



“ *When my PRP journey began, I was alone and utterly terrified. I saw hopelessness in my mirror. But the flame of hope was ignited when I found the PRP Support Group on Facebook.*

*That flame shone brighter as I reached out to my new global family, all on a similar journey. Hope springs iternal.*

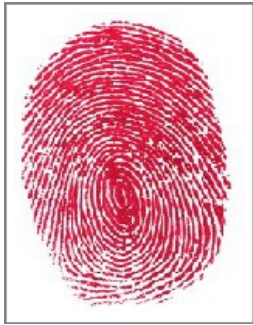
*— Carol T, Swaffham, England, UK*

# SECTION ONE

## What you need to know from the start.

1. What is PRP?
2. What is the NORD PRP Report
3. What constitutes a rare disease?
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# 1. What is PRP?



The first definition I saw as a newly diagnosed PRP patient went like this: "... a rare inflammatory papulosquamous disorder of unknown etiology. Includes distinct, well-demarcated plaques of various sizes with characteristic reddish- orange hue."

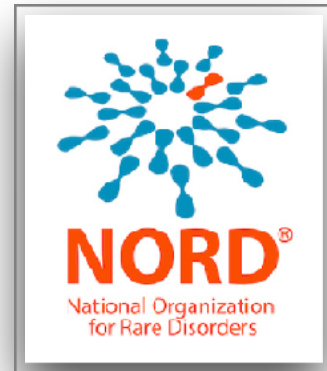


Try these more patient-friendly observations!

- In Latin, PRP stands for scaling (*pityriasis*), redness (*rubra*), and hair follicles (*pilaris*). Just say "Pityriasis rubra pilaris stands for **scaling, redness** and **hair follicles**." Said another way: "I have pityriasis rubra pilaris or PRP that stands for scaling, red and hair follicles." Tap your arm when you say "hair follicles".
- Every PRP patient and every PRP journey is as unique as a fingerprint or a snowflake. **Lorem ipsum dolor sit amet, consectetur adipiscing elit. Nulla sollicitudin est quis est iaculis pellentesque.**
- PRP is an **ultra**-rare skin disorder. I lived in Eching, Germany (near Munich) in the mid-70s. Perhaps that's why I often replace **ultra**-rare to **über**-rare (pronounced like the "o" in Who). To me, **über** sounds more rare than ultra. Only seems to work with PRP. I don't use über to describe a ultra-close shave with an expensive razor.
- Shakespeare wrote: "A rose by any other name would smell as sweet". I also use **disorder** rather than **disease** because disorder sounds less contagious." As a homeowner there are words that conjure up negative thoughts, like mold, infestation, warped, and anything clogged. I avoid using "disease" when dealing with *civilians*. FYI: PRP patients and PRP caregivers are not civilians.
- PRP may impact different parts of the body in a variety of ways for unpredictable periods. That's why the phrase "predictably unpredictable". The National Organization of Rare Disorders has it both ways. Their non-profit organization uses "Disorders" while their website is [rarediseases.org](http://rarediseases.org).

## 2. What is the NORD PRP Report?

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- PRP often appears as a small spot on the face (*or not*) and then spreads elsewhere (usually).
- Pityriasis rubra pilaris (PRP) is a rare skin disorder that causes inflammation of the skin, thickening of the nails and at times shedding of the hair.
- PRP inflames the entire body (*or just parts*), thickens the soles and palms (*or not*), can affect elbows and knees (*or not*), causes loss of hair (*or not*), and can make strange things happen to fingernails and toenails (*or not*).
- PRP may leave clear areas of skin called “islands of sparing” (*or not*).
- PRP may move slowly or quickly. It may come and go or come and stay. Get the picture?
- While every PRP journey is predictably unpredictable, we share a common bond: the daily challenges of body, mind and spirit.
- The exact number of PRP patients is unknown but fall in the unscientific category of not many.
- No treatment option for PRP has been approved by the Federal Drug Administration (FDA) or comparable governmental entities anywhere, e.g., European Medicines Agency (EMA),
- Based on conversations within the PRP community, we can say with metaphysical certitude that PRP isn't a punishment for misbehavior or forgetting to put the toilet seat down. There are thousands of perfectly wonderful people who have — or had — PRP. Moreover, there are many very bad people who don't have it.

### 3. What constitutes a rare disease (463)



While not as unique as a unicorn, rare diseases represent a significant medical challenge. Here are a few facts to better understand the uniqueness of PRP. *Aliquam malesuada turpis vitae risus laoreet mollis. Nam egestas facilisis ante, ut consequat magna suscipit ultrices. In hac habitasse platea dictumst. Etiam lacinia, massa convallis sodales ultricies, ante ex dapibus mi, quis maximus justo nulla vitaenec lobortis est sed u*

- The National Institutes of Health, Genetic and Rare Diseases Information Center has identified over 7,000 different types of diseases, disorders and conditions worldwide. A total of 608 are considered rare skin disorders.
- Approximately 50% of rare diseases do not have a disease-specific foundation supporting or researching their rare disease.
- According to the National Organization of Rare Disorders, more than 90% of rare diseases are still without an FDA-approved drug treatment. *Aliquam malesuada turpis vitae risus laoreet mollis. Nam egestas facilisis ante, ut consequat magna suscipit ultrices.*
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**The calculations may vary,  
but “rare” is still a very small number.**

**United States**

The Orphan Drug Act of 1983 defines a disease as “rare” if it affects less than 200,000 people. With a population of 342 million (2024 est) the National Organization of Rare Disorders estimates a rare U.S. disease population of 30,000.



