Day by Day — Fri 31 Jul to Mon 10 Aug 2026

Written fresh for uterine leiomyosarcoma on 2026-07-31. Nothing here is carried over from the earlier pack.

What is different from a week ago: she is not undiagnosed and unmanaged. She saw **Dr. David Ririe** (Heber Valley Medical Oncology, Intermountain) on **29 July** for an 80-minute initial consult. He has read the PET and the amended pathology with the family, referenced NCCN guidelines, and written a plan.

So this week is not "find an oncologist." It is three things:

> **1. Get the slides moving.** They are the bottleneck for everything else. **2. Line up a sarcoma second opinion in parallel with the Mayo wait, not after it. 3. Be ready for the video follow-up with the right questions.**

Legend: `CALL` · `ONLINE` · `PAPER` · `REST`

The two fixed dates

WHEN	WHAT	NOTE
~Wed 5 Aug	Video follow-up with **Dr. Ririe**	"a week or so" per the 29 Jul note — confirm the exact date
Mon 10 Aug, arrive 9:45am	**Cedars-Sinai Pulmonary**, Beverly Hills — Robert N. Wolfe, MD	Pre-existing pulmonary appointment. Now doubles as a southern-California foothold

Everything below works backwards from those two.

FRIDAY 31 JULY — today

The one job today is **starting the slide request**, because it has the longest tail and blocks the most.

- `CALL` **Intermountain / McKay-Dee pathology.** Ask three things:
  1. Where are the blocks and slides from accession **CLS-24-094710** physically right now — still at Intermountain, in transit to Mayo, or at Mayo?
  2. **How much material is left?** Roughly how many unstained slides could be cut from what remains?

3. What is the process and turnaround to release material to a second institution, and what form is needed? **Get a name and a direct number.** Named humans return calls.

- `CALL` **Mayo pathology, (480) 301-8021** — status of the pending consult. Have accession **CLS-24-094710** and order **730260012** ready. Ask which campus is reading it and who the pathologist is. *(If they will only speak to the referring institution, that is the answer to relay to McKay-Dee — see `00-MAYO-AZ-PHONE.md`.)*
- `ONLINE` Download whatever the MyChart "document you requested" is — there is one waiting.
- `PAPER` Print **`05-QUESTIONS-FOR-DR-RIRIE.md`**. Read it once.

Tonight

- `CALL` **National Leiomyosarcoma Foundation, (303) 808-3437** — listed as 24/7. Disease-specific, free, and the closest thing to a sarcoma nurse navigator that exists. Ask them what a newly diagnosed metastatic uLMS patient should be doing in week one.

SATURDAY 1 AUGUST — organise, no calls

Nothing clinical is open. This is the right use of the day.

- `PAPER` **Build the records packet.** Every second-opinion centre asks for the same four things:
  1. Pathology report — **original AND amended**, including any addenda
  2. Pathology slides or blocks *(the request started yesterday)*
  3. Imaging on disc — the actual **DICOM**, not just the radiologist's report. That means the **PET from 20 Jul** and any CT
  4. Operative note from the **19 Sep 2024 TAH/BSO**
- `PAPER` One-page timeline on a single sheet: Sep 2024 surgery → 2026 cough and dyspnea → 20 Jul PET → 23 Jul lung biopsy → 28 Jul pathology amended → 29 Jul oncology consult. Dates are the spine. Every new doctor will ask for exactly this.
- `ONLINE` Read **one** thing: the NLMSF site. Not a search engine, not forums.
- `ONLINE` Look at **LMSproject (Count Me In)** and the **Rare Cancer Research Foundation**. Both let a patient put her tumour tissue into the research pipeline directly, free, with no gatekeeper and no research centre needed. Sign-up is online and can be started before anything else is settled.

Rest of the day

`REST`. Genuinely.

On statistics: whatever numbers turn up online tonight will be population averages that lag current treatment, and they do not know her age, her performance status, or that she is treatment-naive with resectable-question disease. Skip them. Ask Dr. Ririe instead.

SUNDAY 2 AUGUST — prepare the week

- `PAPER` **Write the call script** and reuse it verbatim all week:

> *"My [relationship] is 39, diagnosed with metastatic uterine leiomyosarcoma. She is under Dr. Ririe at Intermountain Heber Valley, with a pathology over-read pending at Mayo. I would like to arrange a second opinion with a sarcoma specialist. What do you need from me?"*

- `PAPER` **Call log sheet:** date, who, number, name of person, what they said, next step, callback date.
- `PAPER` **Decide who owns what.** One person owns calls, one owns paperwork. Two people doing both means duplicated calls and missed items.
- `REST` Evening off. Monday is heavy.

MONDAY 3 AUGUST — the sarcoma second opinion

The goal today is **one sarcoma centre engaged**, running in parallel with Mayo.

- `CALL` **Huntsman Cancer Institute** — the NCI-designated comprehensive centre closest to Park City. Ask for sarcoma, not general oncology.
- `CALL` **One California sarcoma centre.** UCLA is the standout for this diagnosis — they put a gynaecologic oncologist on the sarcoma expert team, which is exactly the gyn-onc / sarcoma-onc fork uLMS falls into. City of Hope is the alternative. *(Rankings and named specialists: `02-centers-and-specialists.md` §2)*
- Ask every centre the same five:
  1. Self-refer, or physician referral required?
  2. What records do you need, and where do I send them?
  3. Do you need slides or blocks — and do **you** request them, or do I?
  4. Current wait for a new sarcoma patient?
  5. Do you take [insurance]?
- `CALL` **Confirm the Ririe video follow-up date** and get it on the calendar.

