

Patient talk: Patient talk: How to minimize miscommunications when advocating for your care

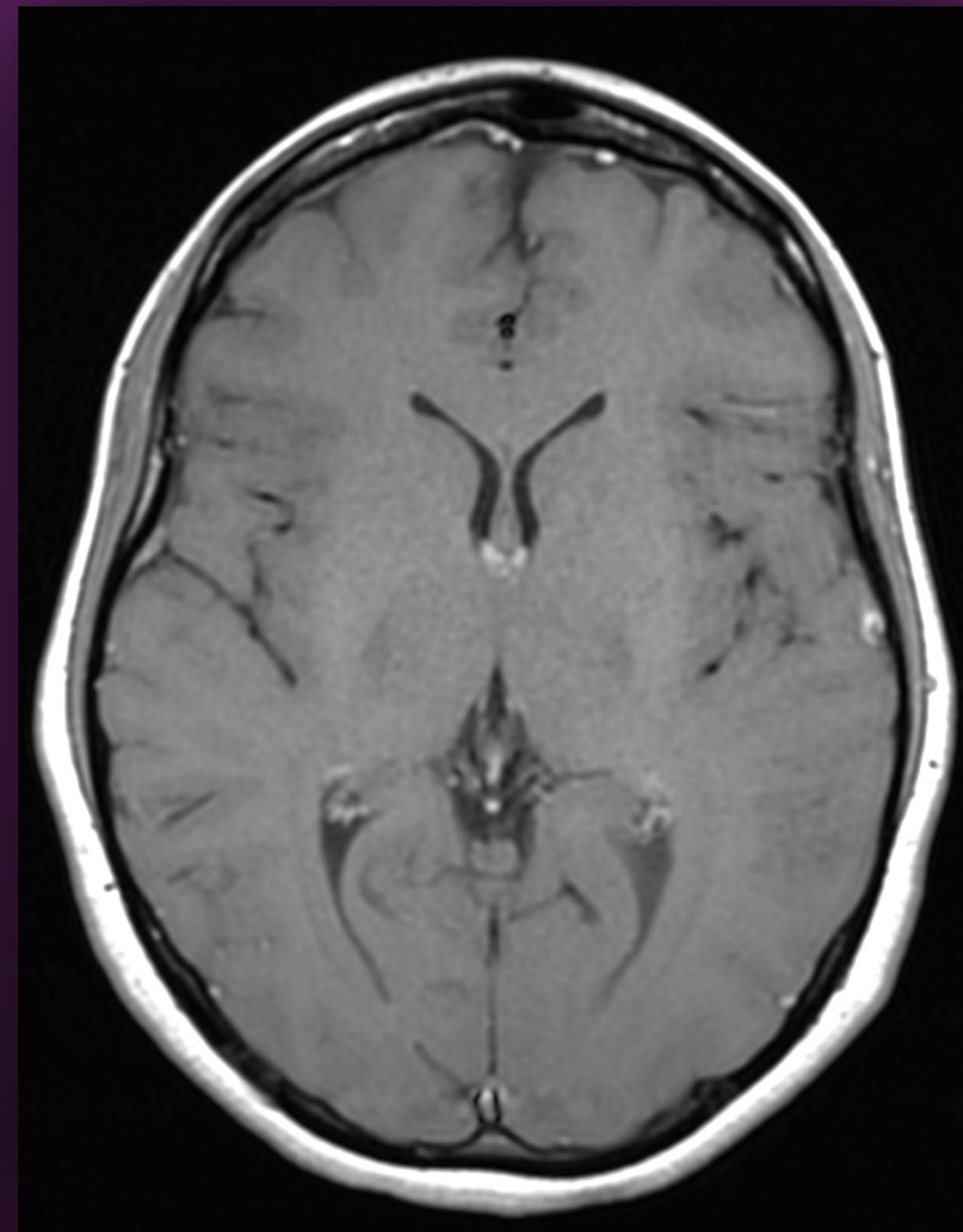
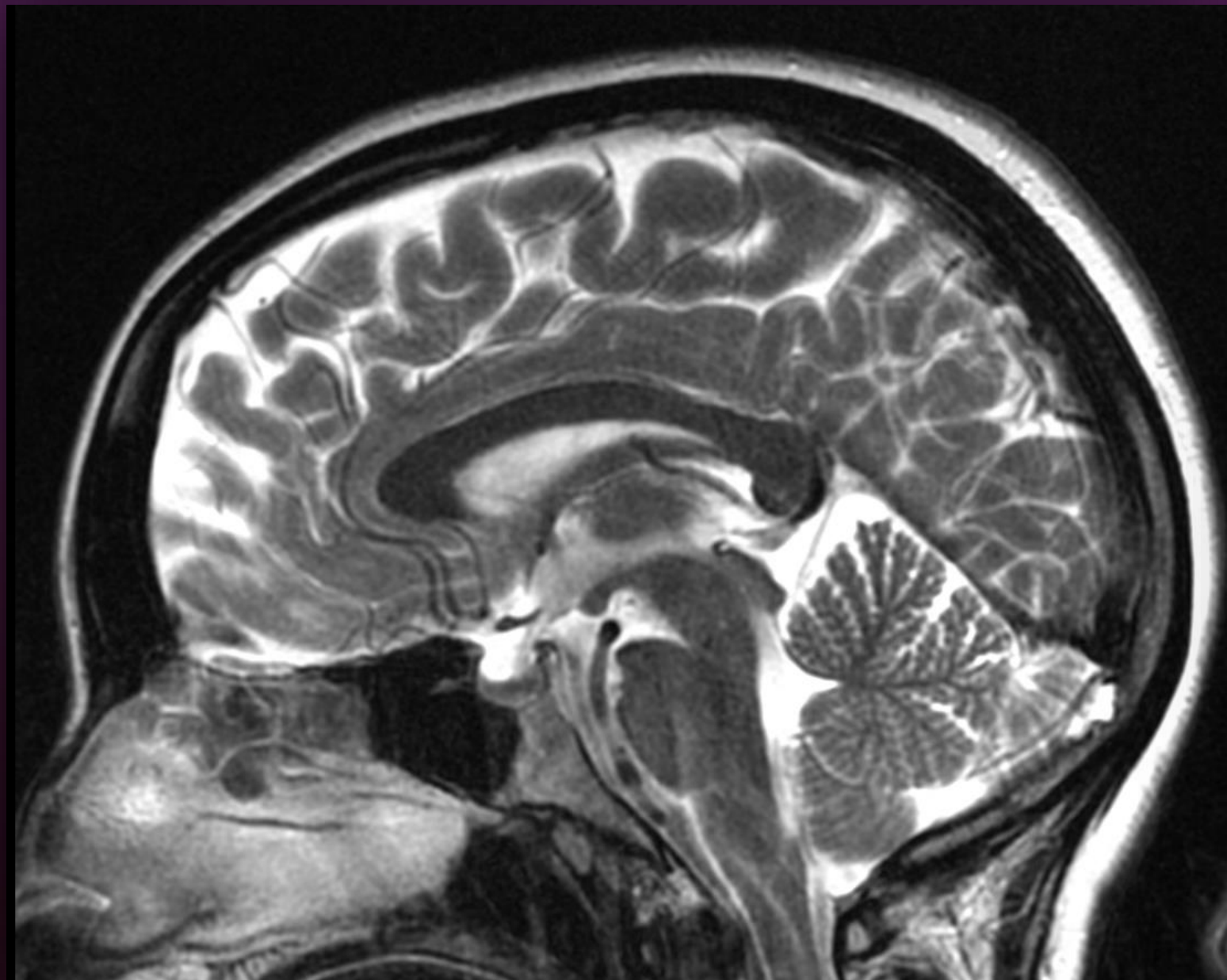
Aubrey Bolan



