

INITIAL QUESTIONS

For Your Neurologist

Hope for HH has created a list of questions to help guide your conversation with your medical provider. These conversations can feel overwhelming and confusing. To maximize the time with your provider, we recommend you identify which questions best apply to your situation and use them as a starting point for the discussion. Being prepared can lessen the fear and improve collaboration.

- 1 Can you show me the HH tumor on the MRI?
- 2 How many HH cases have you treated?
- 3 What type of additional diagnostic testing will you order? (EEG, video EEG, MRI, fMRI *)
- 4 What medications do you typically recommend for the current seizure types?
- 5 At what point do we consider treatment options besides just AED medications?
- 6 Will we have to fail 3 antiepileptic drugs (AEDs) before we consider surgery?
- 7 What other treatment options are available locally? Does this facility have a surgeon experienced in HH surgery and the treatment option you are recommending?
- 8 How do we handle seizures that cluster or last longer than two minutes? (rescue medications for non-gelastic seizures)?
- 9 What will be the follow-up care/ treatment plan be?
- 10 Who will be a part of our Team - can we include an endocrinologist and neuropsychologist?
- 11 If the seizures continue to be uncontrolled – what is the risk of Sudden Unexplained Death in Epilepsy (SUDEP)?

MEDICATION QUESTIONS

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- 1 What do you expect this medication to do?
- 2 What are the potential side effects both long and short term?
- 3 How long will we have to be on this medication to determine if it is working or not?
- 4 How effective is this medication at eliminating gelastic seizures?
- 5 How can this medication impact learning and memory?
- 6 Can this medication affect behavior – either positively or negatively?
- 7 Will this medication be used alone or with others?
- 8 Are blood tests required to monitor drug levels?
- 9 Is there a difference between the efficacy of name brand versus generic?
- 10 Is there an extended release form of this medication?

SURGICAL QUESTIONS

For Your Neurologist

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- 1 Why is surgery necessary?
- 2 What are the potential complications and risks, both short term and long term?
- 3 Will our case be presented to a group of multiple specialties to discuss the best steps forward?
- 4 What is the next step if this proposed surgery doesn't control the seizures?
- 5 What is the risk of doing nothing at this point in time?
- 6 What kind of pre-surgery evaluations will be required?
- 7 Do you have a Patient Liaison to help with pre-surgery appointments?
- 8 What will be the follow-up care (MRI, endocrine, neurology, neuropsychology)?
- 9 Where will follow up care be done (surgical center or closer to home)?
- 10 Are there any options besides surgery, like Ketogenic Diet or CBD?

SURGICAL QUESTIONS

For Your Neurosurgeon

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- 1 How many HH surgeries have you performed and what ages?
- 2 Please explain the procedure. (Will you remove or just disconnect the HH. How long will the surgery take?)
- 3 What do you consider a successful outcome? Seizure-free or something else? Will a second procedure be required?
- 4 What have your short term (6mos – 1yr) and long term (1yr or greater) outcomes been?
- 5 How effective is this procedure at eliminating gelastic and/or other seizure types?
- 6 How effective is this procedure at eliminating rage behaviors?
- 7 Have your previous patients reported memory loss, fluid/salt problems, weight gain or other complications?
- 8 What is the expected recovery time?
- 9 Tell me about your team members and their experience with HH patients including nurses and ICU doctors.
- 10 Are there alternative procedures and treatments? Are they available here?

POST SURGERY QUESTIONS

For Your Neurosurgeon

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- 1 Are there any activity/travel restrictions after being discharged from the hospital?
- 2 Who should I call if questions arise post-surgery? After hours, who should I contact?
- 3 What should the next few days look like before we return for follow up visit?
- 4 What big things should I watch for over the next few days?
- 5 What symptoms would warrant a trip to the Emergency Department?
- 6 If I have a seizure post-surgery, does that mean it was not successful?

INITIAL QUESTIONS

For Your Endocrinologist

Hope for HH has created a list of questions to help guide your conversation with your medical provider. These conversations can feel overwhelming and confusing. To maximize the time with your provider, we recommend you identify which questions best apply to your situation and use them as a starting point for the discussion. Being prepared can lessen the fear and improve collaboration.

- 1 What lab work will be done and why?
- 2 How might a hypothalamic hamartoma affect my endocrine system?
- 3 How might surgery affect my endocrine system?
- 4 What symptoms might I experience if there is a hormone imbalance or deficiency?
- 5 What are the most common endocrine related complications of surgery?

INITIAL QUESTIONS

For Your Pediatric Neuropsychologist

Hope for HH has created a list of questions to help guide your conversation with your medical provider. These conversations can feel overwhelming and confusing. To maximize the time with your provider, we recommend you identify which questions best apply to your situation and use them as a starting point for the discussion. Being prepared can lessen the fear and improve collaboration.

- 1 What testing will you do and how long will it take?
- 2 Can the test be done over two or more days if my child is easily fatigued?
- 3 What specific evaluations will you do for my school-aged child? (Preschool – High School)
- 4 Can you suggest accommodations for an Individualized Education Plan (IEP)?
- 5 What therapies can you suggest for attention and behavior issues?
- 6 Could the HH be responsible for the autistic-like behaviors we are seeing?
- 7 Are there online programs I can do with my child to improve cognitive function?
- 8 How will seizures affect my child's ability to learn?
- 9 Will he/she regain cognitive function if the seizures stop?
- 10 How often should an evaluation be completed?

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For Your Neuropsychologist

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- 1 What kinds of tests will I be doing and why?
- 2 How often should an evaluation be completed?
- 3 What tools are available to help strengthen weaker skills (Executive Function)?
- 4 Are there treatments or online programs that will help with my memory issues?
- 5 What tools are available to manage mental health regarding a chronic condition?
- 6 Are there tools to help with behavior issues (depression, anxiety, OCD, PTSD)?
- 7 What additional resources are available in my area?
- 8 What therapies would be helpful?
- 9 What long term concerns arise from having an HH?

QUESTIONS TO ASK

IF YOU SUSPECT AN HH

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- 1 Have you ever treated anyone with a hypothalamic hamartoma?
- 2 Are you familiar with gelastic or dacrystic seizures?
- 3 Why does my child laugh at inappropriate times?
- 4 Why does the laughter not seem genuine or occur while they are sleeping?
- 5 Why does my child get a funny look in their eyes and then attack a sibling without provocation?