Montana Rare Disease Advisory Council
Meeting Minutes

Date: June 25, 2026
Time: 9:00-10:30am
Place: Zoom / Virtual Meeting

ROLL CALL AND ATTENDANCE

Members Present

- Michele McKinnie (Chair)
- Marshall Bloom
- Maggie Cook-Shimanek
- Jenn Banna
- Joe Cross
- Melanie Reynolds
- Brett Baker
- Caitlin Patera
- Erin Hoch
- Jeremy Royal
- Lynne Wood
- Deborah Gibson

Public Attendee(s)

- Amy Jenks

Members Absent/Late

- Patrick Secor
- Jacqueline Haven
- Kelsey Bell
- Dr. Lynne Wood

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

Council members introduced themselves by role and affiliation for roll call and public context. The Physician Representative joined later due to an urgent hospital consult, and several other designated members provided advance notice that they would be absent or arrive late. Participants were invited to update their display names in the virtual platform to show first name and role for the benefit of public attendees.

LEGISLATIVE REPORT: PROCESS, CONTENT, AND REFLECTION

RDAC had initially planned to use this meeting as a final review of the report as a council. However, internal deadlines for submissions changed in the interim and the report was required to be sent prior to this meeting. Members therefore provided their final input via email rather than through a live, line by line review.

The DPHHS Staff Liaison explained that after RDAC completes its draft, the report is reviewed by DPHHS leadership primarily for grammar and oversight and then formatted into a standard state template; substantive content from RDAC was not changed.

The Chair highlighted key elements of the submitted report: RDAC's mandate and duties, activities since January, membership (including remaining vacant seats), challenges identified using national rare disease "report card" data, and an opening message emphasizing that Montana is not yet adequately meeting the needs of residents living with rare diseases.

Late comments that arrived after the submission deadline have been retained for use in future work and subsequent reports.

RDAC intends to begin next year's report earlier so that a near-final draft is ready by late spring, allowing more time for live discussion before state review and formatting.

FUNDING AND RESOURCES

The council discussed its funding, and the DPHHS Staff Liaison reported that RDAC has a modest support budget of approximately $16,000 intended primarily for administrative purposes.

Possible uses include one in-person council meeting or engagement of a subject matter expert to present to RDAC.

The Staff Liaison will clarify whether the funding is annual, whether it can carry over, and whether it is subject to "use-it-or-lose-it" rules.

POLICY SUBGROUP REPORT-OUT

The Medical Director Representative (policy subgroup lead) summarized recommendations that appear in the report:

Step Therapy/Fail-First Protocols: Drafted example payer policies to allow exceptions when lower-tier medications are contraindicated, have already failed, or when patients are stable on a higher-tier medication that should not be changed.

Medical Nutrition Access: Drafted payer policy language, based on other states' statutes, to support coverage of medically necessary, life-sustaining nutrition for individuals who cannot tolerate typical foods due to rare disease.

Whole Genome Sequencing Coverage: Highlighted gaps in coverage and recommended improving access to whole genome sequencing to support timely diagnosis and treatment.

Telehealth Access to Out-of-State Specialists: Reviewed existing statutory language that allows out-of-state providers in good standing to practice in Montana for a limited number of days per year without full licensure and discussed clarifying whether the 21-day allowance is cumulative versus consecutive to better support ongoing rare disease follow-up care.

Rare Disease Day Recognition (February 28): Proposed recognizing Rare Disease Day in Montana to increase awareness and support outreach.

Genetic Counseling Billing and Reimbursement: Recommended addressing billing barriers so licensed genetic counselors can be appropriately reimbursed.

Medicaid Buy-In for Children with Disabilities: Discussed previously passed but vetoed Medicaid buy-in legislation that families strongly supported, noting long waiting lists for Medicaid waivers and interest in revisiting the bill with a new sponsor.

Support for Newborn Screening Panel Expansion: Recommended RDAC support the existing Newborn Screening Advisory Committee as it works to better align Montana's newborn screening panel with national recommendations.

PROVIDER AND PATIENT EDUCATION SUBGROUP REPORT-OUT

The Advanced Practice Provider Representative and Physician Representative described the subgroup's work:

Aim: Expand education for primary care and subspecialty providers to improve rare disease and medical complexity care within Montana.

The subgroup is exploring a statewide virtual provider education initiative, potentially in partnership with a university-based center that administers Project ECHO and other continuing education series.

Two models are under consideration: a Project ECHO–style program and a structured independent learning series.

Before any program launch, the subgroup will assess provider needs and interest and seek more detail on budget and administrative requirements.

The subgroup will also incorporate patient-facing information into its work, including simple guidance on existing telehealth statutes and processes that families and local providers can use when working with out-of-state specialists.

TELEHEALTH STATUTE AWARENESS AND PATIENT EMPOWERMENT

Discussion highlighted that statutes allowing limited out-of-state practice for providers appear to be poorly known among both providers and families, leading to unnecessary travel for brief follow-up visits.

Members suggested creating a concise “how-to” resource and website content explaining the statute, clarifying cumulative versus consecutive day use, and outlining steps for out-of-state providers to register or otherwise comply.

The Provider and Patient Education Subgroup was identified as the logical group to lead development of these materials.

Council members noted that better use of telehealth options could reduce travel burdens, stress for medically complex children, and costs.

GOVERNANCE, OFF-CYCLE RECOMMENDATIONS, AND SUBGROUP TRANSPARENCY

The Chair emphasized RDAC’s advisory role and noted that members may be called upon as informational witnesses when bills aligned with RDAC’s recommendations are considered.

RDAC discussed how to handle requests for recommendations between annual July reports and whether smaller committees or virtual votes could be used.

The DPHHS Staff Liaison reminded the council that, as a public body, RDAC must maintain transparency, including for subgroup activities; subgroup work and any off-cycle responses will need to be handled in ways that remain publicly accountable.

The Liaison will review practices used by other advisory councils and provide guidance on how RDAC can submit interim recommendations outside the annual report and what public notice requirements apply.

Until this guidance is clarified, subgroup leads will temporarily pause scheduling new subgroup meetings and continue reporting all subgroup work at the regular monthly RDAC meetings.

PUBLIC COMMENT

One member of the public, an administrator of the state's self-funded employee health plan, attended and briefly introduced their role and interest in RDAC's work, given the prevalence and cost of rare disease claims in their population.

The attendee expressed willingness to consider participating more formally if appropriate for RDAC's insurance/payer seat and noted that they already monitor health-related legislation closely.

The DPHHS Staff Liaison will follow up with the attendee regarding the process for applying to serve on RDAC.

OPEN QUESTIONS / FUTURE TOPICS

Challenges in accessing and maintaining life-saving specialty medications when children have split family situations, limited communication between caregivers, and complex coordination between insurance policies and Medicaid.

Questions about how billing classifications such as "pharmacy" versus "medical" affect coverage and access for similar therapies.

Barriers to participation for wheelchair users and others with mobility needs in community activities and special events, including limited accessible parking and seating.

Interest in whether RDAC can make recommendations related to coverage of non-traditional therapies such as music therapy and equine therapy, especially as philanthropic funding sources are closing and families face gaps in care.

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

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

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