HB 943: Establish the Montana Rare Disease Advisory Council

Rare Disease Advisory Council (RDAC) Annual Report

July 1, 2026

DEPARTMENT OF
PUBLIC HEALTH &
HUMAN SERVICES

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OPENING MESSAGE FROM CHAIRPERSON

The 2025 Montana Legislature's decision to create a Rare Disease Advisory Council (RDAC) for the state was an important one. This group of skilled and highly dedicated professionals from diverse fields of study and practice includes individuals and caregivers of children with rare diseases. Access to specialist care, support for all aspects of living with a rare disease, provider education and consultation, and systemic support for necessary tests and treatments are currently not adequately meeting the needs of Montanans living with a rare disease.

In this, our first report to the Montana Legislature, we present our initial work identifying issues and areas where we can make a positive impact for Montanans living with a rare disease and those who care for and about them. Over the next few years, we intend to develop specific recommendations for providers, caregivers, patients, and policymakers. We look forward to collaborating with legislators and others to make a significant difference in the lives of all those living and working with rare diseases in Montana.

Michele McKinnie, Psy.D. Montana RDAC Chair

MEMBER LIST

Chair: **Michele McKinnie, PsyD** —Mental health provider with rare disease experience — **Gallatin County** (Bozeman)

Panelists:

1. Patrick Secor— Academic research institution representative —Gallatin County (Bozeman)
2. Kelsey Bell —Montana Medicaid program representative— Lewis and Clark County (Helena)
3. Maggie Cook-Shimanek, MD, MPH — Department of Labor and Industry representative —Lewis and Clark County (Helena)
4. Caitlyn Patera, DNP, FNP-C — Nurse or APRN with rare disease experience — Lewis and Clark County (Helena)
5. E. Lynne Wood, MD — Physician with rare disease experience —Yellowstone County (Billings)

6. Jaclyn Haven, MS, LCGC — Hospital administrator or designee —Lewis and Clark County (Helena)
7. Joe Cross — Individual with a rare disease —Stillwater County (Columbus)
8. Melanie Reynolds — Individual with a rare disease —Lewis and Clark County (Helena)
9. Erin Hoch — Caregiver of an individual with a rare disease —Flathead County (Kalispell)
10. Jennifer Banna — Representative of a rare disease patient organization operating in Montana —Missoula County (Missoula)
11. Siera Boyd — Pharmacist with rare disease medication experience —Yellowstone County (Billings)
12. Brett Baker — Biopharmaceutical industry representative —Park County (Big Sky)
13. Dr. Marshall Bloom — Scientific community representative engaged in rare disease research —Ravalli County (Hamilton)
14. Deborah Gibson — Montana public health laboratory representative —Lewis and Clark County (Helena)
15. Geneticist or genetic counselor — TBD — TBD
16. Health plan company representative — TBD — TBD

HB 943 BACKGROUND

The 2025 Legislature established the RDAC through House Bill 943 to provide guidance, education, and recommendations to the public, the Legislature, and other government agencies on the needs of individuals with rare diseases in Montana. The council was created to help address the substantial challenges faced by individuals and families affected by rare diseases, including delayed diagnosis, difficulty accessing specialists, barriers to treatment, and the physical, emotional, and financial burdens associated with rare conditions. This report summarizes the council's formation, early activities, subgroup structure, and initial priorities during its first months of operation.

Under HB 943, Montana's RDAC has five core duties, as well as reporting and funding responsibilities. It must convene public hearings and solicit public comment to survey the needs of rare disease patients, caregivers, and providers; consult with experts to develop policy recommendations on access to specialists, coverage, diagnostics, treatment, and other services; publish resources and meeting materials on the Department of Public Health and Human Services (DPHHS) website; identify unmet research needs and opportunities for collaboration with stakeholders and other states; and distribute educational resources to health care providers.

SUMMARY OF COUNCIL ACTIVITIES

From January through May 2026, the RDAC moved from initial organization into active subgroup-based work focused on its first annual report and future priorities. The council's early meetings emphasized introductions, shared purpose, and the importance of including patient and caregiver perspectives in all major discussions. Members also worked to define the council's structure, assign subgroup roles, and establish a practical process for translating meeting information into written deliverables.

