

The Road to a New PRP Community

Name: **Bill McCue**
Location: **Plano, TX**
Occupation: **Retired**
Current Age: **67**
Onset:
▶ Date: **Early August, 2012**
▶ Age: **66**
Diagnosis:
▶ Date: **November 28, 2012**
▶ By: **Dr. Michael Golden**
Onset to Dx: **11-12 weeks**
Biopsies:
▶ Confirming: **1**
▶ Non-Confirming: **3**
Current Status:
▶ Active: **Yes**
▶ Remission: **Not Yet**



Bill McCue, 67, Plano, TX

An Elusive Diagnosis

In early August 2012, I noticed a red, dime-size blemish near my hairline and right temple. Within a few weeks the spot had grown to the size of a quarter. While my scalp itched and was bumpy, it didn't seem like dandruff.

I scheduled an appointment with my dermatologist for the first week of September. By then the red spot was now a one-inch wide red bar extending from my temple to my jaw.

I was initially misdiagnosed with *seborrheic dermatitis*. It took another 12 weeks, four biopsies, six days of hospitalization and a new dermatologist to finally confirm pityriasis rubra pilaris or PRP.

With an occurrence rate of one in 400,000, PRP is an extremely rare disease. Few dermatologists have ever seen it "in the flesh". Statistically, there are an estimated 792 PRPs in the U.S. and 67 in Texas. In fact, I am only one of an estimated 16 PRPs in the DFW Metroplex.

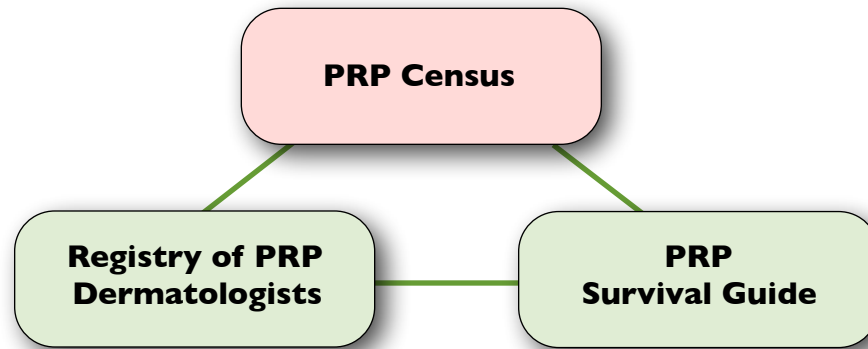
My version of PRP:

- ▶ From mid-September to late December my skin was red, itchy and burned. Every movement was accompanied by excruciating pain.
- ▶ At bedtime I took meds to sleep, slathered my body with greasy ointments and wore wet long johns to protect my skin while I slept.

- ▶ During the day I shed up to two cups of skin.
- ▶ I lost hair; fingernails, toenails, eyebrows, and the ability to sweat and regulate my body temperature.
- ▶ My feet were encased by thick skin that cracked and bled. I was immobilized for six weeks.

Having weathered the initial storm, I now faced the prospect of a three-year journey to remission.

I have heard stories from too many PRP patients who were misdiagnosed and subjected to counter-productive medications. Dermatologists must do a better job diagnosing PRP—it's that simple. It's the reason why I am getting involved.



The Mission

1. To decrease the elapsed time between the onset and diagnosis of PRP.
2. To shorten the time of misdiagnosis and mistreatment.
3. To reverify the longstanding PRP *occurrence rate* of one in 400,000.

The Challenge

There are no reliable metrics upon which to measure the timeliness of a PRP diagnosis. Anecdotal observations indicate that the diagnosis of PRP is too often preceded by befuddlement and misdiagnoses. In my case I was misdiagnosed with *seborrheic dermatitis* and given ever-increasing dosages of prednisone. Ultimately I was hospitalized with technicolor hallucinations that involved tropical fish and a giant, 20-foot yellow rubber duck. Similar versions of my story continue to plague PRP patients worldwide.

