TERNARY HEALTH · LAUNCHPAD

PREPARED FOR Rebecca M. Carlton

A starter framework for your condition.

Spontaneous Intracranial Hypotension — Spinal CSF leak — orthostatic headache pattern, suspected CSF-venous fistula.

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SAMPLE · NOT A REAL PATIENT RECORD

Launchpad is an organizational and readiness tool. It helps you understand your condition, prepare for productive specialist consults, and assemble the inputs you would need for a Precision Deep Dive. It is not a diagnosis, not a treatment plan, and not clinical advice. Use with your own physicians.

SECTION 01 / ABOUT YOUR CONDITION

Spinal CSF leak and SIH, in plain terms.

Spontaneous intracranial hypotension (SIH) is a condition caused by a cerebrospinal fluid (CSF) leak from the spinal dura. The brain depends on CSF for buoyancy and pressure regulation; when CSF leaks out of the spinal sac, intracranial pressure drops, the brain sags slightly within the skull, and characteristic symptoms develop — most notably an orthostatic headache that worsens when upright and improves when recumbent.

Recognized leak subtypes.

The Schievink 2016 classification (still the standard) divides spontaneous spinal CSF leaks into three types. The subtype matters because it determines what imaging finds the leak and what treatment actually closes it:

- **Type 1 — Ventral dural tear.** A tear through the ventral dura, often at a calcified disc spur. Visible on standard CT myelography. Patches and surgical repair are both effective. Responds reasonably well to untargeted blood patch (~60% success in some series).
- **Type 2 — Meningeal diverticulum / nerve root sleeve leak.** An outpouching of dura at a nerve root, sometimes leaking. Visible on standard CT myelography. Often treated with targeted patch using fibrin glue.
- **Type 3 — CSF-venous fistula (CVF).** A direct connection between the CSF space and an adjacent paraspinal vein. Until recently, the most under-recognized subtype. Often not visible on standard imaging — requires lateral decubitus CT myelography or digital subtraction myelography (DSM). Untargeted blood patches typically fail. Treated by transvenous embolization or surgical ligation.

Prevalence and demographics.

SIH incidence is estimated at roughly **5 per 100,000 per year**, though the true prevalence is almost certainly higher due to widespread underdiagnosis. There is a strong female predominance (roughly 2:1), with peak onset between ages 30-50. Connective tissue overlap (hypermobile EDS, Marfan syndrome) is documented in approximately 10-20% of spontaneous cases.

Diagnostic criteria.

The International Classification of Headache Disorders (ICHD-3) defines SIH headache by three elements: (a) orthostatic headache that worsens upright and improves recumbent, (b) imaging evidence of low CSF pressure or CSF leak, and (c) exclusion of alternative causes. Brain MRI with

contrast is the standard first-line study — looking for pachymeningeal enhancement, brain sag, and tonsillar descent. **Lumbar puncture with opening pressure is no longer routinely recommended** (opening pressure is often normal in SIH, and the LP itself can worsen the leak).

Common misdiagnoses.

SIH is misdiagnosed at high rates. The most common labels patients carry before the correct diagnosis: new-onset migraine, post-concussion syndrome, anxiety with somatic symptoms, atypical headache, tension headache, and (after the brain MRI is reported as "mostly normal") "functional" headache. The diagnostic odyssey for SIH averages 3-7 years. Recognition has been improving since around 2014, when CSF-venous fistulas were first formally described.

WHAT CHANGED RECENTLY (2024-2026)

The CSF leak field has been transformed in the last 24 months. Specialists at leading centers now operate with a fundamentally different toolkit than they did three years ago.