A major early task was clarifying the council's statutory duties and how those duties would be carried out through meetings, public input, and subgroup assignments. The council discussed how to survey needs, gather public comment, and identify unmet needs and possible policy responses, all of which are core responsibilities under HB 943. Members also began considering how the council should organize its annual report to be useful to the Governor, the Legislature, and the interim committee.

By spring, the council had shifted into more concrete planning around subgroup work and report development. Members discussed the evolution of subgroup assignments, the need for consistent leads, and how subgroup goals should feed into the larger council report. The council also began identifying future priorities for the next year, with an emphasis on translating discussion into practical action items.

The council's work during this period also reflected a growing awareness of representation and inclusion issues, including the need to consider tribal representation and other gaps that could affect the council's ability to fully reflect Montana's rare disease community. Overall, the January–May period was foundational: the council established its membership, clarified its purpose, launched subgroup work, and began building the framework for its first report and future work plan.

The group's primary successes since its inception have focused on developing multiple subgroups. Initially, three groups were developed based on standard categories used by other state rare disease advisory councils, as captured by the National Organization for Rare Disorders (NORD). Patient and Caregiver Support, Policy and Insurance issues, and Provider and Patient Education subgroups were stood up.

Following the initial subgroup meetings, the Patient and Caregiver Support group was stood down, and its participants were redistributed to provide more comprehensive patient/caregiver and clinical representation in the Policy and Insurance subgroup and the Provider and Patient Education subgroup. Further, both subgroups were open to allowing committee members to participate in either subgroup, if desired.

RDAC CHALLENGES

During the first several months, the RDAC focused on organizing its membership, establishing its working structure, and developing subgroups to advance the council's responsibilities under HB 943. That early work laid the foundation for future progress. Still, it highlighted the practical limits of a new advisory body tasked with covering a broad statutory charge, with a relatively small membership and a limited first-year timeline. The council's minutes show a continued emphasis on making subgroup work more consistent and on ensuring that the council's discussion translates into clear priorities, recommendations, and report language.

A major challenge identified in the council's discussions is representation. The council has discussed the potential need for tribal representation and broader inclusion to ensure it reflects the full diversity of Montana's rare disease community. That concern is especially important because HB 943 directs the council to represent the state's geographic and population diversity and to gather public comment from patients, caregivers, and providers. Ensuring that all affected communities are meaningfully included will strengthen both the quality and credibility of the council's recommendations. In practice, that means future recruitment, outreach, and consultation efforts will be important parts of the council's continued work.

The council also faces the challenge of turning a wide range of duties into a manageable work plan. HB 943 requires the RDAC to survey local needs, consult experts, publish resources, identify unmet needs, distribute educational materials, and submit annual reports to state leaders. Those responsibilities are substantial, especially for a new council still refining subgroup roles and internal processes.

KEY RECOMMENDATIONS

Moving forward, the council's most important tasks will be to define clear subgroup priorities for the coming year, maintain steady communication among members, and continue centering the experiences of patients and caregivers in its work.

Specific recommendations from the council:

1) Policy Subgroup: The RDAC supported the development of a dedicated policy subgroup, recognizing that strong policy will best support Montanans living with rare diseases and their caregivers. The draft policy initiatives generated in this subgroup are included below.
    a. **Step therapy or "fail first"**
        i. **Background:** Step therapy or "fail first" is a utilization management practice in which insurers require patients to try one or more alternative medications before gaining access to the treatment originally prescribed by their physician. While step therapy is intended to control health care costs, it is increasingly applied without adequate consideration of a patient's medical history or the treatment needs identified by their health care provider.
        ii. **Proposed Action:** This subgroup found that Montana Medicaid lacks a written step-therapy policy, resulting in a NORD score of "F" for Montana. Montana Medicaid is willing to review a proposed policy. This group will obtain an example policy for this purpose and make a strong recommendation that Medicaid adopt a policy to create clear, consistent, and transparent decisions regarding step therapy application. This example policy will also be shared with other insurers.
    b. **Medical nutrition access**
        i. **Background:** Access to medical nutrition is essential for individuals living with metabolic and other diseases. The NORD proposes comprehensive coverage mandates and imposes the fewest restrictive coverage requirements. Montana scored a "C" for this measure.
        ii. **Proposed Action:** This group will request a NORD policy example to share with Montana Medicaid. This example policy will also be shared with other insurers.
    c. **Whole genome sequencing coverage**
        i. **Background:** A covered billable code would allow for more rapid rare disease diagnosis in Montana, attributable to decreased transit time for out-of-state testing. Rapid whole-genome sequencing could also be deployed for timely testing and treatment of critically ill infants in the neonatal intensive care unit.

