

QUESTIONS FOR THE MEDICAL TEAM

~3-month-old • Grade 3 IVH • Kaiser Roseville • 2026-05-12

40-45% mortality is NOT normal for a VP shunt (standard is 1-3%). That number is the underlying condition prognosis, not procedure risk. **Do not consent to surgery without a second opinion from UCSF Benioff or Stanford LPCH neurovascular team.**

★ TOP 5 — ASK THESE FIRST

- 1 What did the MRA show? What is the structural diagnosis driving the surgery?**
- 2 Is 40-45% the procedural risk of the shunt, or the overall prognosis for her condition?**
- 3 Can we get an urgent second-opinion call with UCSF Benioff or Stanford LPCH neurovascular before consenting?**
- 4 Has Factor XIII been tested, and was empiric IV vitamin K given with before/after PT/INR?**
- 5 Has clinical genetics been consulted for vascular EDS workup (COL3A1)?**

1 PRE-SURGERY CONSENT

- ▶ What is underlying cause? Just hydrocephalus or also a vascular malformation?
- ▶ Is the shunt the complete treatment, or does the cause need separate treatment?
- ▶ Can EVD (temporary drain) buy us 24-48 hrs for second opinion?
- ▶ How many hours until we must decide?
- ▶ What happens if we wait?

2 IMAGING & DIAGNOSIS

- ▶ MRA done? Vein of Galen Malformation ruled out?
- ▶ MRV done? Sinovenous thrombosis ruled out?
- ▶ SWI/GRE — is there old + new blood (mixed-age)?
- ▶ Choroid plexus normal on contrast MRI?
- ▶ Daily head ultrasounds tracking ventricles?
- ▶ Is bleeding active or stopped?

3 COAGULATION LABS

- ▶ Actual numbers: PT/INR, PTT, platelets, fibrinogen?
- ▶ Empiric IV vit K given? PT/INR before & 4hr after?
- ▶ PIVKA-II sent? (gold-standard vit K test)
- ▶ Factor VIII, IX, XI, XIII, vWF tested?
- ▶ (FXIII is normal on routine coag — must order specifically)
- ▶ D-dimer? DIC ruled out?

4 VESSEL FRAGILITY / GENETICS

- ▶ Mom thinks it's her vessels — PICC failed, no peripheral access
- ▶ Clinical genetics consulted? Vascular EDS (COL3A1) workup?
- ▶ Interventional radiology called for US-guided central access?
- ▶ Body CTA/MRA done to map vascular anatomy?
- ▶ Maternal family hx — bleeding, aneurysms, sudden death young?

5 LATERALITY (SIT VS HETEROTAXY)

- ▶ Situs inversus totalis (benign) OR heterotaxy (high-risk)?
- ▶ Echo + abdominal ultrasound results?
- ▶ LFTs, direct bilirubin, GGT, bile acids?
- ▶ Biliary anatomy normal? Spleen present?
- ▶ Heterotaxy + cholestasis → vit K malabsorption → bleeding

6 SAFETY WORKUP (PROTOCOL, NOT ACCUSATION)

- ▶ Ophthalmology dilated fundoscopic exam done (retinal heme)?
- ▶ Skeletal survey ordered? (AAP requires for infants <2 w/ ICH)
- ▶ These are protocol — getting them done CLEARS the question

7 MEDICATION SAFETY

- ▶ Famotidine 40mg/5mL = adult strength (8mg/mL)
- ▶ Infant dose ~0.4 mL — verify no 10× error
- ▶ Should azithromycin pause? Talk to PCD pulm?
- ▶ Inpatient team in contact with PCD center?

8 TRANSFER & COORDINATION

- ▶ Peds neurosurg of record? Chao, McNatt, or Oakland?
- ▶ Seen in person or telehealth?
- ▶ Written transfer trigger to Kaiser Oakland?
- ▶ Has CASP / Dr. Evans been involved?
- ▶ Written 48-hour care plan?

YOUR RIGHTS AS THE FAMILY

- ✓ Right to a second opinion
- ✓ Right to time to think
- ✓ Refuse non-emergent procedures
- ✓ Request transfer (EMTALA)
- ✓ Access her medical chart
- ✓ Talk to a Kaiser patient advocate

Print this. Bring it bedside. Get answers in writing.

Full brief in family folder
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