

Questions for the Next Oncology Visit

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For the video follow-up with **Dr. David Ririe** (Heber Valley Medical Oncology), expected around the first week of August 2026.

His plan from 29 July is already sound: await Mayo, present at tumour board, run RET/NTRK/ALK fusion testing, follow up by video, then trials versus doxorubicin/trabectedin once the diagnosis is confirmed. These questions are not a challenge to that plan. They are the gaps around it.

Print this. Take notes on it. Bring a second person.

The six that matter most

If the call runs short, ask these. The first three are the ones **not already covered** by the 29 July plan — they add something rather than confirm it, and all three have windows that close.

1. **Are there trials we should screen for BEFORE starting first-line therapy?** ⌚ *Time-critical.* Many sarcoma trials require treatment-naïve status or cap the number of prior lines. She has had surgery only, so she currently qualifies for the widest possible set. **That window closes the day systemic therapy begins** — and it cannot be reopened.
2. **Are the lung nodules potentially resectable? Is metastasectomy on the table?** Surgically removing limited lung metastases is a real option in sarcoma that does not exist in most cancers. It is not mentioned in the 29 July note, so it is worth asking directly whether it has been considered and ruled out, or simply not yet discussed.
3. **If there is any further tissue procedure, can a portion be preserved as viably frozen or flash-frozen tissue rather than all of it going to formalin?** ⌚ *Also time-critical, and only possible before the procedure.* Formalin — standard pathology processing — kills the cells. Frozen tissue is what allows her tumour to be grown as an organoid or cell line and tested against drugs. The Milken Institute guide states plainly that this is **not standardised and often not done routinely, even at top-tier cancer centres**, unless someone asks in advance. Worth asking too whether the 23 July lung biopsy left any frozen or unstained material, and whether pre-treatment blood is worth banking.
4. **Which Mayo campus is reading the specimen, and who is the pathologist?** Mayo Arizona does not list bone and soft tissue among its consultation subspecialties, so the case may have been logged as "other" or routed to Rochester, where Mayo's named sarcoma pathologists actually sit. Worth confirming rather than assuming.

5. Would you support a second opinion at a high-volume sarcoma centre now, in parallel with the Mayo wait — rather than after it? Sequential adds weeks. Parallel costs nothing but a records request.
 6. Should we be requesting slides or blocks now, so they are ready the moment a second centre is engaged? Slide requests run one to three weeks and most centres will not schedule until material arrives. This is the single most common source of delay.
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About the diagnosis

1. What does "probable" mean here in practice — what would the Mayo read have to show to change the diagnosis rather than confirm it?
 2. The report gives the tumour as 6.0 cm in the final diagnosis and 7.0 cm in the gross description. Does that discrepancy matter for staging or treatment?
 3. The specimen was recorded as **disrupted**. What does that mean for how this was handled in 2024, and does it change anything about the plan now?
 4. Has anyone assigned an **FNCLCC grade** — mitotic count, necrosis, differentiation? Is that in the amended report or still to come?
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About the disease right now

1. The PET showed possible uptake in the **right adrenal, liver, or superior kidney**. What is being done to characterise that?
 2. Is the disease confined to lung, or should we assume it is not until that uptake is resolved?
 3. Are the lung nodules potentially resectable, or is that off the table? **Metastasectomy** — surgically removing limited lung metastases — is a real option in sarcoma that does not exist in most cancers. Is it being considered here?
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About treatment and timing

1. What is the realistic timeline — when would treatment start if Mayo confirms?
2. Your note says "doxorubicin/trabectedin." Do you mean the two together, or one and then the other? Worth pinning down. The Milken Institute guide tabulates eight major LMS chemotherapy trials. Five first-line trials were negative. The one first-line result that came back positive was **trabectedin combined with doxorubicin** (NCT02997358) — and that was on progression-free survival, meaning longer before the cancer grew, not proven longer life. If the combination is what the evidence supports, is that the intent here?
3. Doxorubicin versus trabectedin versus a combination: what else decides it?
4. Are there trials we should screen for before starting first-line therapy? Many sarcoma trials require treatment-naïve status or cap prior lines. She has had surgery only. That window closes the moment systemic therapy begins.
5. If a trial looks right but is not in Utah, how do we handle that logistically?

About where she is treated

1. How many uterine leiomyosarcoma patients does this practice see in a year?
2. Do you anticipate referring her to a sarcoma specialist, or managing here with tumour board input?
3. **Who is the sarcoma specialist you would send your own family to?** (*Ask this one. It is the highest-yield question in this document and no amount of research can answer it.*)

Practical

1. Who is the point of contact between visits, and what is the direct number?
2. Is there a nurse navigator or coordinator assigned to her?
3. What symptoms mean call immediately rather than wait for the next visit?
4. Should she see palliative care alongside treatment for symptom management? (*Say "alongside the current treatment" — it preempts the misreading.*)
5. Any activity restrictions in the meantime?

Worth raising once

1. She had **early-stage differentiated thyroid cancer treated surgically in 2021**. Two primary cancers before forty — is that worth a conversation about germline testing, for her and potentially for the twins?

Notes

(space for answers)