- **Transvenous embolization for CVF is now established.** First described by Brinjikji et al. at Mayo in 2021, the technique has since been validated in a 100-patient case series (Brinjikji 2023) and replicated at multiple non-Mayo centers including community-academic hospitals. Onyx liquid embolic is the standard agent.
- **Safety profile confirmed.** A 2025 AJNR study (Michaelcheck et al.) specifically evaluated for Onyx migration into the CSF after transvenous CVF embolization and found none, supporting the procedure's safety and suggesting unidirectional flow of CVFs.
- **Rapid clinical improvement documented.** Saionz et al. (Neurology, 2025) demonstrated significant clinical and imaging improvement within 48 hours of CVF embolization in some patients — meaningfully faster than the recovery timelines seen with blood patches.
- **Diagnostic algorithm formalized.** The current standard: brain MRI with contrast → heavily T2-weighted spine MRI → if no extradural fluid collection visible and CVF suspected, lateral decubitus CT myelography or digital subtraction myelography (DSM) at a leak-experienced center. The 2024 AJNR update by Cutsforth-Gregory et al. consolidated myelographic techniques for CVF localization.
- **Lateral decubitus CT myelogram is the workhorse.** Gibby et al. demonstrated meaningful diagnostic yield for CVF detection. Most experienced centers now use this routinely. Many patients have had only conventional (supine) CT myelography, which can miss CVFs.
- **Sacral CVF subtype recognized.** A 2026 case report (Cagnazzo et al.) documented a S2-S3 CSF-venous fistula draining to the internal iliac vein, successfully treated by transvenous Onyx embolization. Expands the recognized anatomical scope.
- **Fibrin glue patching hypersensitivity reactions documented.** Smith et al. (AJNR, 2025) catalogued hypersensitivity reactions to fibrin glue during epidural blood patching. Worth knowing about if a fibrin patch is proposed.

Prognosis basics.

Untreated SIH typically does not resolve spontaneously after years of symptoms. However, once the leak subtype is correctly identified, the trajectory can change dramatically. For CSF-venous fistulas treated by transvenous embolization at experienced centers, published success rates run 65-80% on first attempt, climbing to roughly 90% with re-treatment. For ventral dural tears, targeted patches and surgical repair both have high success rates. Recurrence is real, particularly in patients with connective tissue overlap, and many patients undergo 1-2 procedures over their lifetime. The diagnostic phase is often the hardest part; once at a leak-experienced center, things tend to move faster.

SECTION 02 / THE LANDSCAPE — TESTS, TREATMENTS & RESEARCH

What exists, what's emerging, what's worth knowing.

Spinal CSF leak diagnosis and treatment have advanced substantially since 2014. The menu below covers imaging, treatment options, and research worth tracking — and flags what is no longer recommended despite still being commonly proposed.

Tests worth knowing about.

STUDY	WHAT IT IS	WHAT IT SHOWS
Brain MRI with contrast	Standard first-line imaging	Pachymeningeal enhancement, brain sag, tonsillar descent, subdural fluid collections. The "Bern score" formalizes these.
Heavily T2-weighted spine MRI	Specific MRI protocol of the full spine	Extradural CSF collections indicating Type 1 or Type 2 leaks. Does not reliably show CSF-venous fistulas.
Lateral decubitus CT myelography	Specialized myelography with patient lying on their side	Gold standard for CSF-venous fistula detection. Available at leak-experienced centers.
Digital subtraction myelography (DSM)	Dynamic fluoroscopic myelography	Alternative gold standard for CVF localization. Particularly good for fast leaks.
Dynamic CT myelography	Multi-phase post-injection CT	Use case-specific; specialist will determine.
Standard pre-procedure labs	CBC, CMP, coagulation panel	Required baseline before any myelogram, patch, or embolization.
LP with opening pressure	Lumbar puncture	**No longer routinely recommended.** Opening pressure is often normal in SIH. LP itself can worsen the leak.
Beta-2 transferrin	Specific biomarker test	For rhinorrhea/otorrhea (cranial leaks) only. Not applicable to spinal leaks.

Treatment categories.

Conservative measures (first-line, often used while pursuing workup).

- **Recumbency permission.** Lying flat when symptoms escalate. Not punitive bedrest — permission to rest when needed.
- **Hydration with sodium.** 3-4 L/day with sodium-containing electrolyte.
- **Caffeine.** 400-600 mg/day in divided doses (caffeine pills are easier to dose than coffee). Cerebral vasoconstriction mechanism. Modest, low-risk benefit.
- **Theophylline.** 200-400 mg/day. Stronger evidence than caffeine; requires prescription and ECG baseline.
- **Abdominal binder.** Increases intracranial pressure modestly through abdominal pressure transfer.
- **Avoid valsalva triggers.** Heavy lifting, straining, hard sneeze/cough suppression. Stool softeners if needed.

