

## Focused Ultrasound for HH

### What is MR guided FUS?

Transcranial magnetic resonance (MR) guided focused ultrasound (FUS) focuses non-ionizing ultrasound waves onto an area of the brain to create a lesion. No instruments are passed through the brain. Doctors have performed brain FUS in adults, but are still learning about its role in children.

### How is the procedure done?

After sedation under general anesthesia, doctors shave and clean your scalp. After numbing the scalp, doctors apply a customized frame to your head. You are then transported to the MR imaging room, and the head frame is secured in place. A water-tight sealed cone filled with cooled water is applied to your scalp. A few sequences are taken with the MRI, and a team of doctors consisting of neurosurgeons, neurologists, and neuro-radiologists carefully plan the area of HH that will be heated and destroyed by the ultrasound waves. After some test runs, doctors will apply acoustic power up to 1500 watts to create a series of thermoablations. The targeted area of the HH will reach 56-60°C, leading to tissue destruction. During this process, you are asleep and do not feel or remember anything. However, your heart rate and blood pressure are monitored. Furthermore, the doctors plan this cavitation area very carefully and ensure that adjacent normal brain is not injured.

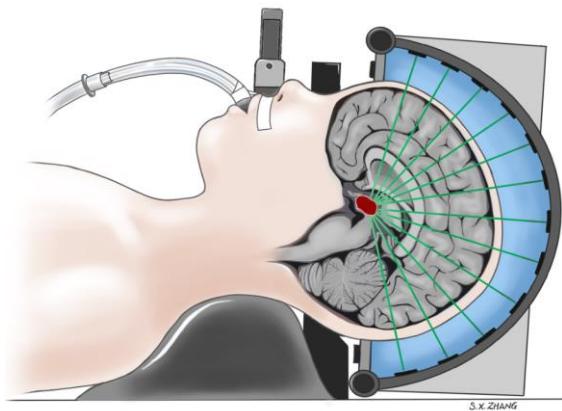


### What can I expect after the procedure?

After the FUS procedure, the frame will be removed from your head, and the endotracheal tube will be removed from your throat. You will wake up in the post-anesthesia care unit. You may have a sore throat and minimal pain from the frame's pin site. Once you are awake, you can eat and walk. You will spend at least one day in the intensive care unit (ICU). Doctors will give you a steroid medication called dexamethasone to reduce brain swelling. You will go home 1-2 days after the procedure. If you have seizures, no changes will be made to your medications right away. You will be followed closely by your neurologist and neurosurgeon in the coming weeks.

### Who qualifies for the FUS trial?

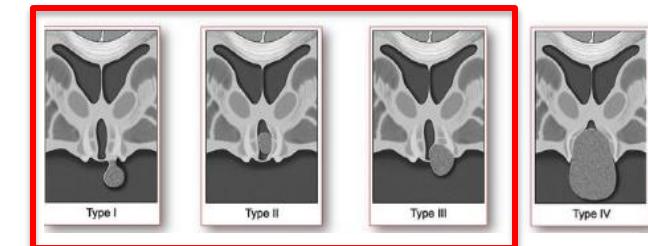
A pilot trial called **“A Feasibility Safety Study of Benign Centrally-Located Intracranial Tumors in Pediatric and Young Adult Subjects”** is currently underway at Nicklaus Children’s Hospital in Miami, Florida. This trial is aimed at assessing the safety of FUS for patients 8-22 years of age with a minimum head circumference of 52cm. The trial enrollment started in 2017 and 5 patients have been treated so far. None of the patients developed



electrolyte, neurologic, or endocrine abnormalities after FUS. Our HH patients, in particular, have been able to enjoy improved seizure outcomes and appetite control.

### Who are the ideal candidates for this trial?

- Kids 12-16 years of age
- With or without prior surgery
- Small or pedunculated HH - Delalande and Fohlen Classification Type I, IIB, or III
- Able to travel to Miami, Florida for the trial



### How can I learn more about FUS?

Learn about Madeline’s journey as an HH patient with hypothalamic hyperphagia:

<http://www.hopeforhh.org/blog/meet-madeleine/>

Learn about the clinical trial:

<https://clinicaltrials.gov/ct2/show/NCT03028246>

Learn about Nicklaus Children’s Hospital FUS team:

<https://www.nicklauschildrens.org/news-and-events/press-releases/insightec-focused-ultrasound-surgery>

### Who can I contact to assess my candidacy?

Contact research Principle Investigator Dr. John Ragheb at: [john.ragheb2@nicklaushealth.org](mailto:john.ragheb2@nicklaushealth.org)

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