Why are Researchers doing this Study?

It is observed that many patients with hydrocephalus who have been treated with a VP shunt suffer from chronic headaches. In this study, we examine the frequency and type of headaches that people with shunts have, and compare them to normal subjects without hydrocephalus, and to hydrocephalus patients who've been treated with a procedure called endoscopic third ventriculostomy, or ETV, which does not require a shunt. The study is important because it informs the researchers about the consequences of long-term shunting.

If I enter the study, what will I have to do?

The research team will ask you to fill-out an initial electronic survey focused on your medical, surgical and headache history. If this shows that you are an appropriate candidate for the study, you will be asked to fill out a second and more detailed survey, then download then login into an encrypted app on your smartphone (Apple or Android).

What happens when you are all signed up?

The app will passively collect data on your activity and well-being. In addition, you will start receiving daily short (less than 3-minute) push notifications about headaches for a total of 3 months. The researchers will not have access to information on your other smartphone applications, such as website activity, email or text message content. They will only collect data related to phone accelerometer, GPS (related to general mobility, not specific location), screen activity, and messaging reciprocity.

Department of Neurological Surgery
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

Contact us for more information on this study:

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Please hold your smart phone's camera on this bar code to watch the video and review the instructions.

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Hydrocephalus Study

Protocol Number: 2024-0645

Principal Investigators (PI):

Bermans Iskandar, MD

Funding for this study is provided by UW Neurosurgery Pediatric Hydrocephalus and Congenital Anomalies Fund

Why will we collect passive phone data?

This will provide insight into the relationship between your headaches and metrics such as physical activity, mobility patterns, sleep quality, and environmental exposures.

Will we collect call or text messages?

Personal data including call audio, text messaging content, GPS coordinates/location data, credit card payments, and internet searches are not visible to the research team. Call and text message logs, app usage, screen unlocks, and Wi-Fi connections will provide information on your digital behavior and usage patterns but without having access to any specific data from these applications.

Benefits

The study will help us better understand the relationship between headaches and shunts.

The subjects who deemed eligible and enroll in the study will receive $25 after completion of the second survey and an additional $25 upon satisfactory completion of the study.

Invitation to Participate in a Research Study

We invite you to take part in a research study about Hydrocephalus.

Participation is voluntary and participants can withdraw from the study at any time. You can participate as a patient with hydrocephalus.

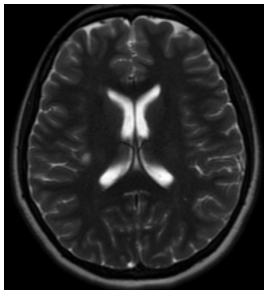
Study Methods

Recruitment

- 50 hydrocephalus patients between the ages of 15 and 45 who have been treated with shunts in the first four years of life.
- 50 hydrocephalus patients between the ages of 15 and 45 who have been successfully treated with ETV in the first four years of life.
- 50 control subjects without hydrocephalus

Determining Eligibility

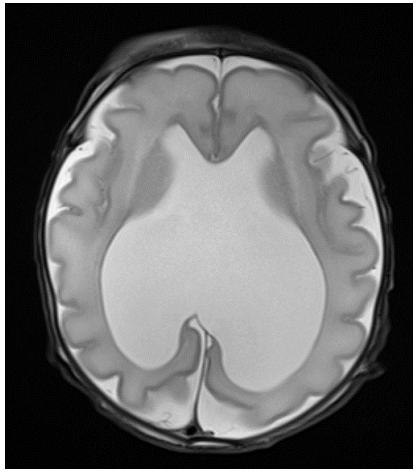
- An initial medical history survey will tell us whether you are eligible for the study.
- Once deemed eligible, a second survey that includes a more detailed medical history will be required.
- You will then download an app on your iPhone or Android (encrypted login) and start receiving daily notifications for a total period of 3 months.

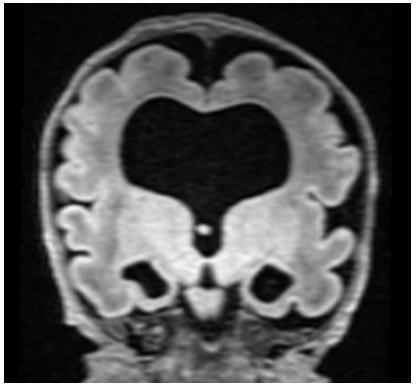


Brain MRI without Hydrocephalus

Study details

- You will receive a daily push notification (takes less than 3 minute to fill out) that asks about headaches.
- The App will collect passive information that tracks your activity to determine whether the headaches correspond to a change in activity level.
- No personal information (texts, website use, phone calls, etc.) will be accessible to the researchers.





Brain MRI images with hydrocephalus