My Experiences with SIH

No measurable brain sag or dural/venous engorgement at any point

Bern score: 0/9



The critical task of
telling the story of our leak
is in our own hands.



Bridging the Gap

Make a Communication Game Plan

Use collaborative tools to take notes

Examples:

- Apple iCloud Notes
- Google Docs

What would you like to get out of your next appointment?

Examples:

- Referral to specialist, spinal CSF leak center, etc.
- Imaging
- Medication
- FMLA/Disability paperwork



Tell Your Spinal CSF Leak Story

- **Why are your symptoms worthy of your doctor's action?**
 - Are they debilitating or potentially life-threatening?
- **What improves (or worsens!) your symptoms?**
 - Physical exertion
 - Time
 - Position
 - Diet (caffeine, fluids, salt, Vitamin A)
- **What happened before your leak symptoms began?**
 - Workout (crossfit, pilates, yoga, boxing, etc.)
 - Childbirth
 - Heavy lifting
 - Physical trauma
 - Surgery
 - Spinal intervention
- **How are your symptoms dramatically different from your "normal"?**

Peterson MC, Holbrook JH, Von Hales D, Smith NL, Staker LV. Contributions of the history, physical examination, and laboratory investigation in making medical diagnoses. West J Med. 1992 Feb;156(2):163-5. PMID: 1536065; PMCID: PMC1003190.



