Montana Rare Disease Advisory Council
Meeting Minutes

April 23, 2026
9 a.m. – 10:30 a.m.
Zoom / Virtual Meeting

ROLL CALL AND ATTENDANCE

Members Present

- Dr. Michele McKinnie
- Kelsey Bell
- Dr. Brett Baker
- Dr. Marshall Bloom
- Sierra Boyd
- Jacqueline Haven
- Joe Cross
- Erin Hoch
- Dr. E. Lynne Wood
- Caitlin Pitera
- Jennifer Banna

Members Absent

- Debbie Gibson
- Dr. Patrick Secor
- Melanie Reynolds

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 began leading council 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, care navigation, service delivery, representation, and access to specialty care to inform future council work.

Participants included clinicians, state and federal representatives, industry, health plan and Medicaid representation, patient and caregiver voices, and technical support. Members introduced themselves for the record and described their professional and lived-experience backgrounds. The council also reaffirmed that this work is intended to be collaborative, practical, and grounded in Montana's unique population and geography.

Council members introduced themselves by role and affiliation for roll call and public context.

REVIEW OF PRIOR WORK

The council reviewed the prior meeting summary and approved the minutes. Members confirmed the summary themes captured the main issues raised previously, including 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: developing referral triggers and diagnostic guidance, expanding specialist input through virtual consultation and case review, promoting trauma-informed diagnosis and psychosocial support, and strengthening navigation resources for families, including support for out-of-state care. Members agreed these themes should continue guiding council discussion and future recommendations.

STATE COMPARISONS

The council discussed a comparison of other states with Rare Disease Advisory Councils, noting that Montana is the 23rd state with an RDAC. The council discussed using NORD's tools to compare state structures, report cards, and available RDAC materials so Montana does not need to "reinvent the wheel." Members noted that NORD appears to provide robust state comparisons, downloadable data, and grading tools that may help identify where Montana is already strong and where gaps remain.

West Virginia was identified as the most comparable model because of its rurality and demographic similarities, while Colorado was noted as another useful reference because of its western legislative structure. Members agreed, however, that no state is a perfect mirror for Montana, and that any external model must be adapted to Montana's geography, populations, and health system realities.

REPRESENTATION AND INCLUSION

The council discussed current membership and confirmed that the remaining open statutory seat is a health plan company representative, with Medicaid separately represented by existing members. Members clarified that the statutory positions are fixed and experts can be invited to participate in discussion, even if they do not have voting status.

A portion of the meeting focused on Indigenous and tribal representation. Members agreed that the council should not attempt to speak for Indigenous communities without meaningful input from those communities. Routes to receive meaningful input were discussed.

SUBGROUP STRUCTURE

The council agreed to test a three-subgroup structure for one month: patient and caregiver support, policy and insurance issues, and provider and patient education. Members noted that these areas overlap substantially, and that the subgroup structure is meant to help organize discussion rather than create rigid silos. The council also agreed that subgroup leads should bring feedback back to the full council so the work stays integrated.

For the pilot month, Maggie Cook-Shimanek volunteered to help organize the policy and insurance subgroup, with Jen Banna interested in participating. Caitlyn Patera and Lynne Wood agreed to co-lead the provider education subgroup, with Marshall Bloom, Ellen Job, and Brett Baker also aligned with that work; Patrick Secor was suggested as another possible contributor. Michele McKinnie agreed to lead the patient and caregiver subgroup, with Joe Cross and Erin Hoch identified as participants.

PROVIDER EDUCATION IDEAS

The provider and patient education subgroup discussed using a Project ECHO-style hub-and-spoke model to support Montana clinicians. Under this model, a multidisciplinary group of specialists would serve as the "hub," while community providers, public health

teams, and advisory groups would serve as the “spokes.” The subgroup envisioned options such as virtual case presentations, didactic sessions, office hours, and periodic lectures to support diagnosis and ongoing care for rare disease patients.

Members noted that this model could also include outside experts, including regional or national specialists, especially when Montana providers need support for difficult diagnostic or treatment questions. The council also discussed using existing Montana models, such as the Indian Country Hepatitis C ECHO series, as a practical example of how virtual education and consultation can work well in the state.

PATIENT SUPPORT NEEDS

The council discussed the patient and caregiver subgroup as a place to identify what families and patients need most, while recognizing that many patient needs overlap with insurance, access, and provider education issues. Caitlyn Patera suggested that the Children and Youth with Special Health Care Needs needs assessment could be a useful resource, since it is already gathering statewide family input and may help identify strengths and gaps in the system. Members agreed that it may be helpful to compare the council’s emerging priorities with those findings once they are released.

The group also noted that the subgroup framework should remain flexible. If the pilot month shows that the categories are too artificial, the council may need to shift to a more integrated approach. Members agreed to use the subgroup work as an experiment and to revise course based on what proves most useful.

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

Continue monthly 90-minute virtual meetings with a consistent schedule. Explore at least one 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.
- Ask absent members to self-select into a subgroup.
- Review NORD resources and identify gaps for future discussion.

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.

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