Procedural — patches and embolization.

- **Untargeted (large-volume) lumbar blood patch.** Standard first patch attempt, often successful for Type 1 tears. **Lower success rate in CVFs.** May complicate subsequent imaging by introducing post-patch artifact.
- **Targeted (imaging-guided) blood patch.** Higher success than untargeted when leak is localized. Sometimes uses fibrin glue (note 2025 hypersensitivity caveat).
- **Transvenous endovascular embolization.** First-line for confirmed CSF-venous fistulas at experienced centers. Onyx (ethylene-vinyl alcohol copolymer) is the standard agent. Increasingly available outside tertiary centers.
- **Percutaneous CT-guided targeted patching for lateral dural tears.** Newer protocol (Amrhein et al., AJNR 2025) for Type 1 leaks at lateral root sleeve locations.

Surgical.

- **Surgical repair / ligation.** For specific cases — failed embolization, anatomically unfavorable CVF locations, complex multi-level Type 1 tears, or surgeon preference at certain centers. Neurosurgical procedure at experienced centers only.

Adjacent considerations.

- **Connective tissue evaluation.** For patients with hypermobility (Beighton positive), family pattern, or aortic root findings — evaluation for hEDS, Marfan, or vEDS changes both risk-stratification and recurrence-prevention strategy.
- **Rebound intracranial hypertension management.** Can occur after successful leak closure. Usually managed medically; worth knowing about.

Lifestyle and supplements.

- Spinal CSF leak does not have a meaningful evidence-based supplement protocol. Caffeine is the closest thing to a supplemental therapy, and it is more accurately a medication.
- Standard repletion (vitamin D, magnesium) may be useful baseline support but does not treat the leak.

- If a connective tissue diagnosis is established, additional supplementation (vitamin C, glycine, copper) may be discussed with the geneticist or rheumatologist.
- Pre-procedural fitness optimization is worth attention if surgery is contemplated.

Active research worth tracking.

The Brinjikji group at Mayo Clinic continues to publish primary research on transvenous embolization techniques and outcomes. Treatment registries are emerging at multiple centers. The Spinal CSF Leak Foundation (spinalcsfleak.org) maintains current patient and provider resources and tracks emerging literature. Worth checking quarterly for treatment landscape updates.

SECTION 03 / BASED ON WHAT YOU TOLD US

Categories to focus on first.

> READ THIS FIRST
>
> The recommendations below are **general directions based on what you have told us so far**. They are not personalized clinical recommendations. To say anything specific — which test, which dose, which provider — we would need your records, labs, imaging, and a deeper case review. Use this section to orient your thinking and your conversations with your physicians.

From your intake, three features stand out: a classic orthostatic headache pattern over four years, brain MRI showing pachymeningeal enhancement, and a failed untargeted blood patch with brief partial relief. Plus a Beighton 6/9 hypermobility score and family pattern suggestive of connective tissue. Several categories from Section 02 are likely to matter most for someone with this profile.

Imaging-first workup is the high-leverage move.

Your symptom pattern combined with failed untargeted patch is consistent with a CSF-venous fistula subtype — the leak type that standard imaging often misses and that untargeted patches typically do not close. The most important next step is specialized myelography (lateral decubitus CT myelogram or DSM) at a leak-experienced center, not another patch attempt.

Specialized imaging matters more than choice of center.

The diagnostic capability you need is specific: lateral decubitus CT myelography or digital subtraction myelography, performed by a radiologist experienced in CSF leak workup. Multiple US academic medical centers offer this. We are intentionally not naming centers here — a quick search on the Spinal CSF Leak Foundation's provider directory will surface current options.

Connective tissue evaluation is parallel-track work.