Demonstrate Credibility

Bring medical records that strengthen your story:

- Notes from previous providers
- Reports from relevant procedures, such as:
 - Lumbar puncture
 - Spinal surgery
 - Spinal block or epidural
 - Imaging (DSM, CT myelogram, MR myelogram, MRI, etc.)
 - Treatment (epidural blood patch, embolization, surgery)
 - Imaging discs and reports

Bring a “support person” if possible!

- Share their perspective on your leak symptoms
- Advocate with you
- Take notes
- Debrief after appointment



Addressing Potential Roadblocks



Errors in medical history

- Respectfully speak up about misunderstandings
- Example: Mistaken history as yoga teacher that justified cervicogenic headache misdiagnosis

Misdiagnosis

- Respectfully ask “why?”
- Address any misunderstandings about your symptoms or history
- Present evidence, such as:
 - Specialist evaluations
 - Diagnostic imaging
 - Treatments tried/failed

When I Reached an Impasse . . .



First Institution:

Right lateral decubitus PCCTM

Possible CVFs called at T10-11 and T11-12
Subsequently embolized



Left lateral decubitus PCCTM T11-12

First Institution:



Second Institution:



Right lateral decubitus PCCTM T3-4

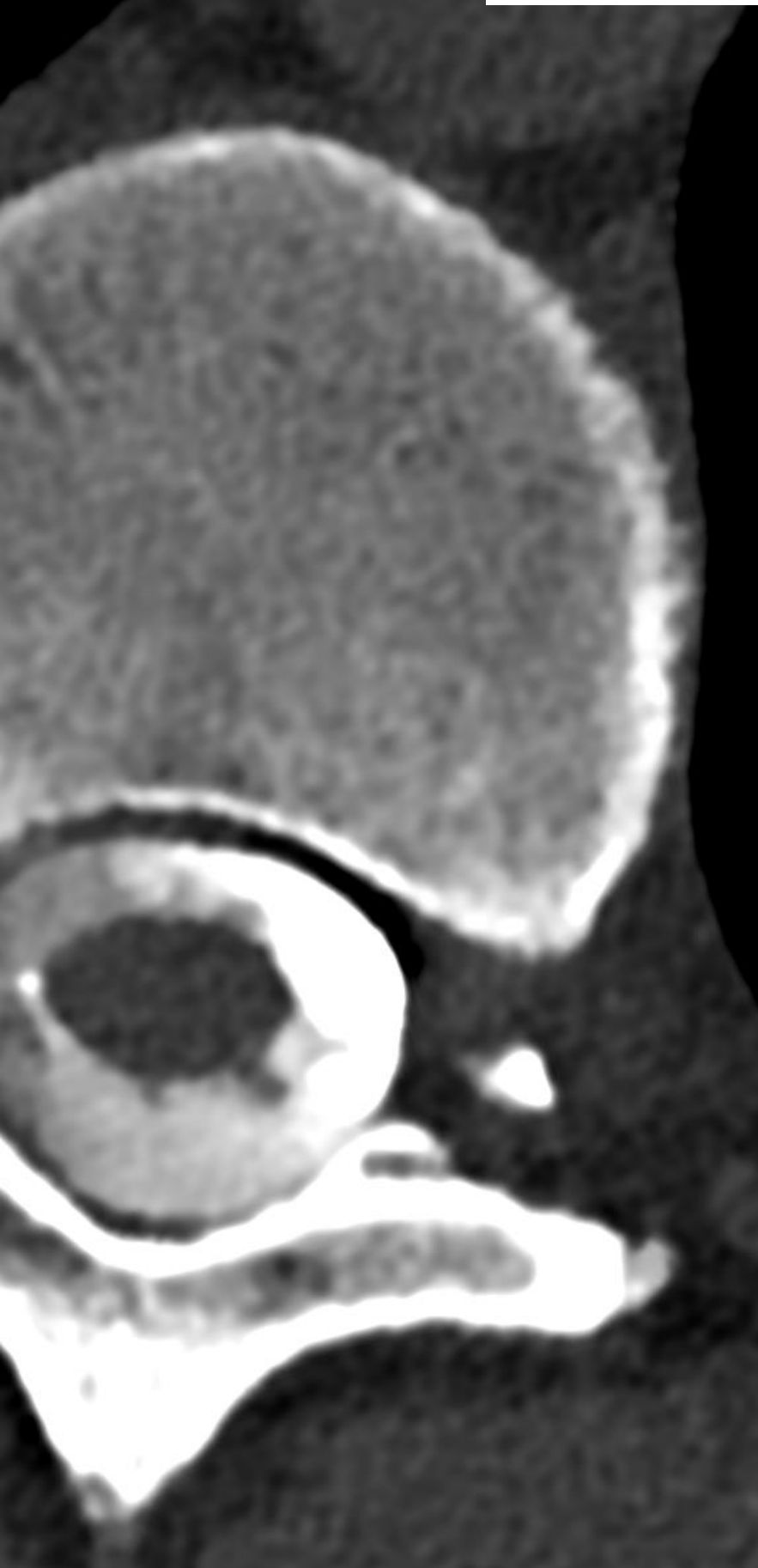
First Institution:



Second Institution:



Left T11-12

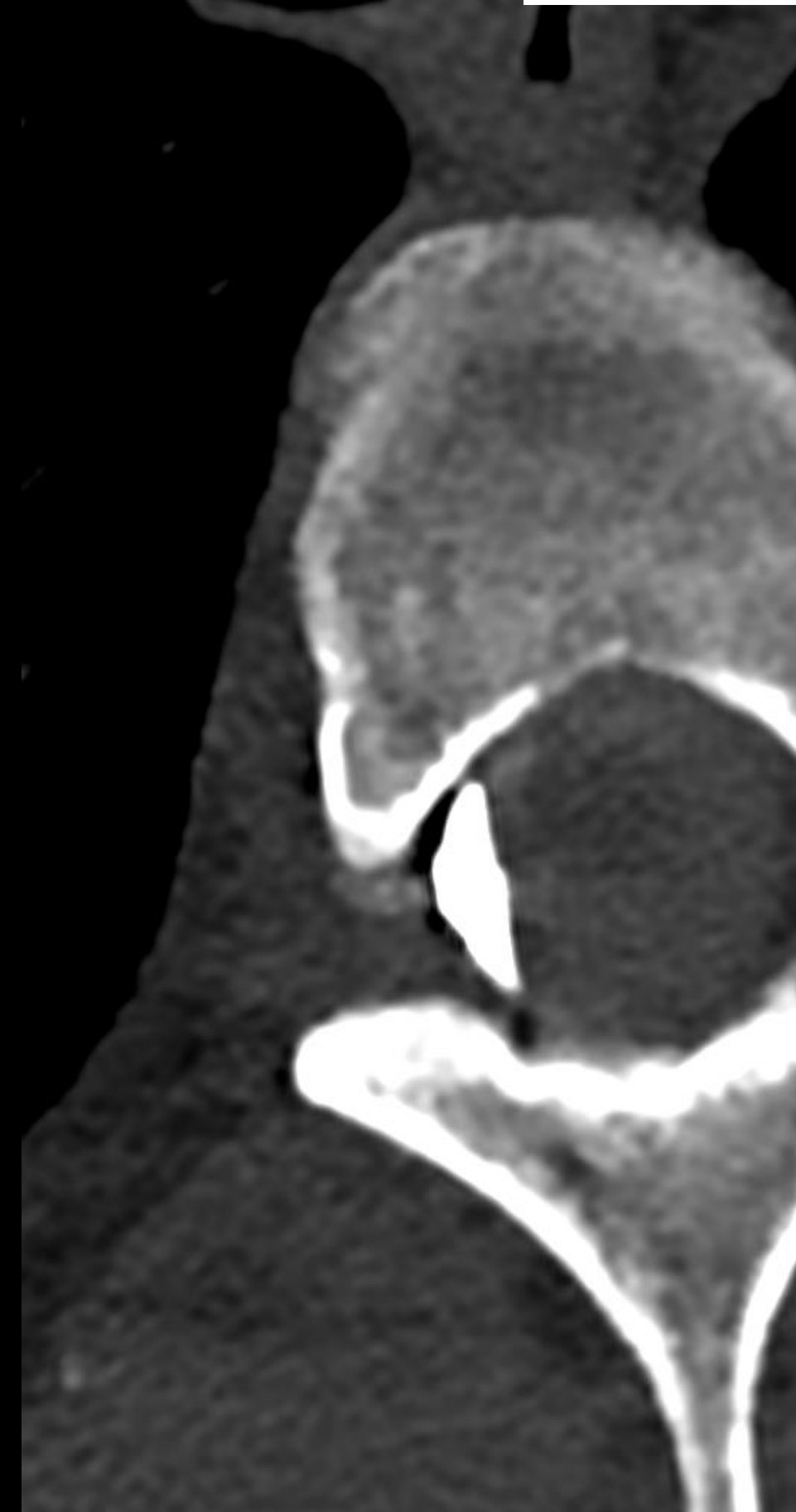


First PCCTM
(First Institution)

