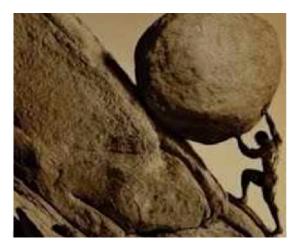


Update #01 - February 20, 2025: 3:00 PM in Texas

I Am Here. Where Are You?

In Greek mythology, Sisyphus was the king of Ephyra. He got on the wrong side of Hades, the god of the dead, by cheating death twice.

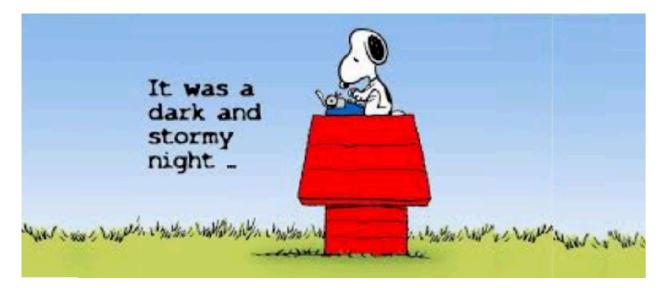
In a rage, Hades forced Sisyphus to roll an immense boulder up a hill every day. As the boulder neared the top, Hades caused it to roll back down. Sisyphus rolled that boulder for all eternity.



For the past decade — and then some — the image of Sisyphus, his boulder and the hill has served as a visual metaphor for the daily challenges of body, mind and spirit we all face as PRP patients.

Whether the PRP diagnosis is adult-onset or juvenile-onset, every PRP journey has an array of setbacks and disappointments. At one time or another ever PRP patients — and let's include caregivers — have rolled a metaphorical PRP boulder up a hill only to watch it roll back.

That's Why We Are all Kindred Spirits.



Publishing a Book About PRP Has Been my Never-Ending Boulder of Sisyphus

I have never retired from writing. I have always been a writer. I have been writing about PRP since September 2013 It was in Month 13 of my own 20-month PRP journey.

1. PRP newsletter (On the Road):

- Published from April 1, 2014 to October 1, 2015.
- Posted 24 issues, 600 pages and an estimated 160,000 words.

2. PRP Survival Guide:

- Website launched on May 20, 2015.
- Currently represents 600 topics for an estimated 600,000 words.

3. 60-Second PRP Roadmap, Peer Review Edition:

- Released in March, 2024.
- Represents 340 pages and nearly 50,000 words.
- This was a **DRAFT** to be reviewed by PRP patients and caregivers.
- The Peer Review Edition is still available at no charge. If you want a copy.please email <u>bill.mccue@prpAlliance.com</u> if you need help.

Based on PRP Feedback I Will Focus on Publishing Four Smaller Books

1. 60-Second PRP Roadmap, First Questions:

- Target release date: May, 2025.
- Content: 60 pages and over 15,000 words.
- Scope: Presents the answers to the first 30 questions that every PRP patient *needs to know*. Written from the patient perspective.

2. 60-Second PRP Roadmap, PRP Glossary of Words & Jargon:

- Target release date: October 2025
- Content: 250 pages and over 62,000 words.
- Scope: defines over 200 words, jargon and terms that every PRP patient *needs to know*. Written from the patient perspective.

3. 60-Second PRP Roadmap, Treating PRP

- Target release date: February, 2026 in conjunction with Rare Disease Day
- Content: 50 pages and over 12,500 words.
- Scope: Presents PRP treatment options based on feedback from PRP patients and caregivers, dermatologists, general practitioners, and other healthcare professionals who specialize in feet, vision, hearing, mental wellness, etc. Written from the PRP patient perspective and outlines a strategy for PRP self-advocacy.

4. 60-Second PRP Roadmap, Self-Advocacy:

- Target release date: June, 2026
- Content: 50 pages and over 12,500 words.
- Scope: Presents an easy-to-manage self-advocacy plan for patients with PRP. Written from the PRP patient perspective and outlines a strategy for PRP self-advocacy.

How Engaged Are You Right Now?

Which of the following boxes would you check? Doesn't matter is you are a PRP patient or caregiver.

□ ARE YOU SUPER-ENGAGED with POSTS and COMMENTS

BRAVO. You are getting **full value** as a member of the PRP Support Group, Please email me at <u>bill.mccue@prpAlliance.com</u> and help me finish FIRST QUESTIONS.

□ ARE YOU ENGAGED with just COMMENTS.

Still a BRAVO. Please email me at **<u>bill.mccue@prpAlliance.com</u>** and help me finish FIRST QUESTIONS.

□ ARE YOU MINIMALLY ENGAGED with just Reactions?

Bravo in lowercase. There is so much more you can get by posting questions and providing comments. Please email me at <u>bill.mccue@prpAlliance.com</u> and help me finish FIRST QUESTIONS.

□ DISENGAGED — WATCHING FROM AFAR

No posts, comments or reactions. Help me complete FIRST QUESTIONS and I GUARANTEE you will benefit as a PRP patient or a PRP caregiver. Please email me at **bill.mccue@prpAlliance.com** and tell me why you only watch from afar?

Where Should You Really Be!

In my humble opinion EVERY PRP patient should be reviewing EVERY word I right about PRP **before** FIRST QUESTIONS IS published. YOU should be an EDITOR who makes absolutely sure I get it right!

- 1. Did I include the right 30 questions? What's missing?
- 2. Did I answer all 30 questions properly? What did I miss or get wrong?
- 3. How can I make FIRST QUESTIONS better?

No One Can Answer Those Three Questions Better Than You.