TUESDAY 4 AUGUST — insurance and money

Unglamorous. Decides what is actually reachable.

- `CALL` **Insurance**, number on the card. Ask for a **case manager assigned to oncology, by name.** Worth the hold music.
  - Which sarcoma centres are in network?

    - Are **routine patient costs during a clinical trial** covered?
    - Prior authorisation needed for an out-of-state second opinion?
- `CALL` **Sarcoma Alliance, (415) 381-7236** — they run a second-opinion grant programme. Ask what it covers even if cost is not the barrier; they also know which centres are responsive.

WEDNESDAY 5 AUGUST — the video follow-up *(confirm date)*

- `PAPER` **Print the questions doc.** Mark the top six.
- Two people on the call. One listens, one writes.
- Ask early: "*Do you mind if I record this?*" Most clinicians say yes.
- The three that add something to his plan, all with closing windows:
    - **Trials before first-line therapy** — the window closes when treatment starts
    - **Metastasectomy** — is resection of the lung nodules on the table
    - **Frozen tissue at the next procedure** — formalin kills the cells, and this is reportedly not done routinely even at top centres unless asked in advance
- Before hanging up: "*Who is my point of contact between visits, and the direct number?*"

THURSDAY 6 AUGUST — chase day

Nothing new. Close loops.

- `CALL` **Mayo again** if no result yet. General pathology consultation is published at 4–8 business days; the specimen went out around 23–29 July, so this is a fair point to ask.
- `CALL` Slides — confirm the release was **actually processed**, not just requested. A request "submitted" is not a request in progress.
- `CALL` Any sarcoma centre that has not called back. Ask about cancellation lists.
- `PAPER` Update the timeline and the call log with everything learned.

FRIDAY 7 AUGUST — assemble for Monday

- `PAPER` Pack the folder for the Cedars appointment: records, timeline, questions, insurance card, medication list, notebook.

- `PAPER` Write the pulmonary-specific questions — this is a **lung** visit, and the lung is where the metastatic disease is:
  - Do you have the 20 Jul PET and the 23 Jul biopsy result?
  - Are you coordinating with Dr. Ririe in Utah?
  - Are the nodules resectable, and is thoracic surgery worth a conversation?
- `CALL` Confirm Monday's appointment and what to bring.

SAT 8 – SUN 9 AUGUST

`REST`. One small task each day, maximum.

- Saturday: read the Monday questions out loud once so they are familiar rather than read cold in the room.
- Sunday: confirm who is going, transport, folder packed.

Do not spend this weekend reading survival statistics. It is the most common thing families do and it reliably makes the following week worse without improving a single decision.

MONDAY 10 AUGUST — Cedars-Sinai pulmonary, 9:45am

Beverly Hills. Robert N. Wolfe, MD.

- Bring the folder. Bring a second person.
- This is a **pulmonary** appointment, not oncology — but the lungs are where the disease is, so it matters.
- Worth raising: whether Cedars' own sarcoma programme should see her while she is in southern California, given the family splits time between Park City and SoCal. *(Cedars is not NCI-designated; see `02-centers-and-specialists.md` §2 for how it ranks.)*

THE ONE-SCREEN VERSION

DAY	THE ONE THING
Fri 31 Jul	**Start the slide request.** Call Mayo for consult status
Sat 1 Aug	Build the records packet. Sign up for LMSproject / RCRF
Sun 2 Aug	Write the call script. Decide who owns calls vs paperwork

DAY	THE ONE THING
Mon 3 Aug	**Engage one sarcoma centre** — Huntsman and/or UCLA
Tue 4 Aug	Insurance case manager, by name
Wed 5 Aug	**Video follow-up with Dr. Ririe** — top five questions
Thu 6 Aug	Chase Mayo, chase slides, chase callbacks
Fri 7 Aug	Pack the folder, write the pulmonary questions
Sat–Sun	Rest
Mon 10 Aug	Cedars pulmonary, 9:45am

IF THE WEEK FALLS APART

Do these three and let the rest go.

1. **Get the slides released.** Nothing else can start without them.
2. **Call the National Leiomyosarcoma Foundation, (303) 808-3437.** Free, disease-specific, and they will carry some of this.
3. **Ask Dr. Ririe two things with closing windows:** trials before first-line therapy, and whether frozen tissue can be preserved at any future procedure. Both are free and neither can be done retroactively.

CALL THE DOCTOR OR GO TO THE ER

Not routine. Ask Dr. Ririe to confirm this list for her specifically, and what number to call after hours.

- **Worsening shortness of breath**, new or increasing oxygen need
- **Coughing up blood**
- **Sudden sharp chest pain**, or pain worse on breathing in
- **Fever**, or any sign of infection
- **New severe pain anywhere**, particularly bone or abdominal
- **Fainting, confusion, or a sudden change in alertness**

Nothing in this document is medical advice. These are questions to ask and people to call. Her doctors decide.