SENATE APPROPRIATIONS COMMITTEE FISCAL NOTE

BILL NO. Senate Bill 983 PRINTER NO. 2000

AMOUNT

No Fiscal Impact General Fund

DATE INTRODUCED PRIME SPONSOR

January 15, 2020 Senator DiSanto

DESCRIPTION AND PURPOSE OF BILL

Senate Bill 983 amends the Newborn Child Testing Act to provide for comprehensive newborn screening and follow-up services for every recommended disorder by two separate mandatory panels. The Department of Health shall be responsible for the first panel of 10 disorders as required under current law. Birthing facilities and healthcare practitioners shall be required to order screening tests for the 24 disorders previously included on the supplemental (optional) panel.

The bill defines "birthing facilities" to mean an inpatient or ambulatory health care facility licensed by the department that provides birthing and newborn care services. The legislation redefines "board" to mean the Newborn Screening and Follow-up Technical Advisory Board.

The bill directs the Department of Health (department) to establish a program of follow-up services which include case management, referrals, confirmatory testing, assessment and diagnosis of newborn children with abnormal, inconclusive or unacceptable screening results up to a child's first year of life.

The bill requires the department with the approval of the Newborn Screening and Follow-up Technical Advisory Board to transmit notice to the Legislative Reference Bureau for publication in the Pennsylvania Bulletin changes of disorders screened on either mandatory list. Prior to making any changes, the board and department will publish a notice in the Pennsylvania Bulletin establishing a public comment period of at least 30 days.

The bill defines the advisory board as a multi-disciplinary committee consisting of members appointed by the secretary. At a minimum, the board shall include:

- An ethicist;
- Three pediatric physicians;
- A neonatologist;
- A genetic counselor;
- A hematologist;
- Two clinical geneticists;

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- · A nurse midwife;
- A parent advocate; and
- A representative recommended by the Hospital Association of Pennsylvania

Senate Bill 983 provides that diseases and conditions mandated for screening and follow-up services shall include: 1) diseases on the combined list of current disorders, 2) diseases added by the board, and 3) conditions listed in the federal Recommended Uniform Screening Panel by the U.S. Department of Health & Human Services.

This legislation shall take in 180 days.

FISCAL IMPACT:

Senate Bill 983 will have no fiscal impact on the Commonwealth. The testing and follow up services required to be provided by the Department of Health will remain the same as under current law. The Department of Human Services already pays for the optional screenings that are becoming mandatory. Therefore, there will be no fiscal impact to the Medical Assistance program.