



General Assembly

January Session, 2025

Proposed Bill No. 802

LCO No. 2322



Referred to Committee on HUMAN SERVICES

Introduced by:

SEN. COHEN, 12th Dist.

REP. RADER, 98th Dist.

**AN ACT CONCERNING A COMPASSIONATE MEDICAID WAIVER
PROGRAM FOR CHILDREN WITH RARE, PROGRESSIVE OR
NEURODEGENERATIVE DISORDERS.**

Be it enacted by the Senate and House of Representatives in General
Assembly convened:

- 1 That title 17b of the general statutes be amended to require the
- 2 Commissioner of Social Services to seek federal approval for a Medicaid
- 3 waiver program under Section 1915(c) of the Social Security Act to
- 4 provide critical services and supports for up to fifty children from birth
- 5 to age eighteen who are diagnosed with rare, progressive or
- 6 neurodegenerative disorders that are often fatal within three years of
- 7 diagnosis.

Statement of Purpose:

To address the urgent needs of the state's critically ill children with rare disorders often leading to a limited life span and ensure equitable access to life-sustaining services and support for families navigating the challenges of such diagnoses.