

# 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)?