  - ii. **Proposed Action:** This group will investigate coverage from Montana Medicaid and other insurers and make recommendations accordingly.

d. **Expand access to telehealth**
  - i. **Background:** The need to access highly specialized medical providers is common for individuals living with rare diseases. Out-of-state travel for these medical encounters is burdensome, both personally and financially.
  - ii. **Proposed Action:** This group will review recently enacted legislation (HB 414) related to telehealth allowances and consider whether additional legislation is needed to ensure ready access to licensed, highly specialized medical professionals who are otherwise unavailable in Montana.

e. **Declare February 28th as Rare Disease Day**
  - i. **Background:** Designating "Rare Disease Day" will provide an opportunity to raise awareness and promote education on rare diseases in Montana.
  - ii. **Proposed Action:** This group is investigating how to propose a designated day in Montana.

f. **Billing for genetic counseling**
  - i. **Background:** Genetic counseling became a licensed profession in Montana in 2021 through *HB 217: Provide for licensure of genetic counselors*; however, there is currently no dedicated Current Procedural Terminology (CPT) code. CPT code 96041 is generally not recognized as billable. Some private payers cover it.
  - ii. **Proposed *Future* Action:** The group will explore further whether Medicaid would consider accepting this code. For a larger-scale impact, legislative avenues across payers will be considered.

g. **Revisit legislation related to Medicaid buy-in**
  - i. **Background:** During the 2025 legislative session, House Bill 881, *Revise Medicaid buy-in program to include children with disabilities*, was passed by the Montana House and Senate, but was vetoed by the Governor on 05/13/25. There are 1700 people (kids/adults with developmental disabilities) who meet the state criteria, waiting on the Developmental Disability Program (DDP) 0208 Waiver (individuals with developmental disabilities) waitlist. Individuals may be on the waitlist for years. Many of these individuals would

qualify for the Medicaid buy-in. There is also a waitlist for the Big Sky Waiver (individuals with physical disabilities). NORD rates Montana's *Medicaid Financial Eligibility* as a "B," but when broken down by age group, Montana children's Medicaid Eligibility is a "D."

ii. **Proposed *Future* Action:** This policy subgroup is exploring whether policy actions would be beneficial to supporting this effort.

h. **Support the Newborn Screening Advisory Committee's newborn screening panel efforts, if appropriate and necessary**
   - i. **Background:** NORD scores Montana as a "C" for newborn screening compared to the nationwide overall average score of "B". Montana does not screen for all the Recommended Uniform Screening Panel (RUSP) conditions for various reasons.
   - ii. **Proposed action:** This group will stand by and provide support to the Newborn Screening Advisory Committee as needed.

2) Provider and Patient Education Subgroup: The RDAC supported the development of a dedicated education subgroup, recognizing the need to expand education to both providers and patients. The recommendations generated in this subgroup are included below.
   - a. The Montana legislature could further support the health and well-being of individuals with rare diseases and their families by:
     - i. Policy considerations:
       - 1. Legislating Medicare/Medicaid policies that support care for families within Montana, but are flexible enough to cover visits to outside specialists where needed, as many patients and families have required specialists in other states to weigh in on their cases
       - 2. Continue to support broad coverage of appropriate telehealth or telemedicine services to make access to care attainable
     - ii. Funding considerations:
       - 1. Appropriate funding for a state-wide provider case conference to allow education of local providers in the latest in diagnosis and treatment of rare diseases, to improve local access
       - 2. Appropriate funding for patient and caregiver support not covered by Medicare/Medicaid, private insurance, or waiver services.