



# PPP DOCTOR DISCUSSION GUIDE

## TALKING WITH YOUR DOCTOR ABOUT PRIMARY PERIODIC PARALYSIS: A HELPFUL GUIDE

### OVERVIEW

Primary Periodic Paralysis (PPP) causes episodes of muscle weakness or temporary paralysis that can affect many parts of your body.<sup>1,2</sup> Make sure you are keeping track of how you're feeling so you can share it with your doctor. Your doctor needs to understand how many episodes of PPP you're having, how long they last, and what is triggering your PPP. It's also important to share if you are experiencing weakness in between episodes.

#### **PREPARATION POINTER: SHARE YOUR HISTORY**

- If you can, bring any previous forms and notes you have from other doctors related to your PPP. This can help your doctor get a sense of your history, especially if you're not yet diagnosed with PPP or your subtype, like Hypokalemic Primary Periodic Paralysis.

#### **PREPARATION POINTER: HAVE OPEN AND HONEST CONVERSATIONS ABOUT HOW YOUR PPP AFFECTS YOU**

- You may just want to say "fine" when your doctor asks you how you're doing, especially if it's not a bad day for your PPP, but it's important to let your doctor know how you're feeling on a regular basis when it comes to your PPP.
- Because PPP is a physically disabling condition, it can take a toll on your ability to do everyday activities, like walking up the steps or picking up groceries.<sup>1</sup> Share examples of this with your doctor, so they understand the full impact of your PPP on your daily life

#### **PREPARATION POINTER: KEEP A RECORD OF YOUR TRIGGERS, SYMPTOMS, AND CHANGES IN YOUR LIFE**

- Be sure to keep track of how many episodes you have and how long they lasted. It's also important to share what is happening before your attacks, so you can identify triggers, for example if stress at work or eating high-carbohydrate meals tend to happen before you have an episode.
- Your doctor will also want to know how your health is in general, any illnesses you've had, or other medical conditions you're diagnosed with.
- Your doctor will also want to know any other prescription medications, over-the-counter medicines, and supplements you are currently taking, for either your PPP or other conditions.

## STARTING THE CONVERSATION

Begin your appointment by telling your doctor that you have kept a record about how you've been feeling that you would like to review. The PPP daily tracker, which can be found at [PPPdiary.com](https://www.pppdiary.com), has been created to help you track your attacks. You can also use your phone or a journal - the most important part is just to make sure you're tracking!

### **PREPARATION POINTER: YOU DON'T NEED TO HAVE ALL THE ANSWERS**

- You may not know everything that is triggering your episodes and that's okay. What's most important is you give your doctor all of the information about your episodes and how you have been feeling so they can review it and work with you on how to best manage your PPP.

## BE YOUR OWN ADVOCATE

It's so important to make sure you work with a doctor who listens to you and who you trust - you know your body and your experience with PPP better than anyone else, so it's so important you have a doctor who listens.

### **PREPARATION POINTER: SHARE YOUR RESEARCH**

- PPP is a rare genetic disorder, which means your provider may not be as familiar with current research as you might be. Make sure you share any research you've conducted, especially if you have questions.
- For more information about PPP, visit [PavingMyPath.com](https://www.pavingmypath.com)
- Make sure you are discussing how to manage your PPP long term with both lifestyle and medication, so you and your doctor have a treatment plan that works best for you.

## KEEPING THE LINE OF COMMUNICATION OPEN

Before you leave your doctor's office, check the list of questions you prepared to make sure they all were answered. Collaborate with your doctor on a management and monitoring plan to follow between today's visit and your next appointment.

### **PREPARATION POINTER: WHAT TO DO IN BETWEEN VISITS**

- Reach out to your doctor between appointments if you feel your PPP is getting worse or more difficult to manage.
- Keep a running list of questions or things you want to talk with your doctor about at your next appointment.
- Continue tracking your episodes.

## REFERENCES:

1. Charles G, Zheng C, Lehmann-Horn F, Jurkat-Rott K, Levitt J. Characterization of hyperkalemic periodic paralysis: a survey of genetically diagnosed individuals. *J Neurol.* 2013;260:2606-2613. 2. Cavel-Greant D, Lehmann-Horn F, Jurkat-Rott K. The impact of permanent muscle weakness on quality of life in periodic paralysis: a survey of 66 patients. *Acta Myol.* 2012;31:126-1

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