



Montana Rare Disease Advisory Council

Meeting Minutes

July 23, 2026

9 a.m. – 10:30 a.m.

Zoom / Virtual Meeting

ROLL CALL AND ATTENDANCE

Members Present

- Rep. Paul Tuss, Montana House of Representatives (sponsor of HB 943)
- Dr. Michele McKinnie (Chair)
- Siera Boyd
- Dr. Patrick Secor
- Jaclyn Haven
- Caitlyn Patera
- Jennifer Banna
- Dr. E. Lynne Wood
- Kelsey Bell
- Joe Cross
- Erin Hoch
- Melanie Reynolds
- Dr. Maggie Cook-Shimanek

Absent members

- Dr. Brett Baker
- Debbie Gibson
- Dr. Marshall Bloom

CALL TO ORDER, PUBLIC ACCESS AND AGENDA REVIEW

The Chair called the meeting to order and confirmed the meeting was open to the public. Members introduced themselves for roll call. The agenda included review of prior minutes, information management procedures, membership composition, subgroup report outs, legislative coordination, and time reserved for public comment.



ATTENDANCE AND INTRODUCTIONS

Members introduced themselves by role, affiliation, and location. The Chair encouraged updating display names to include first names for clarity. No public attendees were present.

REVIEW OF PRIOR MEETING MINUTES

The Staff Liaison noted that minutes undergo required DPHHS formatting before posting to the RDAC website, which can cause delays. Members reviewed the June minutes together. A motion to approve the minutes passed unanimously with no opposition or abstentions.

INFORMATION MANAGEMENT AND PUBLIC INQUIRIES

Members discussed how to manage informational emails, newsletters, and opportunities shared between meetings. Consensus:

- General informational items (e.g., NORD announcements, events, resources) may be forwarded directly to the full group.
- Members who prefer not to receive such items may notify the Chair privately.
- Public inquiries should be forwarded first to the Chair and Staff Liaison, who will determine how to incorporate them into future agendas.
- RDAC may add a recurring agenda item titled “Communication from the Public” to capture themes emerging between meetings.

A member described a recent public inquiry regarding access to high dose controlled medications and provider comfort prescribing them when co managed by out of state specialists. The Chair noted this as an example of issues RDAC may need to elevate.

MEMBERSHIP COMPOSITION AND VACANCIES

The council reviewed current and upcoming vacancies:

- Biopharmaceutical industry representative
- Geneticist / Genetic Counselor
- Health plan company representative

Members agreed that recruiting a commercial health plan representative should be prioritized. Outreach will continue through professional networks, including genetic counselors.



Representative Tuss advised that RDAC may propose a cleanup bill in the next legislative session to refine membership categories. He noted this is common for new councils and carries minimal legislative risk. Members suggested adding tribal representation as a formal seat.

RDAC will prepare membership recommendations for Representative Tuss by late October.

LEGISLATIVE GUIDANCE FROM REPRESENTATIVE TUSS

Representative Tuss emphasized:

- RDAC is an advisory body, but the legislature is looking for actionable, high impact recommendations.
- The upcoming session is unlikely to have significant new funding available; policy changes without major fiscal impact are most feasible.
- RDAC should identify 1–3 improvements that would meaningfully benefit Montanans with rare diseases.
- Inviting NORD to a future meeting would help RDAC learn from successful models in other states.

PROVIDER AND PATIENT/FAMILY EDUCATION SUBGROUP REPORT OUT

The subgroup reflected on its direction and clarified its role, recommending that RDAC should not build or operate statewide programs itself. The sub-group recommended:

- A statewide Rare Disease Project ECHO program
- Standardized referral guides and provider toolkits
- Education resources for newly diagnosed families and schools
- Improved telehealth pathway awareness
- “Rare Disease Champions” within provider networks
- Strengthened continuing education opportunities

Members emphasized the need to prioritize ideas and avoid being overwhelmed. The subgroup will incorporate findings from the Children’s Special Health Services annual needs assessment to ensure recommendations reflect statewide needs.



POLICY AND INSURANCE SUBGROUP REPORT OUT

MEDICAL NUTRITION COVERAGE

Montana scores a C on NORD's medical nutrition metric. The subgroup drafted a payer policy to improve coverage of medically necessary nutrition. Feedback was incorporated from RDAC members and a statewide dietitian. Revised drafts will be redistributed.

STEP THERAPY / FAIL FIRST PROTOCOLS

Montana received an F on NORD's step therapy metric. The subgroup drafted a payer policy allowing exceptions when lower tier medications are contraindicated, have failed, or when patients are stable on higher tier medications. Revisions are underway.

TELEHEALTH ACCESS AND STATUTORY CLARIFICATION

The subgroup drafted language clarifying that Montana's temporary registration statute allows 21 non consecutive days of practice per year for out of state providers, including telehealth encounters. Members raised questions about whether "21 days" applies per provider or per patient; this will be clarified.

The Governor's Licensure Reform Task Force is also reviewing telehealth flexibilities, making RDAC's recommendations timely and complementary.

NORD SUMMIT OPPORTUNITY

NORD will fund two RDAC members to attend:

- RDAC Day: October 25
- NORD Summit: October 26–27
- Location: Washington, D.C.

There was discussion of additional members attending, if funding was available.

RARE DISEASE DAY (FEBRUARY 28)

RDAC considering a request of formal recognition for **Rare Disease Day** in Montana.

NEXT STEPS

MEETING STRUCTURE

The council will continue monthly 90-minute meetings.



ACTION ITEMS

- Determine if additional funding is available for NORD summit travel.

NEXT MEETING AND ADJOURNMENT

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.

2026 RDAC MEETING DATES

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

- August 20
- September 24
- October 22
- November: TBD
- December: TBD