Lou Gehrig's disease), Parkinson's disease, and Alzheimer's disease simultaneously. According to the DOH, there are approximately 900 to 1,200 New Jersey residents who are living with Huntington's disease. The incidence of the disease is estimated between 1 in 8,000 and 1 in 10,000 State residents. There are also about 7,000 at-risk individuals in New Jersey. But since this is a fatal disease, this number may be low since the majority of people who go through genetic counseling decide to not get tested.

This bill was pre-filed for introduction in the 2024-2025 session pending technical review. As reported, the bill includes the changes required by technical review, which has been performed.