

Michigan Rare Disease Advisory Council (MI-RDAC) Membership Application January 2025

The Michigan Department of Health and Human Services (MDHHS) has established the Michigan Rare Disease Advisory Council (MI-RDAC) to support the rare disease community in the state. A rare disease is a condition that affects fewer than 200,000 people in the United States. There are more than 7,000 known rare diseases.

The MI-RDAC serves as an advisory body that provides Michigan's rare disease community with a stronger voice in state government. The responsibilities of the MI-RDAC include 1) providing information about rare diseases through a publicly available website, and 2) in collaboration with MDHHS, investigating and reporting to the state legislature about at least one rare disease per year. Additional information is available on the MI-RDAC website: [Michigan Rare Disease Advisory Council](#).

Participating in the council will provide opportunities to guide and impact statewide efforts to address the needs of individuals affected by these conditions, as well as their families. These opportunities include making formal recommendations to state leaders on issues such as improved access to diagnostic tools and treatments. Other activities will be determined by the council.

The MI-RDAC currently consists of the following: physicians (2), nurse, epidemiologist, rare disease researcher, parent/guardian (2) of child(ren) with a rare disease, individuals (3) with a rare disease, medical ethicist, genetic counselor, Michigan biopharmaceutical industry representative, and patient organization representatives (2). Representation from different groups provide balanced and diverse perspectives that help ensure the greatest impact toward evidence-based solutions to challenges in the rare disease community. MI-RDAC members serve for a term of three years.

Applying to Serve on the MI-RDAC

Applications are being sought to represent the following (one each):

- Administration leadership from a Michigan-based hospital
- Health insurer
- Health maintenance organization
- National pharmaceutical industry or a pharmaceutical company working in the area of rare diseases

Individuals who are interested in serving in the MI-RDAC are expected to demonstrate knowledge, expertise and/or personal experience in rare diseases. As of January 2025, MDHHS requires background checks for all selected council members. Please email completed application forms to mdhhs-rarediseases@michigan.gov. Applications will be reviewed by an MDHHS committee in collaboration with the MI-RDAC chair and vice chair, and approved by the MDHHS Director or their representative.

Applications to serve on the council are being accepted through **February 17, 2025**.

Meetings

Meetings will be held quarterly and will be open to the public. Meeting schedules are posted on the MI-RDAC meetings website: [MI-RDAC Meetings](#).

Contact

For more information or to submit an application, email mdhhs-rarediseases@michigan.gov.