xeris PHARMACEUTICALS

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.[1]

Your family members may not know they have PPP, or, if they are experiencing symptoms, may not realize they could be caused by PPP.[1,2]

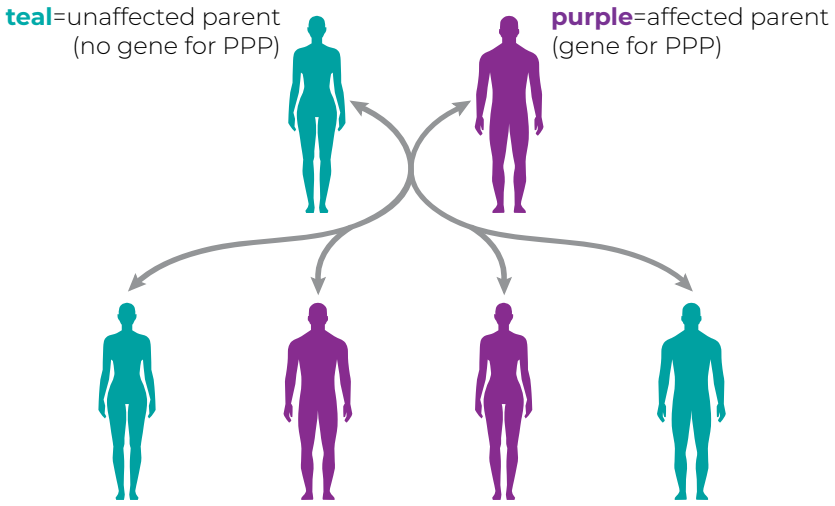
Think back to how you felt when you were finally diagnosed with PPP. At last, you had an answer for why you were feeling the way you were feeling—and a path forward.

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.[1]

PPP affects your muscles and can lead to episodes of muscle weakness and/or temporary paralysis.[1] Some people with PPP develop Permanent Muscle Weakness (PMW), meaning that weakness does not go away in between episodes.[4] PMW is most common in people with PPP who are between the ages of 40 and 50.[2,4]



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.

Tips for a productive conversation

The information in this brochure, along with the family worksheet, can help you have a conversation about PPP. And, to help make the conversation go more smoothly, remember to stick to the **FACTS**:

F

FAMILY CONNECTION AND HISTORY

Discuss the genetic nature of PPP.[1] Your family member should know that he or she, along with other family members, may have also inherited a gene that can cause PPP.

A

ANSWERING QUESTIONS

This may be the first time your family member has heard of PPP, and he or she will probably have questions. Do your best to answer honestly, sharing both your challenges and your triumphs.

C

COMPLETING THE FAMILY WORKSHEET

After you fill out the family worksheet, you can share it with your family member, or even complete it with them. You may notice patterns in your family, which could lead to a more productive conversation with a doctor.

See page 5 for the family worksheet.

T

TALKING TO A DOCTOR

Encourage your family member to talk to a doctor who is familiar with PPP about any symptoms he or she may be experiencing, so that his or her doctor can consider a diagnosis of (and testing for) PPP, and begin treatment, if appropriate.

Find a doctor who diagnoses and treats PPP at pppdocfinder.com.

S

SUPPORT RESOURCES

Set your family up to educate themselves by pointing them to resources they can explore to learn more about PPP.

Community that empowers people with PPP

xeris Care Connection℠ | Periodic Paralysis | Periodic Paralysis International | MDA

PPP family history worksheet

To complete the worksheet, think about if any of your relatives had a confirmed diagnosis of PPP or if they have experienced episodes of paralysis or weakness after exposure to a known trigger of PPP, such as[1]:

- FOODS OR BEVERAGES HIGH IN SALT, CARBOHYDRATES, OR POTASSIUM
- STRESS OR TIREDNESS
- BECOMING COLD
- PERIODS OF INACTIVITY
- RESTING AFTER EXERCISE

Also, write down any additional information you feel is relevant. If you're unsure of what to write, the full worksheet has thought starters for you to consider.

Once you're finished, you can bring the worksheet along to the doctor's office to discuss your family history at appointments.

EXAMPLES

GRANDFATHER	CHILD
☑ Confirmed PPP diagnosis ☑ Had episodes of muscle weakness or paralysis after exposure to triggers	☐ Confirmed PPP diagnosis ☑ Had episodes of muscle weakness or paralysis after exposure to triggers
ADDITIONAL INFORMATION: *Started using a cane around age 40, later moved to a wheelchair after several injuries from falls*	**ADDITIONAL INFORMATION:** *Experienced episodes of muscle weakness after soccer games*

FOLD OUT FOR THE FULL WORKSHEET →

This worksheet can help you and your family members track your family history, which is **important information** for a doctor to have when diagnosing PPP.[3]

"In 2010, I finally began connecting more dots. A wellness physician ...was thinking Parkinson's or multiple sclerosis, so when asked about my family history, I told her no one in my family had anything like that. Later, I would piece together through ancestry and asking questions that my mother, aunt, and cousin all seemed to have PPP."

Teresa XERIS PHARMACEUTICALS PATIENT AMBASSADOR

NOTES

Use this space to keep track of any additional notes and information from conversations with your family members.

TURN THE PAGE AND FOLD OUT FOR THE FULL WORKSHEET

PPP family history worksheet

These symptoms, in combination with others, could be signs of Permanent Muscle Weakness.[4]

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

GRANDMOTHER	GRANDFATHER
☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**	☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**

AUNT/UNCLE	MOTHER/FATHER	AUNT/UNCLE
☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**	☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**	☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**

SISTER/BROTHER	YOU	SISTER/BROTHER
☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**	☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**	☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**

CHILD	CHILD	CHILD
☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**	☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**	☐ Confirmed PPP diagnosis ☐ Had episodes of muscle weakness or paralysis after exposure to triggers **ADDITIONAL INFORMATION:**

How is PPP diagnosed?

Family history is very important when considering a diagnosis of PPP.[2]

A doctor can review family history, complete physical examinations, or perform other tests to confirm a diagnosis of PPP.[1,4] These tests include:

- Electrocardiogram (ECG/EKG)[1]
- Electromyography (EMG)[1]
- Compound muscle action potential (CMAP)[5]

Doctors may also order genetic testing.[5] If the test comes back positive, a diagnosis of PPP can be confirmed.[5] A negative genetic test result does not always rule out a diagnosis of PPP, though. About **30%** of people with PPP do not have one of the common genetic mutations associated with this condition.[1]

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.**

"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

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