



Montana Rare Disease Advisory Council

Meeting Minutes

August 20, 2026

9 a.m.10:30 a.m.

Zoom / Virtual Meeting

ROLL CALL AND ATTENDANCE

Members Present

- Dr. Michele McKinnie (Chair)
- Siera Boyd
- Dr. Patrick Secor
- Dr. E. Lynne Wood
- Kelsey Bell
- Erin Hoch
- Melanie Reynolds
- Dr. Marshall Bloom
- Dr. Brett Baker
- Dr. Maggie Cook-Shimanek

Absent members

- Debbie Gibson
- Jaclyn Haven
- Jennifer Banna
- Joe Cross
- Caitlyn Patera

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

DPHHS Support Staff reported delays in posting minutes due to multi step processes. All videos have now been replaced with written minutes. Members reviewed the June minutes. A motion to approve was made by the Pharmacist Representative and seconded by the Scientific Representative. The motion passed unanimously with no opposition or abstentions.

CLEANUP BILL REVIEW

DPHHS Support Staff reviewed the process and risks associated with reopening RDAC's enabling legislation. Reopening the bill introduces a small risk of losing the bill if contested, though rare disease legislation is generally non controversial. The Legislative Representative cannot formally support a cleanup bill until after the upcoming election.

Members discussed whether the statute requires periodic renewal. DPHHS Support Staff will verify. The group reviewed potential statutory updates, including expanding allowable uses of RDAC's \$16,000 biennial appropriation, adding Indigenous representation, and revisiting membership categories. Members emphasized the need to justify any request for increased funding.

DISCUSSION: WHETHER TO OPEN THE BILL THIS SESSION

The Scientific Representative supported pursuing improvements but advised waiting until after the election so the Legislative Representative can assess the legislative landscape. The Pharmacist Representative recommended waiting until RDAC is more established and has attended the NORD Summit. The Department of Labor & Industry Representative proposed drafting a red line version now while gathering insights from NORD and other states. Members agreed to begin drafting potential changes while awaiting post election guidance.

RDAC'S ROLE AS AN ADVISORY COUNSEL

Council discussed RDAC's role in legislative engagement. Highlighted advocacy as the primary strategy as opposed to formal lobbying. RDAC may submit recommendations.



Those recommendations must be voted on and endorsed as a group. Members may always interact with legislators as private citizens.

NORD SUMMIT AND RDAC DAY

RDAC funding cannot be used for conference travel. NORD will fund attendance for 2 individuals from RDAC. RDAC will be sending the Chair and the Department of Labor & Industry Representative.

The Chair will ask NORD whether RDAC Day is available virtually and whether additional RDAC members may attend. The Rare Disease Patient Representative noted that only 2.8% of last year's attendees were individuals with rare diseases or family members and suggested virtual participation might be more cost effective.

PROVIDER AND PATIENT/FAMILY EDUCATION SUBGROUP REPORT OUT

Physician Representative reported the subgroup has not met since the last meeting. Members are waiting for clarity on RDAC's mission and advisory role before advancing programmatic ideas. Input from NORD and other state RDACs may help refine direction.

POLICY AND INSURANCE SUBGROUP REPORT OUT

The Department of Labor & Industry Representative provided updates on active policy items.

- Rare Disease Day Proclamation: A proclamation request can be submitted through the Governor's Office. Requirements include a purpose statement and a 4–6 "whereas" clause. The Physician Representative volunteered to draft language.
- Telehealth Clarification: A question regarding interpretation of the 21 day exemption and inclusion of telehealth is pending legal analysis.
- Medicaid Buy In: No sponsor identified yet.
- Step Therapy and Medical Nutrition: Additional comments were received; the subgroup will meet to review edits.
- Pending Items: Whole genome sequencing coverage, billing for genetic counseling, and coordination with the Newborn Advisory Council remain on the list but may not advance this session.



- Licensure Reform Task Force: The task force is discussing telehealth and intends to preserve Montana’s existing statutory framework while monitoring implementation gaps.

MEDIA, PUBLIC AWARENESS, AND STRATEGIC COMMUNICATION

Members discussed ways to increase RDAC’s visibility. Ideas included monitoring national rare disease stories, leveraging emerging experimental treatment centers in Montana, issuing news releases tied to national stories, and coordinating messaging across multiple media markets. Members noted the upcoming legislative biennium may be challenging due to anticipated debates around Medicaid and Medicare changes.

The Family Advocate Representative and Public Health Representative can help track emerging rare disease stories through their networks. The Academic Microbiology Representative offered to act as a conduit through MSU and Faculty Senate to help seed stories that local media might pick up. Members agreed to use personal networks to invite public participation in RDAC meetings.

MEETING OPERATIONS AND MEMBER FEEDBACK

The Chair invited feedback on meeting structure and facilitation and encouraged members to share suggestions for improvement.

RARE DISEASE DAY PROCLAMATION NEXT STEPS

The Department of Labor & Industry Representative, Physician Representative, and Chair will collaborate on drafting the proclamation language. The group plans to review and vote on the proclamation in September.

NEXT STEPS

The Chair will confirm whether RDAC Day has a virtual option and share registration materials. Members will continue outreach and visibility efforts.

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.

- September 24
- October 22
- November 19
- December: No meeting.