Montana Rare Disease Advisory Council Meeting Minutes

March 26, 2026
9 a.m. – 10:30 a.m.
Zoom / Virtual Meeting

ROLL CALL AND ATTENDANCE

Members Present

- Dr. Marshall Bloom
- Sierra Boyd
- Dr. Patrick Secor
- Dr. Michele McKinnie
- Joe Cross
- Erin Hoch
- Melanie Reynolds
- Debbie Gibson
- Caitlin Pitera
- Jennifer Banna
- Dr. E. Lynne Wood

Members Absent

- Kelsey Bell
- Dr. Brett Baker
- Jacqueline Haven

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

The meeting was called to order and recorded. Roll call was conducted, and attendance was taken. Michele McKinnie, PsyD was introduced as Presiding Officer and will transition into leading future meetings.

The council's statutory charge is to develop policy and legislative recommendations to improve systems of care, access, and awareness for Montanans with rare diseases.

This meeting focused on identifying real-world challenges in diagnosis and care navigation to inform future work.

Participants included clinicians, state and federal representatives, industry, and patient/caregiver voices. Council members introduced themselves by role and affiliation for roll call and public context.

PATIENT AND FAMILY EXPERIENCE DISCUSSION

- Delayed and difficult diagnoses, often involving misdiagnosis and limited access to second opinions.
- Fragmented care across providers, with limited coordination or whole-person evaluation.
- Frequent need for out-of-state care, creating financial and logistical strain.
- Limited provider familiarity with rare conditions, increasing reliance on patient self-advocacy.
- Significant emotional impact at diagnosis, often without trauma-informed communication or support.
- Dependence on peer networks for information and navigation.

PROVIDER PERSPECTIVE DISCUSSION

- Diagnostic complexity, particularly when rare diseases resemble more common conditions.
- Uncertainty in prognosis and care planning, even with early identification.
- Need for multidisciplinary input prior to testing and diagnosis.
- Workforce shortages and limited specialty access within Montana.
- Gaps in mental health support for patients and families.
- Interest in improved access to specialist consultation without requiring travel.

INSURANCE AND FINANCIAL BARRIERS

- High-cost treatments require extensive approval processes, though Medicaid coverage is generally available once approved.
- Ongoing challenges with coverage for therapies, equipment, and supplies, especially for children.
- Interruptions in care due to administrative policies tied to progress benchmarks.
- Equipment replacement timelines often do not align with patient needs.
- Complex rules for medications, pharmacy requirements, and cross-state care.
- Persistent barriers to accessing out-of-state care and managing associated costs.

COORDINATION AND ACCESS TO SPECIALTY CARE

- Local providers play a key role in coordinating with out-of-state specialists.
- Licensing limitations restrict external specialists from directly managing care in Montana.
- Advanced treatments often require referral outside the state.

PATIENT–PROVIDER ENGAGEMENT

- Strained interactions may arise from prior negative experiences and communication gaps.
- Policy and improvement efforts often separate patient and provider input.
- Strong interest in integrated approaches that include both perspectives in system design.

OPPORTUNITIES FOR COUNCIL WORK

- Develop clear referral triggers and diagnostic guidance for providers across life stages.
- Expand access to specialist input through virtual consultation and case review models.
- Promote trauma-informed diagnosis and improve access to psychosocial support.
- Strengthen navigation resources for families, including support for out-of-state care.

NEXT STEPS

Meeting Structure
The council will continue monthly 90-minute meetings with a consistent schedule. Council will explore 1 in-person meeting annually.

Workgroups
Initial focus areas include: Patient and Caregiver Support, Policy and Insurance/Legislative Issues and Provider Support and Education. Each group will include both provider and patient/caregiver perspectives.

Action Items

- Finalize recurring meeting schedule.
- Identify member participation in workgroups.

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.

2026 RDAC MEETING DATES

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

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