**European Union**

The EU defines a rare disease as one that affects fewer than one in 2,000 people. With a population of 448 million (2024 est) the EU estimates a rare disease population of the European Union is 34,000



**United Kingdom**

Like the EU, the United Kingdom defines a rare disease as one that affects fewer than one in 2,000 people. With a population of 68 million (2024 est) the projected rare disease population of the United Kingdom is 34,000.



**Canada**

The Canadian Organization for Rare Disorders defines a rare disease as one that affects fewer than one in 2,000 people. With a population of 39.1 million (2024 est) the projected rare disease population of Canada is 19,550.



**Australia**

The [source] defines a rare disease as one that affects fewer than five in 10,000 people. With an estimated population of 26.7 million (06/2024) the projected rare disease population of Australia is 13,350.



**World Health Organization**

The [source] defines a rare disease as one that affects fewer than one in 2,000 people. With an estimated world population 8 billion (01/2024) the projected worldwide rare disease population is 4 million.





4.

## What are the Signs of PRP?

Signs and Symptoms are not the same. A *sign* indicates a medical condition that others, including your doctors, can observe objectively.

- The first *signs* of early onset PRP are most likely seen by the patient, spouse, partner, parent or even a close friend.
- Unfortunately, those initial *signs* mimic other more common skin disorders, e.g., psoriasis and eczema.
- Other visible signs may appear before you see a dermatologist. Your PRP journey has begun., but a proper diagnosis requires more fact-finding.

**SIGN =SEE**

### **Mirror ... mirror ... on the wall**

*"It was the second week of August, 2012 when I saw the red spot, nested in my hairline. It was the size of a dime. A few days later it was the size of a quarter and visible to all. I made an appointment with my dermatologist. Two weeks later the quarter was now the size of a dollar bill covering my cheek...temple to chin. It was the first sign that something was amiss with my skin. — Bill M, Texas, USA*

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## 5. What are Symptoms of PRP?

In contrast to a sign, a *symptom* is information patients share, willingly or unwittingly with their healthcare professionals, e.g., answers to questions, unsolicited comments, test results, etc.

The only way my dermatologist would have known I could only sleep three hours at night was for him for me to tell him. At some point during early onset, the patient decides that it's time to see a dermatologist.

**SYMPTOM = SHARE**

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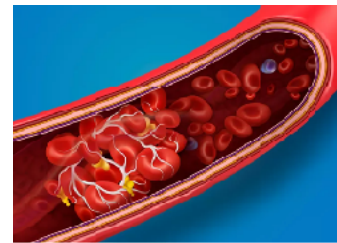
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### A symptom is not a sign

*"The only way for my dermatologist to know I might have a possible blood clot was to feel my warmer-than-it-should -be right leg. I was taken by wheelchair to the ER for an ultrasound that confirmed Deep Vein Thrombosis (DVT). There was no sign. I had unknowingly I shared a warmer than usual leg with an observant healthcare profession. Kudos to Dr, Dominquez at the University of Texas Southwestern (Dallas)"* — **Bill M, Texas, USA.**



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## 6. How does PRP progress?

After spending over a decade reading or listening to stories shared by thousands of PRP patients and caregivers, I have come to the conclusion that two metaphors will aid in (a) telling your own PRP story to others and (b) understanding your own PRP journey.

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### **PRP IS A JOURNEY**

- PRP is a journey that starts somewhere with a warning sign of some sort, e.g., spot, rash, etc., and then follows a path all on its own. Every PRP journey is unique.
- Patients and caregivers are travelers who learn as they go. Sometimes, the road ahead is plagued by hazards and obstacles. There are other times when our road is filled with hope.
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### **PRP IS UNPREDICTABLE**

- Some say PRP will last two to three years; some say three to five years. And some are in it for the “long haul” or six-plus years. A few discover they have a chronic version, and their journey lasts a lifetime. I was one of the lucky ones. My journey lasted only 20 months.
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## PRP IS A FOREST FIRE

PRP is more like a forest fire. Once it starts, it grows. It can get out of control, and, for most, it either is put out with the intervention of firefighters or stops burning. **Praesent et faucibus diam, a ornare nibh.**

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**MANAGE** — Praesent et faucibus diam, a ornare nibh. Duis quis felis gravida, aliquam tortor nec, blandit lacus. Vestibulum quis viverra lacus. Curabitur lobortis nibh magna, uo



**MAINTAIN** — Euismod lacinia. Vivamus cursus erat sit amet volutpat vehicula. Duis finibus pharetra nisl vitae sollicitudin. Suspendisse ligula est, aliquet eget venenatis.



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## ONSET — Where there's smoke, there's fire

Every PRP journey has a beginning — just like a fire. *Donec facilisis fringilla neque et Donec facilisis fringilla ne Donec facilisis fringilla neque et. Donec facilisis fringilla neque etFusce velit lorem, Donec facilisis fringilla neque et. Donec facilisis fringilla ne Donec*

- For many PRPers, the signs of onset may not immediately ignite a serious spark of concern. There's little smoke and the flames are slow to materialize.
- For other PRPers, however, their onset could be described as “mugging in a dark alley requiring a call to 911”. When onset is on a fast track, it's like a forest fire where the transition from smoke to fire is like a runaway train.