The PRP Census

The first step is to conduct a worldwide census of PRP patients using participants in the PRP Support Group Forum which has archived over 29,000 messages going back to 1997.

1. Solicit basic information from the 258 PRPers who responded to the PRP Biopsy Poll (July-August 2013).
2. Solicit basic information from the 217 PRP patients with valid email addresses who did not respond to the PRP Biopsy Poll.
3. Solicit basic information from an indeterminate number of PRP patients who belong to the PRP Support Group Forum, read the messages, but do not participate in the discussions.

The PRP Census Snapshot

The collection of patient information will be divided into three separate harvests: critical, important and helpful. Participation will be made effortless.



Critical

- ▶ Name: **Bill McCue**
- ▶ Location: **Plano, TX, USA**
- ▶ Onset of PRP: **Early August, 2012**
- ▶ Age at onset: **66**
- ▶ Remission status: **N/A (project 2016)**

Important

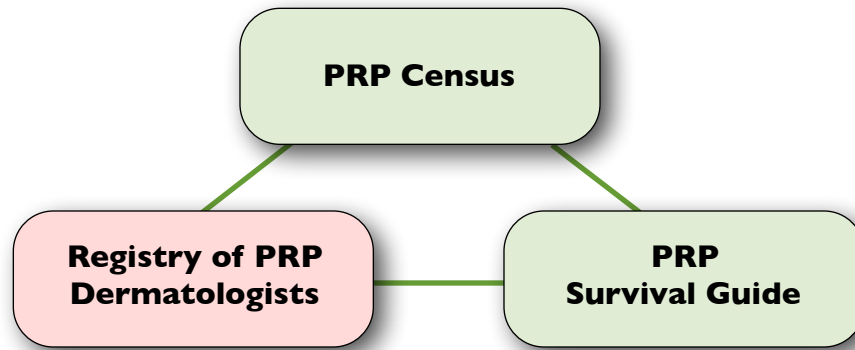
- ▶ First Derm visit: **September 4, 2012**
- ▶ Date of PRP Diagnosis : **November 28, 2012**
- ▶ Diagnosing Dermatologist: **Dr. Michael Golden, Plano, TX**
- ▶ Initial diagnosis: **seborrheic dermatitis**

Helpful

- ▶ PRP Treatment: **Dr. Arturo Dominguez, UT Southwestern Dermatology Clinic, Dallas, TX**
- ▶ PRP biopsies: **Confirming: 1; Non-confirming: 3**

PRP Occurrence Rate

It is anticipated that the initial verification of the PRP Occurrence Rate will be limited to the U.S. (316.8 million population and an estimated 792 PRPs). How close can we get to 792?



The Mission

1. To build a registry of PRP-savvy dermatologists who have hands-on experience diagnosing and treating PRP.
2. To include dermatologists who have not diagnosed PRP but have treated PRP — thus demonstrating a heightened awareness of symptoms and appropriate treatments.
3. To provide an incentive for dermatologists to be listed in the *Registry of PRP-Savvy Dermatologists* by validating their awareness of PRP regarding symptoms and appropriate treatments.

The Challenge

There is no national or international registry of dermatologists with PRP expertise. There is hope that most PRP patients who participate in the *PRP Census* will identify their dermatologists. An alternative to patient identification will be to contact dermatologists directly. It will be far easier to contact 16,000-plus dermatologists in the U.S. than 316.8 million individuals of which 792 have PRP.

Let's look at the Metroplex (Dallas/Fort Worth) in North Texas, for example.

1. According to the American Academy of Dermatologists and the Texas Dermatology Society, there are 192 Board Certified dermatologists in the Metroplex.
2. Statistically there are an estimated 16 PRP patients in the DFW Metroplex.
3. Statistically, only one in 17 dermatologists will have PRP experience and are currently treating an "Active" PRP patient.