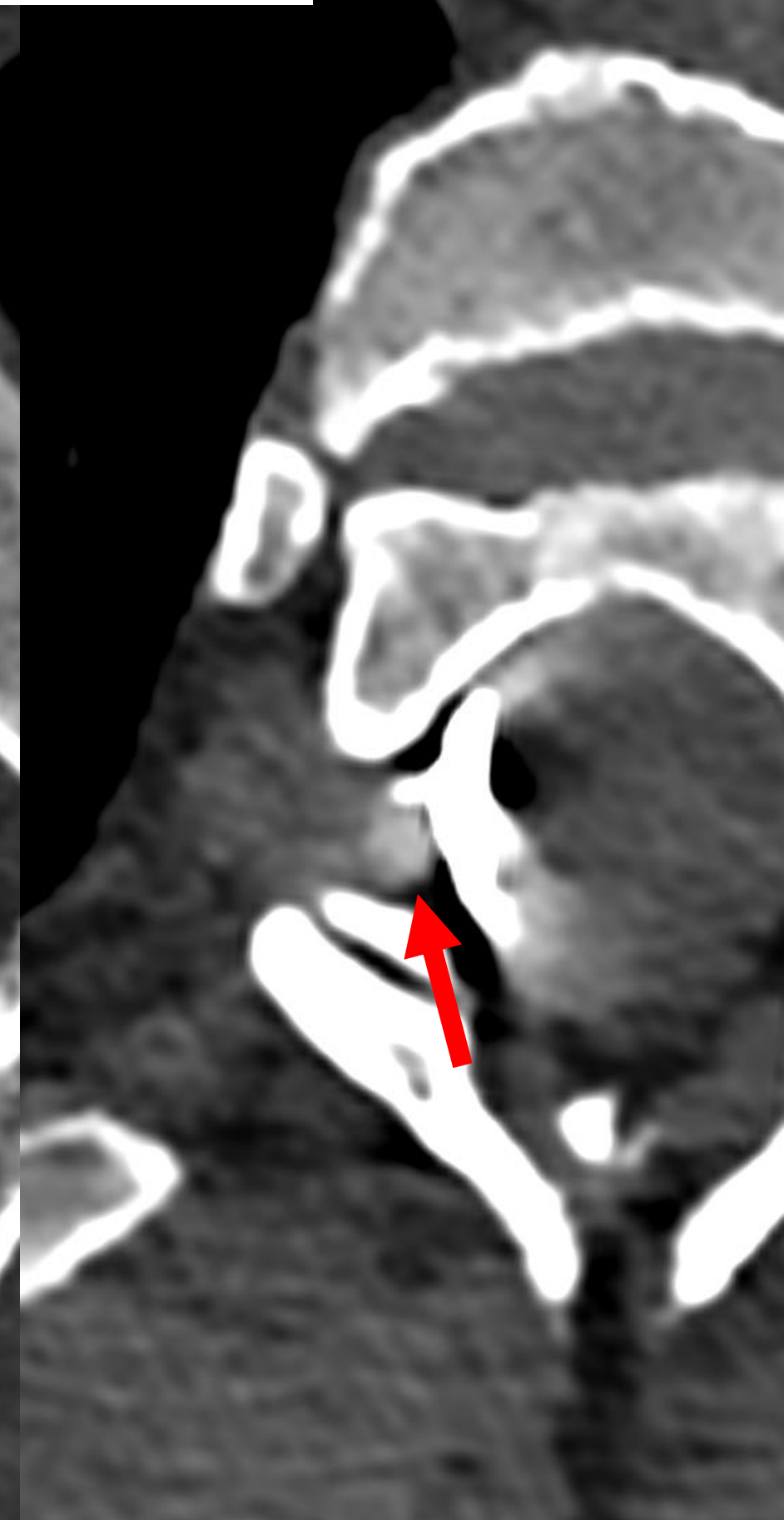


Second PCCTM
(Second Institution)

Right T3-4



First PCCTM
(First Institution)



Second PCCTM
(Second Institution)

Moving Past an Impasse

Consider seeking care elsewhere if:

- You are interested in different:
 - Diagnostic techniques
 - Treatments
 - Specialists
- Your current provider:
 - Treats you with disrespect
 - Makes you feel unsafe



A Lasting Recovery



"Sealaversary"

**Celebrating 1 Year Without
Spinal CSF Leak Symptoms!**

**I wouldn't be here now
without the
compassionate physicians
who chose to
listen to my story
in spite of my
negative imaging**



Bridging the Gap

Thank you