Your Beighton 6/9, family pattern, and mild aortic root dilation are consistent with the connective tissue overlap seen in roughly 10-20% of spontaneous CSF leak cases. Formal evaluation by a geneticist or hEDS-experienced clinician (and consideration of FBN1 sequencing given the aortic finding) is worth pursuing in parallel with the leak workup. The results affect both recurrence-prevention strategy and procedural risk assessment.

Treatment categories worth discussing with your physician.

From Section 02, several categories are commonly explored for cases with your pattern. We are listing **categories**, not specific recommendations — the right choice depends on what your imaging shows and what your specialist team determines.

- Specialized myelography to identify or rule out CSF-venous fistula
- If CVF identified: transvenous embolization is the first-line treatment at experienced centers
- If a Type 1 or Type 2 leak identified: targeted (imaging-guided) blood patch with or without fibrin glue
- Continued conservative measures while workup proceeds: caffeine, hydration, position management, valsalva avoidance
- Connective tissue evaluation as parallel-track work

What to avoid.

Another untargeted lumbar blood patch outside a leak-specialized center is generally low-yield in your scenario and can complicate subsequent imaging by introducing post-patch artifact that obscures CVF identification for weeks. If anyone proposes this as the next step, asking why imaging is not first is a reasonable question.

REALISTIC EXPECTATIONS

Honest framing — not foundation-website optimism. SIH outcomes have improved substantially in the last few years for patients who reach the right specialist team. But the path there is uneven, and recovery is rarely instantaneous.

What the research suggests for cases like yours:

- If your leak is a CSF-venous fistula and is successfully localized, transvenous embolization at an experienced center has 65-80% success on first attempt. With re-treatment, success climbs toward 90%.
- Recovery after successful leak closure can be rapid (days to weeks) for some patients (Saionz 2025 documented 48-hour improvement). For others, recovery is gradual over months. The literature does not yet predict who falls into which group.
- Rebound intracranial hypertension can occur after successful treatment — usually managed medically, but worth knowing about going in.
- Recurrence is real, especially with connective tissue overlap. Many SIH patients undergo 1-2 procedures over their lifetime. This is not a failure of treatment; it is the natural history of the condition in some cases.
- Specialist wait times at top centers are typically 3-6 months. Submitting intake forms now (before workup is complete) is the right move.
- The diagnostic phase is the hardest part of the journey. Once at the right specialist team with the right imaging, the path forward becomes much clearer.

The honest answer for your specific case is that the trajectory depends on what the imaging shows. If a CVF is identified, your odds of substantial improvement after

embolization are good. If imaging does not localize a leak, the path becomes more complex and warrants the deeper case review a Precision Deep Dive provides.

SECTION 04 / QUESTIONS TO BRING TO EACH CONSULT

What to ask each kind of doctor.

A specialist consult is much more productive when you arrive with structured questions. The questions below are written for the specialist categories most relevant to your case. Bring them — printed or on your phone — to the appointment.

For a leak-experienced neuroradiologist

- Given my orthostatic pattern and failed untargeted patch, what is your prior probability that this is a CSF-venous fistula vs another subtype?
- What is your preferred imaging protocol — lateral decubitus CT myelogram, digital subtraction myelography (DSM), or both — and why?
- If imaging localizes a fistula, what is your typical sequencing for embolization vs targeted patch as the first procedure?
- What is your center's recurrence rate in cases with connective tissue overlap?
- How long do you typically wait between imaging and treatment? What does that timeline look like at your center?
- How do you manage rebound intracranial hypertension if it develops post-treatment?

For an interventional neuroradiologist (embolization specialist)

- What is your experience volume with transvenous CSF-venous fistula embolization?
- Do you use Onyx, or another embolic agent, and why?
- What is your protocol for confirming closure post-embolization?
- If first embolization is partial, what is your typical retreatment timeline?

For a neurosurgeon (if surgical option is considered)

- When do you favor surgical ligation over endovascular embolization?
- What is your experience with the specific leak subtype my imaging shows?
- What is your protocol for managing rebound intracranial hypertension post-surgery?

- What is your typical recurrence rate and reoperation rate?