### A red-spot the size of a dime

*“It was mid-August when I saw a red spot, the size of a dime on my forehead. It was partially hidden by my hairline on my right temple. A week later the spot was the size of a quarter. I exercised an abundance of caution and made an appointment with my dermatologist. Two weeks later my “spot” was now a “bar” the size of a dollar bill. It would be another three months before I was properly diagnosed with PRP.” — Bill M, Texas, USA*



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## **ACUTE — Out of control**

Most generally called the Acute Stage, the Red Menace is out of control, and every part of your body part is fair game. [Nhac habitasse platea dictumst.](#) [Nhac habitasse platea.](#)

- Dry, red, flaking skin may engulf the entire body. [Nhac habitasse platea dictumst.](#)
- Quality of life has reached a new low as PRP patients face the most significant challenge to body, mind, and spirit. The duration is unpredictable, lasting weeks or months. [Nhac habitasse platea dictumst.](#) [Nhac habitasse platea dictumst.](#)
- Symptoms become sinister, e.g., the pain of motion, unrelenting itch, heat intolerance, sleep deprivation, loss of energy, overall weakness, and inability to regulate body temperature. [Nhac habitasse platea dictumst.](#) [Nhac habitasse platea dictumst.](#)
- Mobility is compromised as the soles of feet become encased in thick, cracked, swollen and bleeding skin. [Nhac habitasse platea dictumst.](#)
- Dexterity is compromised as fingernails either disappear or grow thick and gnarly. Hands may become victims of swelling. [Nhac habitasse platea dictumst.](#)
- Vision may be seriously compromised by tightness and pulling of the eyelids
- PRP patients and caregivers should seek support from kindred spirits. Don't suffer alone or in silence. [Nhac habitasse platea dictumst.](#) [Nhac habitasse dictumst.](#)

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## MANAGEMENT — Working the Fire

Getting a fire under control is no small feat. The goal is to stabilize your PRP journey and focus on actions to mitigate and manage signs and symptoms on many fronts. No easy task. This was my to-do list in the Acute Stage. [Nhac habitasse platea dictumst.](#)

- Develop a Nightly Routine (10-11 PM) that included a warm bath, removal of flaking skin, and the slathering of Clobetasol and urea lotion (soles), Desonide (face) and triamcinolone (remaining nook and crannies). [Nhac habitasse platea dictumst.](#)
- Sleep through the night. With the help of my dermatologist, we crafted a cocktail of Tylenol, Ambien, and hydroxyzine. If I didn't drink any liquids after 9 PM, I could sleep until 7 AM. [In hac habitasse platea dictumst. Etiam lacinia, masipit ultrices. In hac habitasse plateasa. Nhac habitasse platea dictumst. Nhac habitasse platea](#)
- Stay mentally active. Once I had enough energy to sit at my computer (circa March 2013), everything changed for the good. As a member of an email-based support group, I had access to the archive of emails going back to 1997. Over four months, I read over 29,000 emails and built a PRP database.
- Make the most out of every clinic visit. Learn more about PRP than the dermatologist. Learn what other PRP patients have experienced. [In hac habitasse platea dictumst.](#)

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## MAINTENANCE — Smoldering embers

PRP maintenance is all about managing expectations. How can we slow the progress of our own version of PRP? I soon realized that my progress in PRP is best seen in a rear-view mirror. Day to day, I saw no change. Looking back, however, disclosed progress.

- I prioritized the symptoms that bothered me the most. That was easy: impaired mobility. My feet were swollen, and my soles were encased in thick skin that was cracked and bleeding.
- With a proper PRP diagnosis (four months into my journey), I was prescribed acitretin and a combination of Clobetasol<sup>®</sup> and urea lotion for the soles of my feet. Within six weeks, I was wearing sneakers abandoned four months before. I was walking again.
- Sleep deprivation was the next problem on my list. I eventually had an evening regimen and a pharmaceutical “cocktail” that guaranteed eight hours of sleep. *In hac habitasse platea dictumst. Etiam lacinia, masipit ultrices. In hac habitasse plateasa*
- There are no shortcuts. PRP patients have little or no control over what works and what doesn't. I kept working on my list of “issues” and gradually converted them to Healing Milestones.
- One by one, my list of active symptoms grew shorter and shorter. *Nam egestas facilisis ante, ut consequat magna suscipit ultrices.* I was working the fire!
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## ENDGAME — Extinguished

Even when the firestorm is contained, and the last of the burning embers have been extinguished, the remnants of the inferno remain.

- Neither PRP-savvy dermatologists nor the PRP global community of patients and their caregivers have an agreed-upon standard definition of remission. Sage advice from one of my daughters comes to mind: Whatever floats your boat.
- Every PRP journey is unique. It has taken me years to understand and fully appreciate that “med-free and symptom-free” is not the endgame for every PRP journey. *Nhac habitasse platea dictumst.*
- Remission is absolutely in the eye of the beholder and can include *remission with remnants*. *Fusce velit lorem, commodo ac congue. Fusce velit lorem, commodo ac congue. Fusce velit lorem, commodo ac congue*
- The remission is a decrease in or disappearance of the signs and symptoms of PRP. The caveat is whether or not meds are needed.
- Here’s a six-word gem: “I finally have my life back.”
- For some, “partial” remission means that PRP may still be “lurking,” and the phrase “smoldering below the surface” comes to mind.
- Over time, flora and fauna return to the forest. So, too, for PRP.

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## 7. Is there a cure for PRP?

