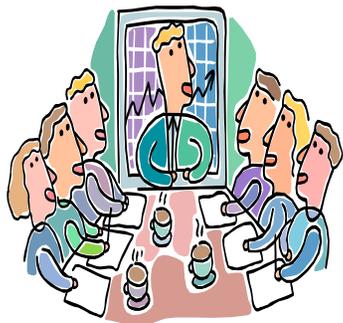


Meetings

All Council meetings are open to the public. Meetings are usually held quarterly at the Department of Health and Mental Hygiene (DHMH), O'Connor Building, 201 West Preston Street, Baltimore, Maryland 21201.

Anyone interested in attending Council meetings, suggesting agenda items that are related to the mission of the Council, or



becoming a member, should contact Johnna Watson, 443-681-3916. Additional information on specific disorders can be found on the DHMH's

Laboratories Administration website at dhmh.maryland.gov/laboratories/Pages/Newborn-Screening

Correspondence should be sent to:

**Johnna Watson,
Department of Health and Mental Hygiene
Laboratories Administration
1770 Ashland Avenue, Rm 341
Baltimore, MD 21205
Fax: 443-681-4505**

E-Mail: johnna.watson@maryland.gov

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
Van Mitchell, Secretary

The services and facilities of the Maryland Department of Health and Mental Hygiene (DHMH) 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 DHMH services, programs, benefits, and employment opportunities.

(Revised 7/16)

Maryland State Advisory Council on Hereditary and Congenital Disorders



A Health Advocate and Resource for all Marylanders

phpa.dhmh.maryland.gov/genetics/pages/advisorycouncil
410-681-3916

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 and Mental Hygiene 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 Department of Health and Mental Hygiene; 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.
- Added urea cycle defects, organic acidurias, and fatty acid oxidation defects to the newborn screening list in 2003.
- 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.
- Recommended Congenital Adrenal Hyperplasia (CHA) to newborn screening.
- Developed slide presentation on newborn screening for nurses, obstetricians, pediatricians, and family practitioners.
- Advocated for expansion of newborn screening to include all disorders recommended by the March of Dimes and the American College of Medical Genetics.
- 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 decide on the methodology to screen for CF, and to educate physicians and parents.
- Formed the Newborn Laboratory Advisory Workgroup, which meets monthly to discuss newborn screening testing issues.



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

- The Monumental City Medical Society;
- The Medical and Chirurgical Faculty of the State of Maryland;
- The faculty of the University of Maryland School of Medicine; and
- 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 and Mental Hygiene, 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.