For a geneticist or hEDS-experienced clinician

- Does my Beighton 6/9 and family pattern meet the 2017 hEDS criteria?
- Given my mild aortic root dilation, is FBN1 sequencing (Marfan workup) warranted?
- What surveillance schedule do you recommend if hEDS is confirmed, given my CSF leak history?
- Are there connective-tissue-specific considerations for my upcoming procedural workup?

For your primary care physician

- Can you help coordinate referrals and records to leak-experienced centers?
- Can you order the full spine MRI with heavily T2-weighted protocol that specialists will want?
- What is the best way to document my condition for disability accommodation or FMLA paperwork?
- Can you write the conservative-management prescriptions (theophylline, etc.) while specialist workup is in progress?

SECTION 05 / NEXT STEPS

Your first 30 days, and what to gather along the way.

Two parts. First, a 30-day preparation checklist — the practical actions that get you organized and into the right system. Second, a data and testing checklist — what to gather, where to get it, and what we would want to see if you decide to go deeper.

Your 30-day preparation checklist.

01 **Obtain all prior imaging on CD or via PACS export.** Brain MRI, any spine imaging, the original radiology reports. You will need these for any specialist intake. Request them now even if you have them digitally — physical CDs are still the most reliable handoff format.

02 **Request a full spine MRI with heavily T2-weighted protocol.** Through your PCP. Specify: "rule out CSF leak; please use heavily T2-weighted sequences per SIH protocol." This is a pre-consult requirement at most leak-experienced centers.

03 **Submit intake forms to 2-3 leak-experienced centers.** The Spinal CSF Leak Foundation maintains a current provider directory and intake guidance templates. Submit to multiple centers simultaneously — waitlists vary, and you can choose later.

04 **Schedule formal hEDS evaluation.** Through a geneticist or hEDS-experienced rheumatologist. The Ehlers-Danlos Society maintains a provider directory.

05 **Continue or begin conservative measures.** Caffeine 400-600 mg/day in divided doses, hydration with sodium, position management as needed. Begin a theophylline trial through your PCP if appropriate.

06 **Document orthostatic pattern.** Headache severity by hour of day, posture correlation, trigger events. A four-week diary is what specialists want to see at intake.

07 **Connect with patient community.** Spinal CSF Leak Foundation forums, advocacy groups. Useful for current waitlist intelligence and navigation tactics.

08 **Build a specialist-handoff document.** One-page summary: symptom timeline, prior workup, prior procedures, imaging findings, current medications, prior treatments tried. Saves time at every new consult.

Tailored data and testing checklist.

Most patients with spinal CSF leak benefit from gathering data across six categories. Imaging is the most critical for SIH specifically; other categories support the broader workup. No pricing —

costs vary by insurance, geography, and provider.

01 / IMAGING — THE DIAGNOSTIC AXIS

Brain MRI, spine MRI, specialized myelography

For SIH, imaging is not just supportive — it is the diagnostic axis. The right imaging at the right center finds the leak; the wrong imaging misses it.

What to gather: Brain MRI with contrast (required); heavily T2-weighted full spine MRI (required); lateral decubitus CT myelography or digital subtraction myelography (specialist-directed, at a leak-experienced center); echocardiogram (cardiology baseline if connective tissue concern, looking for aortic root and valve findings).

Where: *Brain and spine MRI via PCP referral at standard imaging centers. Specialized myelography only at leak-experienced academic medical centers. Echocardiogram via PCP or cardiology referral.*

02 / BLOOD WORK

Pre-procedure panels, autoimmune workup, repletion

Lab work for SIH is largely about pre-procedural readiness and ruling out alternatives. There is no specific blood marker for CSF leak.

What to gather: CBC, CMP, coagulation panel (PT/INR, aPTT) for pre-procedure; ANA and ENA panel for autoimmune headache mimics; ESR and hsCRP for inflammation baseline; vitamin D 25-OH, B12, ferritin for repletion baseline; if vEDS workup contemplated, serum copper and ceruloplasmin may be discussed.

