

Year 2023

- **September 2023: Initial Seizure & Symptoms**
 - **Event:** First focal seizure episode.
 - **Frequency:** 1/2 times a month.
 - **Symptoms (Lasting 1-2 min):** Aura of burning smell, urge of vomiting (no actual vomiting), lip smacking, and rushing to the washroom to prevent vomiting.
 - **Action:** Family consulted a gastroenterologist, ENT specialist, and pediatrician; problem remained unidentified.
- **November 2023: Seizure Escalation & New Symptoms**
 - **Frequency:** Increased to once a week.
 - **Symptoms:** Started with burning smell aura, urge of vomiting, plus new symptoms: **left side lip twitching** and **broadening eyes** during the seizure.
 - **Action:** Continued consulting pediatrics.
- **Later November 2023: Symptom Progression**
 - **Frequency:** Increased to 1-2 times a week (seizure lasting 1-2 minutes).
 - **Symptoms:** Burning smell aura, urge of vomiting, plus new symptoms: **not able to talk** (blabbering), and **nausea** for a couple of minutes after the seizure.

Year 2024

- **January 2024: Diagnosis & Imaging**
 - **Action:** Consulting with a **Neurologist** began.
 - **Finding:** MRI suggested a **lesion in the midbrain-temporal lobe**.
 - **Action:** Neurosurgeons had varying opinions due to the complex location and mostly suggested **wait-watch-compare**.
 - **Medication:** Started **Levetiracetam**, which *did not* help control seizures.
- **February 2024: Visual Impairment Detected**

- **Action:** Neuro-ophthalmology evaluation performed.
 - **Findings:** Vision and fundus were normal. **Perimetry/Visual field was impacted on the right side**, and **right side homonymous hemianopia** was detected.
- **April 2024: Lesion Check & Management**
 - **Finding:** Differential MRI (compared to Jan 2024) suggested the lesion was **static**.
 - **Status:** Seizures were still happening.
 - **Action:** Neurosurgeons suggested biopsy, direct chemotherapy, or continue wait and watch. Family decided for wait and watch.
- **July 2024: Continued Observation**
 - **Finding:** Differential MRI showed **no significant difference in the lesion**.
 - **Action:** Continued wait and watch.
- **August 2024: Seizure Control Achieved**
 - **Medication:** Seizures were finally controlled and reduced to **zero** with the following doses:
 - **Clobazam** 5 mg once a day | (0-0-5)mg.
 - **Carbamazepine** 200 mg twice a day | (100-100-200)mg.
- **September 2024: Worsening Ocular Issues**
 - **Action:** Neuro-ophthalmology re-evaluation done.
 - **Findings:** Right side visual field still impacted, eyesight vision degraded (major impact on **left eye**), and the left eye was intermittently squinting (toward the outside/further left).
 - **Action:** Started **spectacles (eye glasses)**.
 - **Imaging:** Repeated MRI showed no significant difference in the lesion. Continue to wait and watch for tumor.
- **December 2024: Motor Skill Decline**
 - **Symptom:** Child started to keep her **right hand fist usually closed** and experienced **degradation in handwriting**.

- **Imaging:** Repeated MRI showed no significant difference in the lesion.
Continue to wait and watch for tumor.
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Year 2025

- **March 2025: Hand Use & Auras**
 - **Symptom:** Less use of the right hand and occurrence of **seizure auras** (but not actual seizures).
- **April 2025: Surgery**
 - **Action:** Child underwent **left pterional craniotomy with microsurgical excision of a mesial temporal space-occupying lesion (SOL)**. * **Result:** Only about **20% of the lesion** could be removed; the remaining 80% was left due to the complex location near the optical nerves.
 - **Post-Op Status:** little relief in the left eye intermittent squint (potentially due to pressure relief, but still intermittent). The right hand was still less used, with the fist mostly closed. Vision was still affected (eyesight degradation and right side field vision).
- **July 2025: Pathology/Oncology Results**
 - **Action:** Oncology reports came from two different labs for two parts of the tissue sample.
 - **Findings (Negative):** Nothing found in IHC, FISH, or MGMT. Advanced NGS panel report from TATA was negative.
 - **Finding (Positive):** Advanced NGS panel report from Medgenome showed **DBN1/BRAF fusion**.
- **August 2025: Treatment Planning**
 - **Action:** Visited couple Oncologists.
 - **Outcome:** Opinions are varying: some suggesting **targeted therapy** and others suggesting **chemotherapy (V+C)**.
 - **Next Action Plan :** Decide between Targeted v/s chemotherapy (**V+C**).
Currently undergoing physiotherapy for hand and fingers.