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- According to the Merriam-Webster Dictionary, a *CURE* usually refers to a complete restoration of health. In contrast, *TREATMENT* refers to a process that improves health but may not include the complete elimination of disease.
- The consensus among dermatologists is that there is NO CURE for *pityriasis rubra pilaris*. This is NOT what a PRP patient or caregiver wants to hear.
- While there is no “Magic Bullet” to make PRP disappear, there are remedies to relieve specific signs and symptoms. Unfortunately, what works for one doesn’t work for all.
- We often hear that PRP will “run its course.” For many, “a tincture of time” is another unsatisfactory option, given the indeterminate length of a PRP journey.
- The best we can hope for and work towards is to be symptom-free, med- free (PRP-specific drugs) and free of relapses.
- While “Find a Cure” sounds like a worthy objective, the Federal Drug Administration has yet to approve a treatment for PRP. Simply stated, our patient population in the US is too small to make a traditional drug trial cost-effective. An inconsequential patient population is an insurmountable barrier to commercial investment in the research and development required to show evidence of the safety and efficacy of treatments.
- In the US alone, there are 25-30 million patients who, together, suffer from approximately 7,000 rare diseases—some of which affect as few as about a dozen individuals. Advocating FDA-approved treatments for PRP is still a noble cause.

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# Why Me?

## 8. Is PRP my fault?

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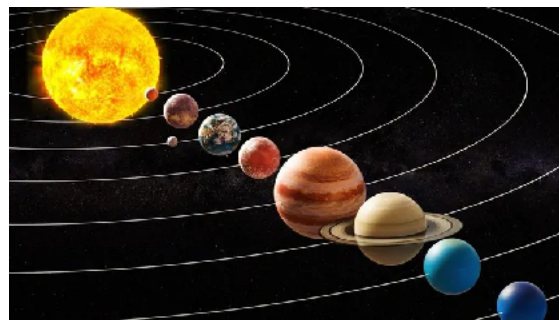
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## 9. What are Healing Milestones?

Healing Milestones are one way for PRP patients and caregivers to measure progress. The PRP global community has adopted a celebratory approach to disease recovery, recognizing various healing milestones. The following milestones are examples of symptoms that PRP patients and caregivers *feel* and signs that everyone else *observes*.

### Feet & Mobility Milestones

- Drive myself to Walmart. BM, USA
- I can flex my toes without them cracking. GH, Canada
- NOT using Walmart electric cart for disabled customers. . BM, USA
- NOT renewing the handicapped placard. KB, USA
- Feet are no longer encased in thick skin. DR, Australia
- Feet are no longer bleeding. CT, England

### THE FIRST HEALING MILESTONE — A PRP DIAGNOSIS

“In my humble opinion, the first healing milestone is the “official” diagnosis of PRP (clinical observation of a dermatologist supported by a biopsy and a dermatopathologist). No more guessing. Lorem ipsum dolor sit amet, co, co dolor sit amet, co, co, coning elit” — **Bill M, Texas, USA**



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### Energy & Fatigue Milestones

- I kicked a soccer ball around with my daughter.
- Restarted exercising
- Rode my byclce for the first time since...
- Hiked for the first time since...
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- Feet no longer swollen. Put on my sneakers for the first time in three months.

### Hands & Dexterity Milestones

- I was able to button buttons and zipper zippers.
- Opening a jar of Vlastic Sweet Relish without a pair of pliers.
- Fingernals that disappeared have returned
- Gnarly nails have returned to normal
- Nitrile Gloves — I no longer wear them. orem ipsum dolor sit amet, consectetur

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#### **Heaing Milestones re: eyes & vision**

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#### **Heaing Milestones re: ears & hearing**

- Had “jelly beans” (skin and wax) removed by an ENT specialist.
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- Started to sweat for the first time in over a year
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#### **Heaing Milestones re: sleep deprivation**

- Sleeping for eight hours with nom interuptions
- Needing to set my alarm my alarm for 7:00 AM becaue I don’t want to oversleep
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### **Heaing Milestones re: work/employment**

- Returnng to work.
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### **Socialization Milestones**

- Went to a good restaurant for dinner
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### **Financial Healt Milestones**

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### **Mental Wellness & Self-esteem Milestones**

- Wearing earrings for the first time in months. Lorem ipsum dolor sit amet, orem ipsum dolor sit amet, consectetur adipiscing elit. consectetur adipiscing elit. Lorem ipsum dolor sit amet, consectetur adipiscing elit. orem ipsum dolor sit amet,
- Needed a haircut (hairless for six months). orem ipsum dolor sit amet, consectetur adipiscing elit. orem ipsum dolor sit amet, consectetur adipiscing elit. orem ipsum dolor sit amet, consectetur adipiscing elit.
- Scalp was amess. Shaved my head and bought six wigs
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### **PRP Treatment Milestones**

- Not refilling a prescription for acitretin after 12 months.
- No longer need to wear a sauna suit.
- Scheduling an ANNUAL clinic visit rather than a three-month or six-month return. Lorem ipsum dolor sit amet, consectetur adipiscing elit. In tristique sed purus et condimentum. Praesent ornare mi id nisi mollis dignissim. Fusce velit lorem, commodo ac congue vi

