



## Medication and Testing

Some treatment plans for TSC may be daunting. Here are some prompts to help facilitate a dialogue with your provider to help you feel confident about their intended treatment and surveillance plan.

### Initial questions to ask

- What is this test or medication for?
- Why is this test or treatment a good option for me, and what risks are there to consider?
  - Are there any potential complications I should consider?
  - What are the side effects of this medication?
    - If there are potential side effects, what are my options for managing them?
    - Who do I call, or where do I go, if I begin noticing or experiencing concerning symptoms?
- How long will it take for the medication to start working?
  - What does a “titration phase” mean?
  - What is a “loading dose” and when do we plan on dose-reducing?
  - If this is an anti-seizure medicine, what’s an acceptable number of breakthrough seizures – when should I call?
  - What do I need to do if I miss a dose of this medication?
- Are there any other treatment options?
  - If not, what are the risks and benefits of waiting?
  - If I elect to decline this test or medication, what signs or symptoms should I be aware of to reconsider?
- Do you have any recommendations for a second opinion?
  - **SIDENOTE:** It is a myth that providers get upset when asked about second opinions. Second opinions can be a crucial affirming step when you are faced with an important decision, and many healthcare providers appreciate input from their peers – a second set of eyes.

### Testing and results

- What would be achieved by knowing the results of this test?
- Can you help me understand the accuracy of this test?

- Will there be another follow-up test, depending on findings from the initial?
- When will I receive test results? Who will discuss them with me?

### **Insurance**

- Will my insurance cover this test or treatment?

### **Lifestyle changes**

- Are there any other considerations I should be aware of before starting this medication? Should I plan to:
  - Change my diet?
  - Notice any changes to sleep schedule?
  - Prepare for any behavioral changes?
  - Avoid anything specific, such as any potential food-drug, alcohol-drug, drug-drug, or supplement-drug interactions?
    - **SIDENOTE:** be sure your healthcare team knows about every supplement that you take, no matter how safe or “over the counter” they are, they could impact certain the way drugs are absorbed.