The Dermatologist Snapshot

The following information will be sought from PRP-savvy dermatologists. The "Snapshots" below reflect the basic information for my two dermatologists:

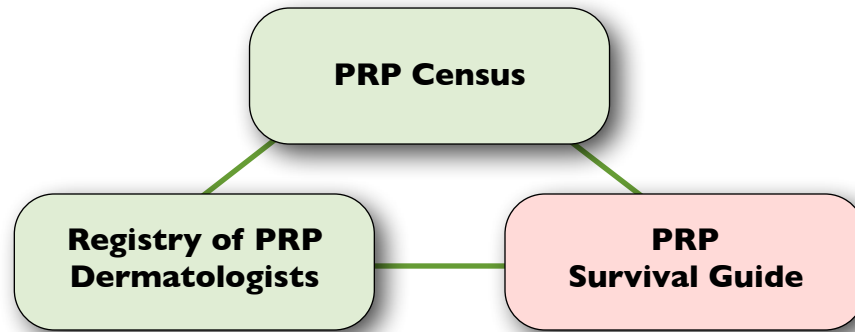
- ▶ Name: Michael Golden, MD
- ▶ Location: Plano, TX, USA
- ▶ Phone: (972) 596.4121
- ▶ Website: www.dermatologyplano.com
- ▶ PRP Expertise
 - I have diagnosed PRP
 - I have treated PRP
 - I have neither diagnosed nor treated PRP but have observed PRP "in the flesh"

- ▶ Name: Arturo Dominguez
- ▶ Location: UT Southwestern, Dallas, TX, USA
- ▶ Phone: (214) 645-2400
- ▶ Website: www.utswmedicine.edu
- ▶ PRP Expertise
 - I have diagnosed PRP
 - I have treated PRP
 - I have neither diagnosed nor treated PRP but have observed PRP "in the flesh"

The Ongoing Value

The *Registry of PRP-Savvy Dermatologists* provides ongoing opportunities for 800-plus dermatologists in the U.S. to access:

1. Anecdotal information about diagnosing and treating PRP from fellow dermatologists with hands-on experience.
2. Ongoing PRP-related polls, surveys and other information.



The Mission

1. To publish a comprehensive manual to help PRP patients navigate the road to remission.
2. To improve the diagnostic skills of dermatologists by sharing the diagnostic experiences of other PRP dermatologists, including misdiagnoses.
3. To improve the treatment protocol for PRP patients based on the experiences of dermatologists with PRP patients.
4. **Patients who are improving.** One day the tide turns. For me it was the day my left knee cap was wet with sweat. Weird. Within a week my ability to sweat extended to my back. At the same time I had a remarkable burst of energy—from 20% to 60%. It was so dramatic a change that I called my dermatologist with the good

The Challenge

The *PRP Survival Guide* will target PRP patients who are scared, suffering, coping, improving and symptom-free.

1. **Patients who are scared** have just gotten their diagnosis and discover that they may be in PRP hell for an average of three to four years. I was diagnosed with PRP on September 28, 2012. I was scared for over six months.
2. **Patients who are suffering.** This was the period from late September through mid-January when I morphed from red skin to itchy skin to flaking skin (2 cups a day). The soles of my feet became entombed in thick skin that cracked and bled. I was immobilized. It was a miserable existence. The beast in my darkness was depression.
3. **Patients who are coping.** Better said, they are *suffering with hope*. The PRP Support Group has been a beacon of hope since late 1997. Messages from active PRP patients and those in remission are a godsend to many and appreciated by all. I transitioned from suffering to coping when there was more dog hair than skin on my hardwood floors.



news. Of course, there are some spots and flakes scattered hither and yon, my nails are gone and I'm nearly hairless except for my Walter White, *Breaking Bad* goatee.

5. **Patients who are symptom-free.** There comes a time for many PRP patients when the term *symptom-free* applies. These brave souls and their families have weathered the storm. Their stories should be embraced as PRP-lore. On September 28, 2012, I would have devoured onset-to-remission stories as a remedy for fear.

The PRP Survival Guide

The *PRP Survival Guide* will be only be available online at prpAlliance.com. Each month the *PRP Survival Guide* will be updated to reflect copyediting (corrections) and new information.