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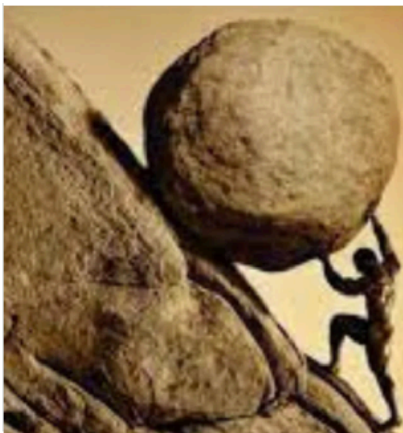
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### Daily Living Milestones

- Swept the dark hardwood floors and realized there was more Old English Sheepdog than me. Lorem ipsum dolor sit amet, consectetur adipiscing elit. In tristique sed
- Taking my first pain-free and nearly tingle-free shower in ages. Lorem ipsum dolor sit amet, consectetur adipiscing elit. In tristique sed purus et condimentum. Lorem
- A Healing Milestone is a sign of progress and hope. Perhaps the PRP Support Group should issue merit badges for every Healing Milestone we celebrate!
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- ADVOCACY — Lorem ipsum dolor sit amet, consectetur adipiscing elit. In tristique sed purus et condimentum. Praesent ornare mi id nisi mollis dignissim. Fusce velit
- ENGAGED with the Facebook wing of the PRP Support Group Lorem ipsum dolor sit amet, consectetur adipiscing elit. In tristique sed purus et condimentum Lorem ipsum dolor sit amet, consectetur adipiscing elit. In tristique sed purus et.
- ITCHING — I no longer itch. Lorem ipsum dolor sit amet, consectetur adipiscing elit. In tristique sed purus et condimentum Lorem ipsum dolor sit amet, consectetur adipiscing elit. In tristique sed purus et.



IN GREEK MYTHOLOGY, SISPHYUS SPENDS ETERNITY PUSHING A BOULDER UP A MOUNTAIN ONLY TO HAVE IT ROLL BACK TO THE BOTTOM. UNLIKE SUSPHYUS, THE PRP BOULDER DOESN'T ROLL BACK TO THE BOTTOM.

..... THERE IS HOPE.





## 10. What are the Metrics of PRP?

PRP is an über-rare skin disorder. You should know the metrics for where you live. For example, based on the estimated population for 2023, there are 841 PRPers in the USA, 78 in Texas and 16 in the Dallas-Fort Worth area. It does include me because I'm in remission. *Donec facilisis fringilla neque etDonec facilisis fringilla neque etFusce velit lorem, commodo ac congue vitae,*

**PREVALENCE** —In March 2003, Dr. Andrew Griffiths, a London-based dermatologist, delivered a “Dowling Oration” to members of the British Association of Dermatology (BAD) assembled in Liverpool, England. Dr. Griffiths reflected on 35 years of diagnosing, treating, and researching *pityriasis rubra pilaris*. He unilaterally set the PRP prevalence rate at one in 400,000. While the methodology used by Dr. Griffiths is subject to debate, dermatologists worldwide have accepted his estimates.



**OCCURRENCE BY LOCATION** —Based on population estimates for 2023, the following patient populations reflect PRP patient population estimates. PRP Global Database reports 0,000 PRP profiles, of which 0,000 are in the US and 0,000 are international. *Fusce velit lorem, commodo ac congue vitae, sodales sit amet velit.*

**OCCURRENCE BY AGE** — Based on 0,000 patient profiles reporting onset age, there are 000 patients 18 years and older and 000 less than 18 years of age. Fusce velit lorem, commodo ac congue vitae, sodales sit amet velit. Fusce velit lorem, commodo ac congue

**OCCURRENCE BY TYPE** — The following is provides a sharper focus on the broader categories of Adult Onset (54%) versus Juvenile Onset (45%). Donec facilisis fringilla neque etDonec facilisis fringilla neque etFusce velit lorem, commodo ac congue vitae,

**Type 1 — Classical Adult Onset PRP**

- 50% of all PRP cases
- Odds: One in 800,000

**Type 2 — Atypical Adult Onset PRP**

- 5% of all PRP cases
- Odds: One in 8 million

**Type 3 — Classical Juvenile Onset PRP**

- 10% of all PRP cases
- Odds: One in 4 million

**Type 4 — Circumscribed Juvenile Onset PRP**

- 10% of all PRP cases
- Odds: One in 1.6 million

**Type 5 — Atypical Juvenile**

- Odds: One in 8 million
- 5% of all PRP cases

**Type 6 — HIV Associated**

- Type 6 is simply too rare a diagnosis to provide meaningful statistics.





## 11. What should I say to family & friends?

It's your story. You are the storyteller!

When it comes to PRP, you're the subject matter expert. At the very beginning, even when you are befuddled and bewildered by PRP, you are the subject matter expert in the eyes of family and friends. These aren't passersby and gawkers at Walmart.

- Choose the right time and place. Quiet. Private. Unrushed. You initiate and control the conversation. *Praesent ornare mi id nisi mollis dignissim. Fusce velit lorem, commodo ac congue vitae, sodales sit amet velit. Donec facilisis fringilla neque et.*
- I had my talking points. I had a story to tell. "PRP stands for pityriasis rubra pilaris. PRP is a journey. Mine started in August when I saw a spot the size of a dime on my forehead. PRP is a sporadic skin disorder effecting one in 400,000 people. There are ONLY and estimated 850 in the USA. PRP is predictably unpredictable. It could last one year or five years or longer. I'm being treated at UT Southwestern and joined a PRP Support Group."

