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TO: The Honorable Thomas Mac Middleton, Chair
Members, Senate Finance Committee

FROM: Joseph A. Schwartz, III
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DATE: February 26, 2014

RE: **SUPPORT WITH AMENDMENT** – Senate Bill 654 – *Health – Down Syndrome – Required Information*

On behalf of MedChi, the Maryland State Medical Society (MedChi), the American Congress of Obstetricians and Gynecologists, Maryland Section (MDACOG) and the Maryland Chapter of the American Academy of Pediatrics (MDAAP), we support Senate Bill 654 with amendment.

Senate Bill 654 will create a mechanism to provide information to expectant parents who receive a prenatal test for Down Syndrome and parents of a child diagnosed with Down Syndrome. The bill requires the Department of Health and Mental Hygiene (DHMH) to identify up-to-date, evidence-based, written information about Down Syndrome and distribute that information to health care facilities and health care providers that provide prenatal care, postnatal care, or genetic counseling to expectant parents who receive a prenatal test result for Down Syndrome and parents of a child diagnosed with Down Syndrome. The information must also be available on the DHMH website. A health care facility or health care provider must then provide the information from DHMH to the parent.

The physician community that provides services to the parents and their children who are diagnosed with Down Syndrome support the collection and dissemination of information proposed by the legislation but would request the bill be amended to make the distribution of the information by facilities and providers permissive instead of mandatory. This information should be communicated to the parents but the setting in which it is communicated, and the additional services and supports that these families need, requires flexibility in the treating community to determine when and how the information is communicated. This information compiled by DHMH will be one small component of the counseling and information these families will need.

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It will undoubtedly be the case that these families will be referred to genetic counselors that will provide more extensive information than can be communicated in materials compiled by the Department. The physician community does not want to create the possibility that receipt of this information is sufficient for the families to understand the significance of the diagnosis and treatment, and supports that will be needed. Amending the bill from “shall” to “may” will ensure that the physician community that is treating the parents and children have the flexibility to provide the information when and as appropriate.

For more information call:

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