

Rare Disease Advisory Council

Monday June 17, 2024

1:00PM - 2:00PM

Virtual Meeting

AGENDA

I. WELCOME & ROLL CALL

II. MEMBERSHIP UPDATE

Member of Senate	Senator Clarence Lam
Member of the House of Delegates	Delegate Jamila Woods
Secretary of Health or Designee	Vacant
Chair of the Advisory Council on Hereditary Disorders	Jamie Fraser, MD, PhD
MDH Office of Minority Health and Health Disparities	Camille Blake- Fall
Maryland Medical Assistance Program	Mary Mussman
Maryland Insurance Administration	Jamie Sexton
Rep from Academic Research Institute that receive rare disease grant funding	Vacant
Geneticist	Vacant
Registered nurse or advanced practice nurse with experience treating rare diseases	Vacant
One physician w/ experience treating rare diseases	Vacant
Hospital Administrator	Peter Hill, MD
Pharmacist with experience dispensing drugs to treat rare disease	Kristopher Rusinko
Individual with a rare disease	Eleanor Brannon
Individual with a rare disease	Vacant
Caregiver of an individual with a rare disease	Jeneva Stone
Rep of a rare disease patient organization	Lauren Schillinger

Rep of the biopharmaceutical industry	Matt Meehan
Rep of a health insurance carrier	Vacant
Member of the the scientific community who is engaged in rare disease research	Constance Smith-Hicks
Rep of an org that provides case management for individuals enrolled in Rare Expensive Case Management	Vacant

III. REVIEW OF COUNCIL DUTIES

- a. Convene public hearings, make inquiries, and solicit comments from the public to assist the Council with a first-year survey of the needs of individuals with a rare disease,, caregivers, and health care providers in the state;
- b. Consult with experts on rare diseases to develop policy recommendations to improve patient access to and the Quality of rare disease specialists, affordable and comprehensive health care coverage, relevant diagnostics, timely treatment, and other needed services;
- c. Research and make recommendations to state agencies and insurers that provide services to individuals with a rare disease on the impact of prior authorization, cost-sharing, tiering, or other utilization management procedures on the provision of treatment and care for patients;
- d. Establish best practices and protocols to include in state planning related to natural disasters and public health emergencies or other emergency declarations to enable continuity of care for rare disease patients and ensure that safeguards against discrimination for rare disease patients are in place;
- e. Evaluate and make recommendations regarding coverage of prescription drugs for rare disease patients, including patients with private health insurance coverage and patients enrolled in the Maryland Medical Assistance Program, to improve coverage of diagnostics, and to facilitate access to necessary health care providers with expertise in the treatment of rare diseases;
- f. Publish a list of existing and publicly accessible resources on research, diagnosis, treatment, and education relating to rare disease on the Council’s webpage;
- g. Identify areas of unmet needs for research that con inform future studies and reports by the Council;
- h. Identify and distribute educational resources for health care providers to foster recognition and optimize treatment of rare diseases in the state; and
- i. Research and identify best practices to ensure continuity of care for rare disease patients transitioning from pediatric to adult care.

IV. REVIEW OF COUNCIL DELIVERABLES

- a. [Health, General §13-5002](#)
 - i. (h) (1) The initial meeting of the Council shall occur on or before December 30, 2024.
 - ii. (2) On or before October 1, 2025, the Council shall meet at least once per month in person or through an online meeting platform at a time designated by the chair.

- iii. (3) After October 1, 2025, the Council shall meet at least once per quarter in person or through an online meeting platform at a time designated by the chair.
- b. [Health, General §13–5004](#)
 - i. (a) On or before December 1 each year, beginning in 2024, the Council shall submit a report to the Governor and, in accordance with § 2–1257 of the State Government Article, the General Assembly.
 - ii. (b) The report required under subsection (a) of this section shall:
 - iii. (1) Describe the activities of the Council under § 13–4803(a) of this subtitle;
 - iv. (2) Describe the funding sources of the Council, including grants that were applied for and accepted and the remaining balances of any current grants; and
 - v. (3) Provide recommendations on the ways to address the needs of individuals living with rare diseases in the State.

V. MEETING SCHEDULE

- a. Required to meet once a month until October 1, 2025