PRIMARY PERIODIC PARALYSIS

DAILY TRACKER & 1-MONTH DIARY

THIS DIARY IS FOR GUIDANCE PURPOSES ONLY.

The content within this diary is for personal use to aid in a discussion with your doctor and is not intended for self-diagnosis. The information contained here is not a substitute for medical diagnosis or professional treatment. You should consult your doctor about your diagnosis and any treatment options.

Capturing this information will help guide you and your doctor in discussions about your condition and individual management needs.

DAILY TRACKER TOOL

In this tracker, you'll find an easy-to-use, printable tool that enables you to keep a record of your episodes, including:

- When they occurred
- What triggers were involved
- How severe they were
- How they affected you

1-MONTH DIARY

Also in this tracker, you can print an at-a-glance record that lets you summarize your episodes over a 1-month period including:

- A summary of your episodes
- How lifestyle modifications and medications worked
- How the episodes impacted your life

DAILY TRACKER

DIRECTIONS THIS FORM INCLUDES ROOM FOR YOU TO KEEP A RECORD OF EPISODES.
PRINT A NEW COPY AS NEEDED TO KEEP AN ONGOING RECORD THAT WILL HELP YOU:

- Capture important details about your Primary Periodic Paralysis episodes.
- Get a clearer understanding of repeating patterns to help you understand and manage triggers.
- Use your daily forms to complete a 1-Month Diary that you can share with your doctor to help him or her better understand how your condition has been affecting your life.

EPISODE EXPERIENCE	DATE	DATE
What potential triggers might have caused the episode?	☐ Rest after exercise or activity ☐ Feeling cold ☐ After high carb foods ☐ Experiencing excitement or stress ☐ After salty foods ☐ Noise ☐ Sudden changes in temp ☐ Flashing lights ☐ Alcohol ☐ Menstrual period ☐ Lack of sleep ☐ Other; specify. _____	☐ Rest after exercise or activity ☐ Feeling cold ☐ After high carb foods ☐ Experiencing excitement or stress ☐ After salty foods ☐ Noise ☐ Sudden changes in temp ☐ Flashing lights ☐ Alcohol ☐ Menstrual period ☐ Lack of sleep ☐ Other; specify. _____
How long did the episode last?	☐ Less than an hour ☐ Between 5 and 10 hours ☐ Between 1 and 3 hours ☐ Between 10 and 24 hours ☐ Between 3 and 5 hours ☐ Longer than 24 hours	☐ Less than an hour ☐ Between 5 and 10 hours ☐ Between 1 and 3 hours ☐ Between 10 and 24 hours ☐ Between 3 and 5 hours ☐ Longer than 24 hours
How bad was the episode?	**1** = mild complaints of muscle weakness but capable of performing daily tasks **2** = capable of walking without help of a cane/walker, but not capable of performing daily tasks **3** = only capable of walking with a cane / walker or with support of another person **4** = bound to bed or wheelchair due to the episode **5** = ER or ICU admission due to severe weakness or paralysis	**1** = mild complaints of muscle weakness but capable of performing daily tasks **2** = capable of walking without help of a cane/walker, but not capable of performing daily tasks **3** = only capable of walking with a cane / walker or with support of another person **4** = bound to bed or wheelchair due to the episode **5** = ER or ICU admission due to severe weakness or paralysis
What muscles were affected during the episode?	☐ Arms ☐ Legs ☐ Face ☐ Hands ☐ Neck ☐ Feet Other; specify. _____	☐ Arms ☐ Legs ☐ Face ☐ Hands ☐ Neck ☐ Feet Other; specify. _____
How did you manage the episode?	☐ Medication ☐ Prescription; specify. _____ ☐ Supplements; specify. _____ ☐ Other; specify. _____ ☐ Nothing	☐ Medication ☐ Prescription; specify. _____ ☐ Supplements; specify. _____ ☐ Other; specify. _____ ☐ Nothing
Check and rate any symptoms based on how you felt the first day after the episode, with 1 being mild and 5 being severe.	☐ Weak _____ ☐ Tired _____ ☐ Muscle stiffness / pain _____ Other; specify. _____	☐ Weak _____ ☐ Tired _____ ☐ Muscle stiffness / pain _____ Other; specify. _____
How did you feel after the episode?	☐ Anxious ☐ Sad ☐ Angry ☐ Neutral ☐ None of these ☐ Other; specify. _____	☐ Anxious ☐ Sad ☐ Angry ☐ Neutral ☐ None of these ☐ Other; specify. _____

