Montana Rare Disease Advisory Council
Meeting Minutes

May 21, 2026
9 a.m. – 10:30 a.m.
Zoom / Virtual Meeting

ROLL CALL AND ATTENDANCE

Members Present

- Dr. Michele McKinnie (Chair)
- Kelsey Bell
- Dr. Brett Baker
- Dr. Marshall Bloom
- Sierra Boyd
- Dr. Patrick Secor
- Jacqueline Haven
- Erin Hoch
- Melanie Reynolds
- Debbie Gibson
- Caitlin Pitera
- Jennifer Banna
- Dr. E. Lynne Wood

Members Absent

- Joe Cross – Patient with late-onset Pompe disease, Columbus, MT

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 opened with greetings, roll call, and member introductions. Michele McKinnie, PsyD served as presiding officer, and Jeremy Royal provided DPHHS support and technical assistance.

Members introduced themselves by role and background, including family/caregiver, provider, scientific, laboratory, Medicaid, and patient perspectives. The group also discussed the practical value of clear name labels in Zoom and the possibility of public observers at future meetings.

The council approved the prior minutes by motion and vote. Members also noted that the meeting schedule should be posted more clearly so participants can plan ahead. Council members introduced themselves by role and affiliation for roll call and public context.

RECAP OF PREVIOUS MEETING OUTCOMES

The council reviewed the prior meeting's main themes and confirmed that the previous summary captured the core issues well. Those themes included patient and family experience, provider perspectives, insurance and financial barriers, access to specialty care, and patient-provider engagement.

The council reiterated four early opportunities for action: referral triggers and diagnostic guidance, virtual specialist consultation and case review, trauma-informed diagnosis and psychosocial support, and stronger navigation support for families, including out-of-state care.

Members also reviewed state comparisons presented earlier, including West Virginia and Colorado, and discussed using NORD tools to avoid recreating existing models. The group agreed that Montana should adapt useful external examples to its own geography and system realities.

REVIEW AND DISCUSSION: CURRENT SUB-GROUPS

The subgroup experiment was reviewed in detail, with members discussing whether the council should continue in separate silos or move toward a more integrated full-group model. The general view was that the workgroups were useful for organizing ideas, but they should remain fluid and connected to the full council.

The provider education group focused on a Project ECHO-style model to move specialist knowledge into rural Montana communities. Their discussion centered on how to bridge the gap between specialty expertise and primary or community providers, including case consultation, virtual education, and practical examples already used in Montana.

The policy and legislative group used the NORD report card and identified several potential work areas, including genetic counseling reimbursement, whole genome sequencing coverage, medical nutrition, Medicaid buy-in, fail-first policies, Rare Disease Day recognition, and newborn screening.

The patient and caregiver discussion emphasized support after diagnosis, resource navigation, respite, mental health, being heard by providers, and better care coordination. Members agreed that lived experience should be present in the provider and policy groups so that the work stays grounded in real-world needs.

ONBOARDING AND EXITING MEMBERS

The council discussed membership changes and noted that Ellen Jobb was leaving because she is moving out of state. Because statutory seats require Montana residency, the vacant genetic counselor position will need to go through the standard application and approval process.

Jeremy Royal explained that the state cannot fast-track appointments and that the open seat must follow the normal RDAC application pathway. Members also discussed the open insurance representative seat and the importance of tribal representation, noting that some representation gaps may need to be addressed later through legislative change.

UPCOMING JULY 2026 REPORT

Jeremy Royal explained that the July report will likely be 2 to 5 pages in length. The report is expected to summarize the council's creation, membership, subgroup structure, current work, and next steps, with an emphasis on recommendations rather than completed deliverables, as the group is in its early stages of development.

The audience was identified as the governor, the legislature, and the Children, Family, Health, and Human Services Interim Committee. Members suggested using Representative Paul Tuss as an informed legislative contact.

Members agreed that the draft should be reviewed by the full council before submission. Melanie Reynolds, Caitlyn Patera, and Erin Hoch all supported having everyone review the report, with delegation by section if needed. 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

The council discussed keeping monthly meetings through the summer, with flexibility if needed. Several members said a predictable schedule would help them plan, and Michele McKinnie said they would aim to finalize recurring dates soon.

Members also discussed whether future subgroup meetings should remain separate, be restructured, or be folded into broader council discussions. The consensus was that the groups should remain flexible, with invitations shared broadly so members can participate where they are most useful.

There was also interest in keeping the work open and practical rather than overly rigid. The subgroup structure was described as a working tool, not a permanent committee design.

NEXT STEPS

The council agreed that Jeremy and Michele would organize subgroup materials and circulate them to the full council. Subgroup leaders were asked to send slides, notes, and supporting documents so they can be assembled for broader review.

The group also agreed to continue refining the July report and to review a draft at the next meeting. Jeremy will clarify the report audience and timeline, and members will continue shaping recommendations based on the subgroup work and NORD findings.

Planned June tasks include finalizing workgroup participation, determining who will review and edit the report, and continuing to gather supporting materials. The council also noted that one or more new members may still be appointed before the June meeting, but likely not in time to fully participate before then.

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.

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