

# BE YOUR FAMILY FACILITATOR

**IN PRIMARY PERIODIC PARALYSIS (PPP)**

Talking about PPP with  
your family can be hard.

This guide can help you  
start the conversation.



# Sharing your experience can empower your family

## PPP IS OFTEN AN INHERITED CONDITION.<sup>1</sup>

Your family members may not know they have PPP, or, if they are experiencing symptoms, may not realize they could be caused by PPP.<sup>1,2</sup>

Think back to how you felt when you were finally diagnosed with PPP. At last, you had an answer for why you were feeling the way you were feeling—and a path forward.

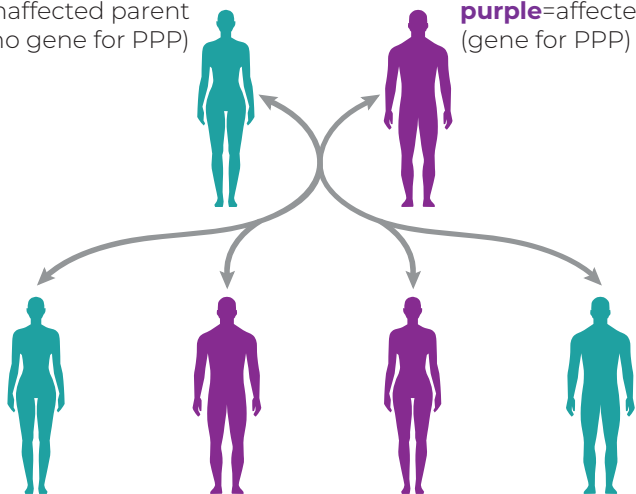
As your Family Facilitator, you can help guide your family members' paths by encouraging them to discuss the possibility of PPP with their doctors.

## WHAT CAUSES PPP?

PPP is a rare condition caused by a change, called a mutation, in your genes. If someone has a gene that causes PPP, there is a 50% chance that each of his or her children will inherit that gene, too.<sup>1</sup>

PPP affects your muscles and can lead to episodes of muscle weakness and/or temporary paralysis.<sup>1</sup> Some people with PPP develop Permanent Muscle Weakness (PMW), meaning that weakness does not go away in between episodes.<sup>3</sup> PMW is most common in people with PPP who are between the ages of 40 and 50.<sup>2,3</sup>

**teal**=unaffected parent (no gene for PPP)      **purple**=affected parent (gene for PPP)



# Talking to a family member about PPP

If you're reading this, you might be worried that some of your family members may also have this condition. This is a sensitive topic, and while you don't want to frighten anyone, you do want to pass along facts and useful information about PPP.

Talking openly about PPP is a brave decision. By sharing your own knowledge and experience, you can act as a source of information and inspiration. You can also help remove the stigma from this rare, often-misunderstood condition.

*I'd like to talk with you about a genetic condition I have—is that okay with you? I think this information will be important for you and the rest of our family, too.*



## PLANNING THE CONVERSATION: KNOW WHAT YOU WANT TO SAY AND HOW TO SAY IT

Think about what you want to say. Imagine if you didn't know you had PPP, but there was a chance you could be living with it, or could pass it on to your children. What would you wish someone had told you?

Also, consider your family member's preferences—would he or she prefer to have the conversation in person or over the phone? Alone or with the support of other family members?

## STARTING THE CONVERSATION: KEEP IT NICE AND SIMPLE

Start off on a positive note by letting your family member know why you wanted to have this conversation in the first place: to empower them with knowledge.



# PPP family history worksheet

**These symptoms, in combination with others, could be signs of Permanent Muscle Weakness.<sup>3</sup>**

Consider the following when filling out the additional information section of this worksheet:

- Have any of your family members experienced injuries in their 40s and 50s from falls due to symptoms of weakness or paralysis?
- Have any of your family members experienced permanent weakness in their 40s and 50s, which resulted in use of a cane, wheelchair, scooter, or walker?

**ALSO, CONSIDER:**

- Do you know how old these family members were when they started experiencing episodes of weakness or paralysis?



"After learning more about PPP, I realized that both my father and my paternal grandfather, who are both deceased, had experienced PPP symptoms. My dad had been diagnosed with low potassium, but no one had made the connection to PPP."

*Janine* XERIS PHARMACEUTICALS® PATIENT AMBASSADOR

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# How is PPP diagnosed?

**Family history is very important when considering a diagnosis of PPP.<sup>2</sup>**

A doctor can review family history, complete physical examinations, or perform other tests to confirm a diagnosis of PPP! These tests include:

- Electrocardiogram (ECG/EKG)<sup>1</sup>
- Electromyography (EMG)<sup>1</sup>
- Compound muscle action potential (CMAP)<sup>4</sup>

Doctors may also order genetic testing.<sup>4</sup> If the test comes back positive, a diagnosis of PPP can be confirmed. A negative genetic test result does not always rule out a diagnosis of PPP, though.<sup>1</sup> About **30%** of people may have a negative or inconclusive test, but still have PPP!<sup>1</sup>

**MEET DENNIS - WHO WAS DIAGNOSED BECAUSE OF A FAMILY EXPERIENCE WITH PPP**

Dennis is the fourth generation in his family to be diagnosed with PPP. He had his first PPP episode at only 14 years old when he was about 1,100 miles away from home. After waking up paralyzed from a large spaghetti dinner the night before, Dennis heard his mom say, "Sounds like Little Denny has the spells." Dennis knew that "the spells" was the term his family used to describe the paralysis his father, grandfather, and great-grandmother experienced.

Because of his family's history with PPP, Dennis was able start a conversation with his family doctor, which ultimately led to him being diagnosed with PPP and led him down a path to find answers.



"Although I knew from my family's experiences that having PPP wasn't the worst thing in the world, I felt upset about it because I understood that I would be dealing with it for the rest of my life, just as my father, grandfather, and great-grandmother had . . . To someone who is newly diagnosed . . . PPP is a challenge. But you have people to talk to . . . you're not by yourself. You're going to be able to make it."

*Dennis* XERIS PHARMACEUTICALS® PATIENT AMBASSADOR

# You can make a difference by being your Family Facilitator.

**TALK TO YOUR FAMILY ABOUT PPP.**

**SUPPORT AND EDUCATIONAL RESOURCES ARE AVAILABLE**

Sign up for more information about PPP at [PavingMyPath.com](https://www.pavingmypath.com).



*"I want other people living with PPP to know they are not alone. With perspective and courage, we can keep moving forward...We can aspire to a lot. We can persevere."*

*Leslie* XERIS PHARMACEUTICALS® PATIENT AMBASSADOR

**REFERENCES:** **1.** Statland JM, Fontaine B, Hanna MG, et al. Review of the diagnosis and treatment of periodic paralysis. *Muscle Nerve*. 2018;57:522-530. **2.** Charles C, 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. **3.** 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;31:126-133. **4.** Weber F, Jurkat-Rott K, Lehmann-Horn F. Hyperkalemic Periodic Paralysis. *GeneReviews*®. NCBI Bookshelf. A service of the National Library of Medicine, National Institutes of Health.

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