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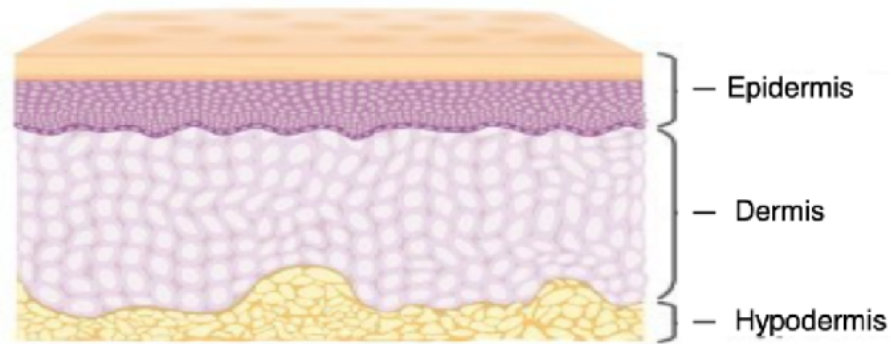
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- When family and friends want more information, refer them to the 60- Second PRP Roadmap and the *PRP Survival Guide*. *Raesent ornare mi id nisi mollis dignissim. Fusce velit lorem, commodo ac congue vitae, sodales sit amet velit.*
- Share the challenges you have already faced and the healing milestones. you have celebrated. *raesent ornare mi id nisi mollis dignissim. Fusce velit lorem, commodo ac congue vitae, sodales sit amet velit. Donec facilisis fringilla neque et*
- Some PRPers don't want to accept the fact that they have PRP. Once they do, however, family and friends will rally around you.
- If you sense that a family member or friend is uncomfortable with the topic, just tell them you just wanted to ensure they know you will be okay and immediately change the conversation.
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## 12. What should you know about your own skin

### FACTS ABOUT SKIN — THE BASICS

- Our skin is made up of three layers. The *epidermis* is the outermost layer that acts as a barrier.
- The middle layer is comprised of sweat glands, hair follicles and connective tissues. Remember that *pilaris* in pityriasis rubra pilaris is all about hair follicles.
- The third and innermost layer is the hypodermis. The hypodermis helps conserve the body's heat and protect it from injury by acting as a shock absorber.

### THE METRICS OF SKIN

- Skin is the heaviest organ of the human body. The skin of an average adult weighs around 9.92 lbs (4.5 kgs) — the same as a gallon of paint or a bowling ball.
- The average adult has approximately 21 square feet of skin (2 square meters) — the surface area of a twin XL mattress.
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- Your skin typically renews itself every 28 days. PRP patients are more like the snow-making machines used at ski resorts.





### SKIN IS A 24/7 PROTECTION SYSTEM

- Our skin serves as a protective shield against injury and infection
- Our skin regulates body temperature.
- Our skin contains secretions that can kill or prevent bacteria
- Our skin helps to make vitamin D when exposed to the sun Our skin removes excess waste in the form of sweat
- Among its many functions, the skin is an incredible organ that protects the body from external agents.

### SKIN, PAIN & ITCH

- Skin is a sensory organ. Some of the nerves in your skin are connected to muscles instead of the brain, sending signals through the spinal cord. That's why we react so quickly to pain and itch.
- Your skin has at least five different types of receptors that respond to pain and touch. Lucky us.
- Based on the shared experiences of several thousand PRP patients, the phrase "This too shall pass" is yet another PRP mantra.
- You don't have to be a dermatologist. Still, you can demonstrate your PRP- savviness by knowing more about your skin than your family and friends. Your insights and confidence will establish you as a subject matter expert on your version of PRP.

#### **Block Quote Headline**

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### 13. Who came up with our name?

Storytelling can be a therapeutic part of a PRP journey. Family and friends want to know what's going on. Lorem ipsum dolor sit amet, consectetur adipiscing elit. Fusce vehicula lectus egetas libero tristique scelerisque. Nunc euismod eget eros in varius. Donec vitae sagittis

When James Shooter was admitted to St. Bartholomew's Hospital in London, England, in 1828, he unwittingly became the world's first patient with what the medical community would eventually call *pityriasis rubra pilaris*. In 1828, however, Mr. Shooter's skin disorder did not yet have a name.

Seven years passed before Claudius Tarral, a French dermatologist, wrote about the case in "Traite theorique et pratique des maladies de la peau" (*Treatise on Skin Diseases*) in 1835. Tarral saw it as a variant of psoriasis.

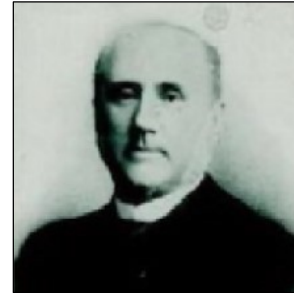
It would take another 21 years (1856) before Marie Guillaume Alphonse Devergie, a dermatologist and forensic doctor at St. Louis Hospital in Paris, published the most complete description of PRP. Devergie's article was considered the "original description" of PRP.



**Dr. Marie Devergie**

While Devergie saw the skin disorder as a combination of skin maladies, it would take 21 more years (1877) before another Frenchman and dermatologist named Richaud recognized PRP as a distinct entity.

In 1889, 12 years after Richaud, 43 years after Devergie and 54 years after Tarral, Ernest Besnier presented nine cases in a 120-page article. He forever fixed the name of the disease as *pityriasis rubra pilaris* from the Latin: *pityriasis* (scalelike skin), *rubra* (red) and *pilaris* (hair follicles).