1-MONTH DIARY

DIRECTIONS PRINT AND FILL IN A COPY OF THIS FORM EVERY MONTH TO HELP YOU ASSESS HOW YOU'VE BEEN FEELING OVER THIS TIME. THEN, TAKE YOUR COMPLETED FORM OR FORMS TO YOUR NEXT DOCTOR APPOINTMENT TO:

- Assess trends in your episode triggers, areas of your body most affected, how severe your episodes have been, and how long they tend to last.
- Provide your doctor with a snapshot view of your health and how Primary Periodic Paralysis has been affecting you since your last visit.
- Help guide your discussions with your doctor so that he or she can better understand how you feel, and make any changes in your care that may be needed.

FROM DATE: _____ **TO DATE:** _____

INFORMATION	DETAILED DESCRIPTION
Your personal and health information	**NAME** _____ **DATE OF BIRTH** _____ **PHONE** (___) _____ ☐ Mobile ☐ Home ☐ Office **DIAGNOSIS** ☐ Hypokalemic periodic paralysis ☐ Hyperkalemic periodic paralysis ☐ Other type of Primary Periodic Paralysis; specify: _____ Affected gene (if applicable): ☐ CACNA1S ☐ SCN4A ☐ KCNJ18 ☐ RYR1 ☐ Don't know Treatment for episodes; specify. _____ Family history of Primary Periodic Paralysis ☐ Yes (☐ Mother ☐ Father ☐ Sibling ☐ Other relative; specify. _____) ☐ None ☐ Don't know Your current doctor and contact details: _____ Previous physicians you have consulted: _____
Overview of your episodes in the last 1 month	**MOST COMMON TRIGGERS** ☐ Rest after exercise or activity ☐ After high carb foods/meals ☐ After salty foods/meals ☐ Sudden changes in temperature ☐ Feeling cold ☐ Experiencing excitement or stress ☐ Noise ☐ Flashing lights ☐ Alcohol ☐ Menstrual period ☐ Lack of sleep ☐ Other; specify. _____
How bad were the episodes?	**1** = mild complaints of muscle weakness but capable of performing daily tasks **2** = capable of walking without help of a cane / walker, but not capable of performing daily tasks **3** = only capable of walking with a cane/walker or with support of another person **4** = bound to bed or wheelchair due to the episode **5** = ER or ICU admission due to severe weakness or paralysis
Muscles most commonly affected	☐ Arms ☐ Legs ☐ Face ☐ Hands ☐ Neck ☐ Feet Other; specify. _____
Total number of episodes per week	Week 1 _____ Week 2 _____ Week 3 _____ Week 4 _____ Total number of episodes for the month _____
Impact on everyday living	I am unable to attend work or school ☐ Always ☐ Mostly ☐ Sometimes ☐ Rarely ☐ Never I miss out of events with my family and friends ☐ Always ☐ Mostly ☐ Sometimes ☐ Rarely ☐ Never I miss out on basic family time ☐ Always ☐ Mostly ☐ Sometimes ☐ Rarely ☐ Never I miss out of events with my family and friends ☐ Always ☐ Mostly ☐ Sometimes ☐ Rarely ☐ Never I have had to give up my hobbies ☐ Always ☐ Mostly ☐ Sometimes ☐ Rarely ☐ Never Other impact; specify. _____
Overall emotions & feelings	☐ Anxious ☐ Sad ☐ Angry ☐ Neutral ☐ Other; specify. _____ ☐ None of the these
Primary Periodic Paralysis management	**ARE YOU SATISFIED WITH THE WAY YOUR PRIMARY PERIODIC PARALYSIS IS CURRENTLYMANAGED?** ☐ Yes, why? _____ ☐ No, why? _____ **WHAT ARE YOUR TREATMENT GOALS?** _____

Your questions for your doctor

Notes

1375 West Fulton Street, Suite 1300,
Chicago, IL 60607
xerispharma.com

xeris® PHARMACEUTICALS