Where: *Your PCP through standard insurance is the cheapest path. For self-ordered labs: Quest Diagnostics direct, Labcorp OnDemand, Function Health, Marek Health.*

03 / DEXA / BODY COMPOSITION

Bone density baseline (if connective tissue concern)

Particularly relevant if Marfan, vEDS, or osteogenesis imperfecta is in the connective tissue differential. Also useful as a general chronic-illness baseline.

What to gather: DEXA scan for bone mineral density and body composition.

Where: *BodySpec (mobile DEXA, multi-city), DexaFit (fitness-oriented chains), or hospital radiology departments (physician-ordered).*

04 / GENOME / GENETIC TESTING

Connective tissue differential

For SIH with connective tissue overlap features, genetic testing is the most informative single workup. hEDS is currently a clinical diagnosis (no genetic test) but other connective tissue disorders have specific genetic markers.

What to gather: FBN1 sequencing (Marfan), COL3A1 (vascular EDS), broader connective tissue panel if first-line testing negative. Consumer-level 23andMe or AncestryDNA provides limited but informative screening; Promethease or SelfDecode adds variant interpretation.

Where: *Clinical-grade panels through GeneDx, Invitae, or hospital genetics — physician-ordered. Consumer screening via 23andMe or AncestryDNA, then Promethease for variant analysis. Nebula Genomics offers consumer whole genome sequencing.*

05 / WEARABLE & CONTINUOUS DATA

Heart rate, posture, sleep, activity

Wearable data is less central for SIH than for some other chronic conditions, but documenting your orthostatic pattern objectively (and tracking activity tolerance) provides useful context for specialist visits.

What to gather: Heart rate (continuous), heart rate variability, sleep duration and quality, daily step count, activity intensity. Posture/positional time can be inferred from some devices.

Where: *Apple Watch (best ecosystem integration), Garmin (best HR accuracy), Whoop (best HRV + recovery scoring), Oura Ring (best sleep tracking).*

06 / LIFESTYLE TRACKING

Headache diary, triggers, conservative-treatment response

For SIH, the most valuable input you can give any specialist is a quantitative headache diary by hour of day. It directly documents the orthostatic pattern.

What to gather: Headache severity by hour (0-10 scale); posture correlation (worse upright, better recumbent — track explicitly); valsalva trigger events (lifting, cough, sneeze, straining); conservative treatment response (caffeine, theophylline, position changes); medication and supplement log with start dates.

Where: *Migraine Buddy app (general headache tracking, useful for SIH too), N1-Headache (n-of-1 trial-oriented app), or paper diary. Whichever you will actually keep.*

IF YOU DECIDE TO GO DEEPER

What we would want to see for a Precision Deep Dive.

If you decide to engage Ternary Health for a full Precision Deep Dive ($6,500, 40-60 pages, personalized clinical action plan), the inputs below would shape what we can deliver:

- All brain and spine imaging on CD or via PACS export — raw DICOM files, not just radiologist reports. The image data carries more than the report.
- Complete medical records, last 5 years minimum
- Recent labs (within 12 months) including the panels recommended in Section 02
- Prior procedure notes (blood patch, any embolization or surgery) with operator notes if obtainable
- Genetic testing results if completed
- 4+ weeks of headache diary with hourly severity tracking

- Beighton score documentation by a clinician
- Family medical pedigree (3 generations if available)
- Current medications and supplements with doses, start dates, and observed responses
- Insurance information for specialist coordination

What a Precision Deep Dive adds. Beyond this Launchpad's scope: a personalized 40-60 page clinical action plan with named providers matched to your case, specific interpretation of your imaging (including raw DICOM review by our neuroradiology consultant), a personalized disease model identifying the drivers in your specific case, ranked interventions with leverage scoring, a 90-day execution roadmap with named medications and decision gates, and 30 days of asynchronous follow-up support.

Launchpad credit. Your $400 Launchpad fee credits toward a Precision Deep Dive booked within 90 days.

Prepared with the same methodology applied to every Ternary engagement — scoped to the Launchpad tier ($400). Built on the published spinal CSF leak literature through Q2 2026, with primary references available on request.

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