alternating hemiplegia of childhood foundation
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ahc study

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Our goal is to conduct a natural history study in which we identify quantifiable scales, both reported by a doctor and by the patient and family, that correlate with disease progression in AHC. In addition, we want to collect plasma and urine to identify biomarkers that track with the clinical markers of disease progression.

We collect, process, and store samples and information from those with AHC, and their family members, until researchers anywhere in the world need them for research.

Samples and information in this bank will be used for research on AHC and related disorders.

What would you have to do?

- ☑ Give medical and family history information.
- ☑ Give a blood and urine sample (can be done later when a blood draw is medically necessary). If done later, we will provide you with all the supplies and a FedEx shipping label to send the sample back to us at Massachusetts General Hospital
- ☑ Have a videotaped physical exam.
- ☑ If you agree, we will contact you every six months for medical updates. Ideally, we would like to see you in person every 12 months, alternating with an internet-based video exam.

How long would it take?

- ☑ It will take 45 to 75 minutes to finish each research visit.

What else do I need to know?

- ☑ We get DNA from the blood sample and isolate protein from the urine sample. DNA is forever. Research genetic test results are NOT available to those who join the research study. You will get no direct benefit from taking part in this research.
- ☑ Taking part in research is voluntary.