**Dr. Ernest Besnier**

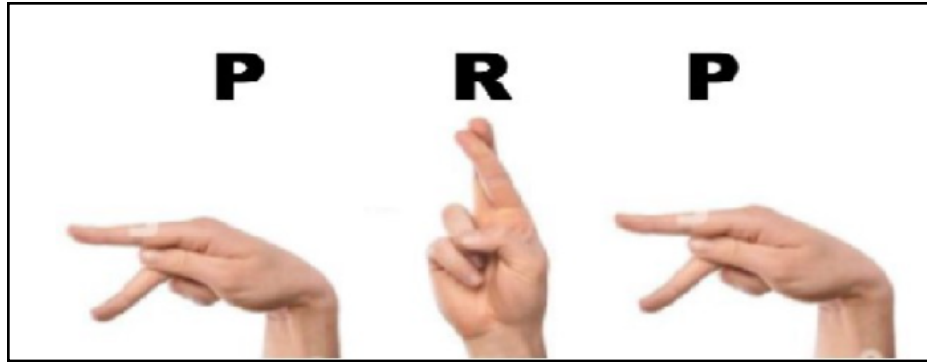
Besnier, too, was a Frenchman and dermatologist. He was also the medical director of the St. Louis Hospital in Paris — the same hospital as Devergie.

Like many rare disease communities, the PRP community laments the snail's pace at which PRP research progresses. What should we expect—it took 61 years and four dermatologists from France just to get the name right.



Remember: in 1828, James Shooter became the first PRP patient when he was admitted to St. Bartholomew's Hospital in London, England. Dr. Ernest Besnier "coined" the name *pityriasis rubra pilaris*. Lorem ipsum dolor sit amet, consectetur adipiscing elit. Fusce vehicula lectus egestas libero tristique scelerisque. Nunc euismod eget eros in varius. Donec vitae sagittis





### 13. How is PRP pronounced?

Mostly, everyone you know — family, friends, co-workers — will defer to how YOU pronounce pityriasis rubra pilaris, whether your pronunciation is correct. The fact is, even dermatologists don't seem to agree. Consectetur adipiscing elit. Fusce velit lorem, commodo ac congue vitae, sodales sit amet velit. In tristique sed purus et condimentum. Praesent ornare mi id nisi mollis dignissim.

Consectetur adipiscing elit. In tristique sed purus et condimentum. Praesent ornare mi id nisi mollis dignissim. Fusce velit lorem, commodo ac congue vitae, sodales sit amet velit.

- pity-RYE-a-sis ROO-bra pill-LAR-is (preferred)
- pity-REE-a-sis ROO-bra pill-LAR-is
- pity-RYE-a-sis ROO-bra pill-LAIR-is
- pity-REE-a-sis ROO-bra pill-LAIR-is

Whatever pronunciation you use, say it with confidence. Say it with authority. Your audience — whether a family member, friend, co-worker, employer, teacher or school administrator — is predisposed to consider you the subject matter expert.

Let's face it — you ARE the subject matter expert of your version of PRP. Moreover, you will become an even more informed subject matter expert daily.

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## 14. Is asking Dr. Internet for answers about PRP a “Fool’s Errand?”

The spot that appeared on my forehead in August 2012 was initially misdiagnosed as *seborrheic dermatitis*. It took four months, four biopsies, and six days in a hospital before a second dermatologist heard the words: “You have *pityriasis rubra pilaris*.”

Like most PRP patients, there was an implicit referral to Dr. Internet, Dr. Google and sometimes Dr. Yahoo.

Eleven years ago, information about PRP written for patients was sparse. There were few websites written expressly for PRP patients and caregivers,

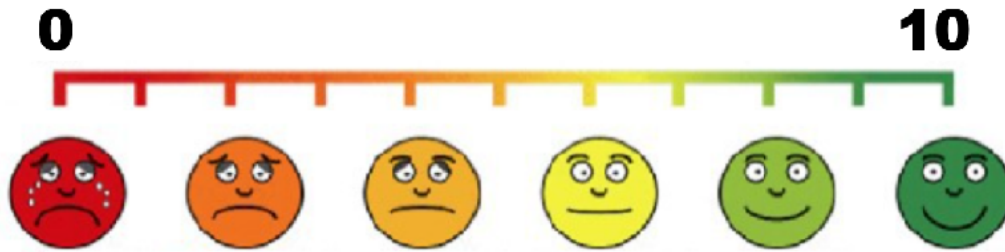
Today, more information from the patient perspective can be found, e.g., the 5,000-word NORD PRP Report and the *PRP Survival Guide*.

Today, a Google search for *pityriasis rubra pilaris* will return over 200,000 web pages. The deeper you dive into the rabbit hole, the more you may find frustration rather than answers, e.g., research papers written by dermatologists for dermatologists.

It also didn’t take long to realize that the same questions were being asked and the same answers were being offered.

The National Institutes of Health guidelines allow patients and caregivers to find and evaluate health-related information online. Check out Appendix F: Finding health information on the internet and Appendix G: Evaluating health information on the internet. Consectetur adipiscing elit. In tristique sed purus et condimentum. Praesent ornare mi id nisi mollis dignissim. Fusce velit lorem, commodo Praesent ornare mi id nisi mollis dignissim. Fusce velit lorem, commodo ac congue vitae, sodales sit amet velit. Consectetur adipiscing elit. In tristique sed purus et condimentum. Praesent ornare





## 15. What are the “Quality of Life “Impacts of PRP?

A series of “Quality of Life” focus groups were organized in April and July (2021) involving 40 PRP patients as part of ongoing research at Oregon Health and Science University. The following is the Discussion Guide used to conduct those focus groups. The questions helped us to frame the issues related to “Quality of Life” as they pertain to PRP.

