

Meetings

All Council meetings are open to the public. Meetings are held biannually at the Maryland Department of Health (MDH), O'Connor Building, 201 West Preston Street, Baltimore, MD 21201.

Anyone interested in attending Council meetings, becoming a member or suggesting agenda items that are related to the mission of the Council, should contact Johnna Watson at 443-681-3916. Additional information can be found on the MDH's Office of Genetics and People with Special Health Care Needs website:

www.phpa.health.maryland.gov/genetics



Correspondence should be sent to:

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How you can become involved

- Attend Advisory Council meetings;
- Submit Advisory Council agenda items;
- Volunteer to serve on a subcommittee of the Advisory Council; and
- Recommend individuals to serve on the Advisory Council.



Larry Hogan, Governor
Boyd Rutherford, Lt. Governor
Robert R. Neall, Secretary

The services and facilities of the Maryland Department of Health (MDH) are operated on a non-discriminatory basis. This policy prohibits discrimination on the basis of race, color, sex, or national origin and applies to the provisions of employment and granting of advantages, privileges, and accommodations.

The Department, in compliance with the Americans with Disabilities Act, ensures that qualified individuals with disabilities are given an opportunity to participate in and benefit from MDH services, programs, benefits, and employment opportunities.

(Revised 5/19)

Maryland State Advisory Council on Hereditary and Congenital Disorders



A Health Advocate and Resource for all Marylanders

www.phpa.health.maryland.gov/genetics
443-681-3916

Mission of the Council

The mission of the State Advisory Council on Hereditary and Congenital Disorders is to ensure that the policies and programs offered by the State of Maryland to its citizens with hereditary and congenital disorders preserve and protect their freedom, health, and well-being.

Council Duties

- Gather and give out information to further the public's understanding of hereditary and congenital disorders;
- Continually re-evaluate the need for and the effectiveness of State hereditary and congenital disorders programs;
- Make recommendations to end discrimination that might result from identification of an individual as a carrier of a hereditary disorder;
- Advise the Secretary of Health regarding addition of new disorders on the Maryland Newborn Screening Panel;
- Advise the Secretary of Health as to the need for rules, regulations, and standards for the detection and management of hereditary and congenital disorders;
- Participate actively in the development of regulations adopted by the Maryland Department of Health; and
- Assist the Department in prioritizing its efforts.

Council Accomplishments

- Supported legislation that mandated HMOs provide coverage to individuals with cleft lip and cleft palate.
- Advocated increasing the age of eligibility for individuals with cleft lip and cleft palate in the HealthChoice's Rare and Expensive Case Management Program from 15 to 20 years of age.
- Sponsored and endorsed the Transition Summit, which brought together medical, education, and human service professionals with a panel of young people with hereditary and congenital disorders and family members.
- Advocated for expansion of newborn screening to include all disorders recommended by the March of Dimes and the American College of Medical Genetics.
- Advocated for expanded newborn screening using new technology (Tandem Mass Spectrometry) to increase the number of disorders screened as well as the accuracy of testing for existing disorders.
- Formed the Cystic Fibrosis (CF) Workgroup to determine the methodology to screen for CF, and to educate physicians and parents.
- Formed the Newborn Screening Laboratory Advisory Workgroup to discuss newborn screening testing issues.
- Recommended screening for Severe Combined Immunodeficiency Disorders, which began in 2016.
- Recommended screening for Pompe, MPS-I, Fabry, spinal muscular atrophy and X-linked adrenoleukodystrophy.



Membership

The Advisory Council consists of **11** voting members and **4** nonvoting members.

Of the 11 voting members:

Five (5) shall be consumers appointed by the Secretary of Health, none of whom may be:

- A health professional or spouse of a health professional; or
- An individual or spouse of an individual involved in the administration or ownership of any health care institution or health insurance organization.

The Secretary of Health shall appoint **one (1)** professional member in the field of hereditary and congenital disorders from each of the following organizations:

- The Medical and Chirurgical Faculty of the State of Maryland;
- The faculty of the University of Maryland School of Medicine;
- Children's National Health System; and
- The faculties of Johns Hopkins Medical Institutions.



One (1) shall be a member of the Senate appointed by the President of the Senate;

One (1) shall be a member of the House of Delegates appointed by the Speaker of the House;

Four (4) nonvoting members shall be representatives of Department of Health, appointed by the Secretary.

The term of a voting member is four (4) years. A voting member may serve two (2) full four-year terms.