

Primary Periodic Paralysis (PPP) Commitment Statement

Background Statement

PPP advocates and mentors came together at a Thought Leader Summit with Xeris Pharmaceuticals® to align on our mutual commitment to support the PPP community. This commitment statement reflects our efforts to make an impact for everyone in the PPP community, and it outlines the vision, goals, and objectives that guide us.

The Reasons for Our Commitment

The PPP community deserves our utmost commitment for several reasons:

- **PPP is a rare condition with devastating consequences when it is not managed and treated properly.** Because PPP is so rare and can be mistaken for other health conditions, it may sometimes take 20+ years to get a diagnosis.¹
- **Patients and caregivers deserve to have their needs met.** They have a right to be heard, helped, supported, and feel connected at every stage of the journey.
- **Patients and caregivers deserve the best possible quality of life.** With proper management, support, and treatment, those affected with PPP can live meaningful, beautiful, and productive lives.
- **Increased education, awareness, and collaboration are crucial.** They strengthen this community and create better outcomes.

The Energy Behind Our Collaboration

As advocates, mentors, and patients, we have very personal reasons for collaborating on this statement:

- **Patients and caregivers best understand the community's needs.** Our lived experience gives us a unique understanding of the needs, goals, and hopes of the community and what matters most.
- **We want to pay it forward.** We are grateful for the answers and support we received from the community during our journey with PPP, and we want to repay that by using our knowledge to help others have better experiences.
- **Together, we are stronger.** As individuals living with this disease, caring for a loved one, or advocating, we may sometimes experience moments of physical weakness. But as we pour our hearts into the PPP community, we become stronger together.

Reference:

1. 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.



Kirsten, PPP Patient Mentor



Dennis, PPP Patient Mentor



Janine, PPP Patient Mentor



Paul, PPP Patient Mentor

“ Our goal as a community is to raise awareness so that people who live with PPP won't have to struggle to get a diagnosis and the care they deserve to have a better quality of life.

– Cienna Ditri, president of the Periodic Paralysis Association, diagnosed with PPP in 2018

Our Goals and Objectives

As we move forward with hope, courage, and intention, we commit to expanding our support of the PPP community by concentrating on the following goals:

- 1 Identify and address unmet needs among patients and caregivers.** These include potentially devastating gaps in knowledge, understanding, connection, and access to resources.
- 2 Increase awareness in the medical community.** Greater knowledge about PPP is crucial for timely, accurate diagnosis of PPP, as well as effective treatment and meaningful support. Patients deserve to be heard, believed, and understood by medical professionals. We are committed to helping HCPs understand PPP, its triggers and symptoms, and its impact on quality of life.
- 3 Increase awareness among the public.** Greater public understanding of PPP as an unpredictable but life-altering condition helps inform us as patients and caregivers. We believe the PPP community deserves to be more widely recognized, and we want to make it easier and more accessible for the public to learn about PPP.
- 4 Listen and advocate.** We are dedicated advocates who want to ensure patients are heard, believed, and understood. We are here to listen to patients' stories and concerns, and we want to support, encourage, and champion the needs of patients and caregivers. We also commit to building stronger connections within our community, because strength and hope come from sharing our experiences, feelings, challenges, and victories.
- 5 Collaborate in advocacy.** Our community includes advocates and leaders from different organizations, all of whom bring individual strengths and perspectives. Vibrant collaboration between those organizations will benefit everyone in our community.
- 6 Support rigorous PPP management.** Proper treatment can change lives. We believe every patient deserves access to the very best in treatment options, management tools, and specialized care, and we are committed to supporting that access.

Our Passion

Living with PPP or caring for a loved one affected by PPP presents an array of challenges. By working together in strength, partnership, and courage, we can improve the lives of our community as we face those many challenges. We are excited to share our passionate commitment to support our community.



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