### Physical Impacts

- What was the first sign that something was wrong?
- Please discuss your experience with the physical symptoms of PRP.
- What symptoms bothered you the most? Did that change throughout your PRP journey?
- What symptoms bothered you the least [annoying rather than serious], and did that change throughout your PRP journey?
- Are there any symptoms of PRP that you feel were not given adequate attention *by your dermatologist*? If so, what were they?
- What was the FIRST SIGN that you were *getting better*?
- What other symptoms we haven’t discussed yet should be given adequate attention in a PRP quality of life questionnaire?
- If you are comfortable, please share how PRP affected your mental health.
- Is/was your mental state particularly affected by specific symptoms or limitations imposed by PRP? If so, what are they?

- At what point, if any, during your PRP did you feel you had hit “rock bottom?” What made you think that way?
- At what point in the course of your PRP did your mental state start to improve?
- What kinds of coping strategies did you use to manage your mental health?
- Can you think of any ways that your physician could have helped you improve your mental health while you had PRP?

### **Daily Living Impacts**

- Please tell us about how your daily routine is/was impacted by PRP. What daily activities are made more difficult because of PRP symptoms?
- Are there any activities of daily living (personal hygiene, mobility, eating, etc.) you are/were unable to perform without assistance?
- How did you adapt your lifestyle to fit your limitations, if any? How was your sleep affected by PRP?

### **Social Impacts**

- Did PRP change your relationships with family, friends, or coworkers? If so, how?
- Did PRP change the way you interacted with strangers?

### **Financial Impacts**

- Did PRP's physical, psychological, social, or daily living effects affect your finances in a significant way?
- Did the cost associated with PRP medical care significantly impact your finances?

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## 16. What is PRP advocacy?

The PRP Alliance was established in 2013 with the three-part advocacy mission:

1. Advocate for the timely and accurate **diagnosis** of PRP (Grade: C+)
2. Advocate for more effective and accessible PRP **treatment** options. (Grade: C-)
3. Advocate for an increase in PRP-specific **research**. Grade: B+

And along the way, we were continually reminded that PRP is an ultra-rare disorder and PRP-savvy dermatologists can be just as rare.

### **PRP Advocacy begins with PRP global community**

Answer the question: what are the advocacy expectations for the PRP global community for the next three years? Answer: Establish a research cohort of 1,000 PRP patients, develop, focus on FDA approval of treatment option for PRP.

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## RareDERM

Question to be answered: How involved should the PRP global community be with GlobalSkin's RareDERM?

RareDERM

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**Thirntion, Member, RareDerm Advisory Committee, GlobalSkin**







## Federal Drug Administration



Question to be answered: How involved should the PRP global community regarding the FDA's The Center for Biologics Evaluation and Research (CBER) has a longstanding history of regulating and advancing development of biological products for use in rare diseases and conditions.

- In addition to regulatory oversight of clinical studies, CBER provides proactive scientific and regulatory advice to medical researchers and manufacturers of complex biological products throughout the development process.
- The ultimate goal of the Center for Biologics Evaluation and Research (CBER) is to accelerate the approval of safe and effective innovative medical products.
- Conduct research to address challenges in the development and regulatory evaluation of medical products
- Among the priorities of interest to the PRP global community: advancing manufacturing technologies for biologic products.
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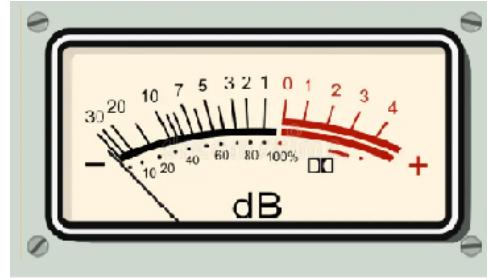
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## Rise above the noise level

For the past 12 years I have learned firsthand that it is impossible to rise above the noise level as a PRP advocate. We are simply too rare to make any noise



- My National Organization of Rare Disorders strategy failed.
- My Genetic and Rare Diseases Information Center strategy failed.
- My American Academy of Dermatology strategy failed

Nine years ago, however, I attended a conference of patient organization leaders in Canada. Sixty patient leaders signed what we called the Vancouver Resolution that resulted in the formation of the International Alliance of Dermatology Patient Organizations aka GlobalSkin.

It was my honor to be a founding Member of the Board of Directors. While GlobalSkin has been able to rise above the noise level, PRP has not

### We need to build a better mousetrap!

*“Praesent ornare mi id nisi mollis dignissim. Praesent ornare mi id nisi mollis dignissim. Praesent ornare mi id nisi mollis dignissim. Praesent ornare mi id nisi mollis dignissim.*



*Praesent ornare mi id nisi mollis dignissim. Praesent ornare mi id nisi mollis dignissim. Praesent ornare mi id nisi mollis dignissim praesent ornare midni. GlobalSkin's RareDERM, the FDA's Center for Biologics Evaluation and Research, the National Organization of Rare Disorders, the EveryLife Foundation and 20 of the nation's leading teaching hospitals are the mousetrap.” — Bill McCue, PRP Alliance,*

