# Montana Rare Disease Advisory Council
# Meeting Minutes

Feb 25, 2026
9 a.m. – 10:30 a.m.
Zoom / Virtual Meeting

## ROLL CALL AND ATTENDANCE

Members Present

**Legislative / Executive**

- Rep. Paul Tuss, Montana House of Representatives (sponsor of HB 943)

**State agencies / programs**

- Kelsey Bell – Member Health Management Bureau Chief, Health Resources Division, DPHHS (Medicaid representative)

**Clinical / research experts**

- Dr. Brett Baker – Founder, Microbion Corporation (biotech, orphan drugs, lung infections)
- Dr. Marshall Bloom – Associate Director for Scientific Management, Rocky Mountain Laboratories (NIAID/NIH)
- Sierra Boyd – Pediatric Clinical Pharmacist Specialist, Billings Clinic
- Dr. Patrick Secor – Professor of Microbiology, Montana State University (phage–bacteria research, CF, microbiome, Lyme disease)
- Dr. Michele McKinnie – Licensed psychologist, private practice in Bozeman
- Jacqueline Haven – Chief Administrative Officer of Genetics, Shodair Children's Hospital / Montana Medical Genetics Program

**Patients and caregivers (lived experience)**

- Joe Cross – Patient with late-onset Pompe disease, Columbus, MT
- Erin Hoch – Parent of a child with infantile Pompe disease
- Melanie Reynolds – Patient with myelofibrosis (rare blood cancer)

**Absent members**

- Debbie Gibson
- Caitlin Pitera
- Jennifer Banna (Rural Institute – email/attendance issue noted)
- Dr. E. Lynne Wood

## CALL TO ORDER, PUBLIC ACCESS, AND AGENDA REVIEW

The Council Chair called the meeting to order and confirmed the meeting was open to the public, with public comment scheduled near the end of the agenda.

The DPHHS Staff Liaison noted that the Zoom link and agendas are posted on the RDAC website and will continue to be available there for future meetings.

## ATTENDANCE AND INTRODUCTIONS

Council members introduced themselves by role and affiliation for roll call and public context. The Physician Representative joined later due to an urgent hospital consult, and several other designated members provided advance notice that they would be absent or arrive late. Participants were invited to update their display names in the virtual platform to show first name and role for the benefit of public attendees.

## COUNCIL COMPOSITION AND PURPOSE

The council reflected broad representation across patients, caregivers, clinicians, researchers, Medicaid, genetics, pharmacy, and behavioral health. Members expressed interest in learning from other states' RDACs, especially those with similar rural profiles. The group also noted the need to define a focused charter and realistic scope given the council's advisory role and limited budget.

## PATIENT AND FAMILY EXPERIENCE

Rare disease patients and families described significant travel burden, delayed diagnosis, financial strain, and emotional stress. Caregivers emphasized the need for support beyond medical treatment, including respite, mental health, and community participation. Members highlighted the importance of including lived experience in all council work.

## PROVIDER AND SYSTEM PERSPECTIVE

Montana's small and highly connected health ecosystem may make collaboration easier than in larger states. Newborn screening and genetics infrastructure were identified as strengths, including the state genetics program and in-state testing capacity. Provider education, rare-disease literacy, and better communication across disciplines were identified as ongoing needs.

## INSURANCE, ACCESS, AND POLICY BARRIERS

Members discussed barriers to specialty pharmacy access, genetic testing, Medicaid policy, and reimbursement for genetic counseling. Out-of-state care remains common for rare-disease patients, creating financial and logistical hardship. Several potential low-cost policy changes were identified as early opportunities for council action.

## BEHAVIORAL HEALTH AND PSYCHOSOCIAL SUPPORT

Mental health and behavioral health were identified as core issues, not secondary concerns. Patients and caregivers described isolation, trauma, mistrust, and the need for more support. The council discussed partnerships with behavioral health organizations and academic researchers to better understand psychosocial needs.

## DATA, RESEARCH, AND PARTNERSHIPS

Members expressed strong interest in a rare-disease data repository or registry to quantify travel, cost, diagnosis delays, and out-of-state care. The council noted opportunities to partner with Montana universities, Shodair, MSU, UM, and others on research, training, and outreach. Rural Health Transformation funds and other external opportunities were identified as possible sources of support for infrastructure and workforce development.

## OPPORTUNITIES FOR COUNCIL WORK

- Develop a focused set of 3–5 strategic priorities for the next 1–3 years.
- Create workgroups around community engagement, policy/access/systems, and provider education/early diagnosis.
- Pursue early wins through administrative or policy changes that do not require significant new funding.
- Build a stronger public-facing narrative about the burden of rare disease in Montana.

## NEXT STEPS

Meeting Structure

The council will continue monthly 90-minute meetings for now. Future meetings will be set farther in advance once a presiding officer is appointed. The group also expressed interest in reviewing similar councils in other rural states to identify transferable models and charter language.

Workgroups

Initial focus areas include community engagement, policy/access/systems, and provider education and early diagnosis. Behavioral health and psychosocial support

may also warrant explicit attention. The council will refine these workgroups once governance is finalized.

Action Items

- Compile the SWOT analysis and discussion summary.
- Circulate a priority-selection tool to narrow strategic focus areas.
- Review HB 943 and related rules for charter/bylaw requirements.
- Send scheduling surveys and finalize upcoming meeting dates.
- Follow up on attendance and communication issues for absent members.

## NEXT MEETING AND ADJOURNMENT

The Chair requested that future meeting summaries continue to include upcoming meeting dates at the bottom to support calendar planning.

With business concluded, a motion to adjourn was made and seconded. The council voted in favor, with no opposition.

The Chair formally adjourned the meeting and noted that guidance on subgroup meetings and off-cycle recommendations will be shared as soon as available.

## 2026 RDAC MEETING DATES

Meetings are online, via ZOOM link, running from 9 a.m.-10:30 a.m.

- March 26
- April 23
- May 21
- June 25
- July 23
- August 20
- September 24
- October 22
- November: TBD
- December: TBD