



PRP: THE ROAD LESS TRAVELED

Our journey from onset to remission

April 1, 2014

PAGES 2-5 THE CENSUS

Over 1,000 PRP patients and surrogates have shared valuable data compiled by the PRP Alliance for the PRP Community.

PAGE 6-7 MEET & GREET

The PRP Alliance hopes to jumpstart face-to-face, Meet & Greet gatherings between two or more PRP patients. *Lindsay Sprick* and *Ginny Maxwell* share the details of their two encounters.

PAGES 8-9 SUPPORT GROUPS

The road from onset to remission need not be traveled alone. Important resources are available to newly diagnosed PRP patients who deserve our help.

PAGE 10 THE REGISTRY

The PRP Census helped identify over 400 PRP-savvy dermatologists, clinics or hospitals who diagnosed and/or treated PRP. Now what?

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We are in this together!

Some say stress is a trigger for the onset of *pityriasis rubra pilaris*. Perhaps. Two weeks before my onset of PRP, I was one of two finalists for the position of staff writer for an international franchise. Having been retired for nearly eight years and missing my life in marketing communications, there was an incredible amount of self-imposed stress to get that job. I fired all my creative guns for over two months, but fell short. I licked my wounds of disappointment and moved on ... or so I thought.



By early August, a dime-size blemish appeared on my forehead. Day after day, week after week it spread from head to toe. For nearly five months I disintegrated in front of my family and friends. Each day I had one goal — to survive that day. Every evening my only goal was to sleep until the following morning. Meds. Lotions. Itching. Pain. Cracked and bleeding soles. White snow drifts on dark hardwood floors. Passing mirrors and seeing a stranger. Using the handicapped cart at Walmart.

My body was dissolving in slow motion. One day I noticed that my fingernails were gone, a process unnoticed for many weeks. In early October 2013, I looked in the mirror and saw an uncanny similarity to Walter White, the meth-cooking high school chemist of *Breaking Bad*. I laughed. It helped.



In early November 2013, I had a renewal of spirit and energy and began the first-ever PRP Worldwide Census. I had weaned myself from acitretin, creams and ointments. A few lingering red spots on my chest and a crusty patch on my lower leg remained as daily reminders that the pendulum could swing back at anytime. Fight the fear. Fight the fight.

I know I'm on the road to remission. I don't want to walk it alone. I want to ride in a crowded bus filled with PRP patients and caregivers chanting: "We are in this together." We are all different. We are all special. We are a community that must be heard".

Bill McCue
Plano, TX

The 2014 PRP Worldwide Census

How to find patients with PRP

Think *jelly beans*. You can scientifically calculate that there are around 225,000 jelly beans in a 31 cubic foot LG refrigerator. We are told that the prevalence rate for an “active” PRP patient is one in 400,000. We can therefore calculate that there are 792 “active”

PRP patients in the U.S. based on a population of 316.8 million.



Or perhaps *a needle in the haystack* would be a more accurate metaphor to consider. One of the most reliable ways to find

a needle in a haystack is to burn the haystack and sift through the ashes with a metal detector. Since this was not an option, I doggedly sifted through nearly 30,000 messages in the PRP Support Group archive to find 1,300-plus email addresses.

Or think *Where's Waldo*. Imagine a convention hall with 1,300 PRP patients. Pass out 1,300 census forms and 1,300 pens. Ask 12 questions. Collect the forms and start counting. It worked. Over 700 PRP patients or their caregivers submitted a PRP Census form, sent an email or found a way to be counted;

The List

It took eight months to build a list of 1,308 PRP patients. These are current or past subscribers/members of the PRP Support Group and/or the PRP Facebook Support Group. The following were removed along the way, although their data was preserved:

- **Subtract 13 Opt-Outers** of which 14 provided enough data to be included in the Onset Age Poll. “Out-Opters” are removed from the mailing list for all future polls but will be reinstated upon request.
- **Subtract 19 deceased** of which 12 are included in the Census based on information provided by a surviving spouse or family member.
- **Subtract 15 Misdiagnosed with PRP** who were initially diagnosed with PRP only to discover that the diagnosis was flawed.
- **Subtract 449 Invalid Email Addresses.** Amazingly, 147 of these PRP patients provided sufficient data in messages — some spanning a decade or more — to be included in the PRP Community Database.
- **Subtract 271 Missing in Action.** These PRP patients simply failed to respond. We will keep the light for any PRP travelers whose journey from onset to remission brings them back home to us.

Research Projects

The PRP Alliance has offered to support the Thomas Jefferson University PRP Phase II Research Project. Specifically, we have volunteered to contact 793 PRP patients and encourage their participation.

In the next three pages we will share some of the demographics of the PRP community. We hope to somehow whet the appetite of PRP researchers, while great at research, they too are hamstrung by regulations regarding who and how they solicit candidates. We need to find a way to help TJU.



* Post a personal appeal to both the PRP Support Group and the PRP Facebook Support Group.

* Take on the role of an advocate and *work the list* of 793 PRP patients as one might work a list of registered voters as an advocate of a cause or candidate.

The PRP Worldwide Census will continue unabated as new PRP patients join our ranks and others go into remission. We are in this together for the long haul. It's time we acted that way.

PRP Community Database

Whet the Appetite for Medical Research?

In Search of Answers

From the outset, the PRP Worldwide Census was designed to answer four questions to satisfy my own curiosity:

1. What are the variations in onset age? *I was 66.*
2. What are the variations in onset symptoms? *I had a blemish on my forehead.*
3. What are the diseases that mimic PRP and delay a timely diagnosis? *I was misdiagnosed with seborrheic dermatitis.*
4. Are there really 792 “active” PRP patients in the U.S., and who are the 15 “active” patients in the Dallas-Fort Worth Metroplex besides me?

The PRP Worldwide Census is not medical research. It is primarily a simple survey to better define our own PRP community. The PRP Census does provide, however, a snapshot of a patient population ripe for medical research.

Onset Age

Why is onset age important? Seriously, I don’t have a clue. Personally, I wanted to know more about the experiences of the PRP patients in the “60 to <70” group. Perhaps the Onset Age data will inspire a medical research project somewhere? Who knows? And that’s the point.

Onset Age	Actual	Actual	Pctg
Birth to < 2	32	111	15.8%
2 to < 5	40		
5 to < 10	39		
10 to < 20	44	225	32.1%
20 to < 30	29		
30 to < 40	59		
40 to < 50	93		
50 to < 60	163	366	52.1%
60 to < 70	141		
70 to < 80	54		
80 to < 90	8		

Onset of Symptoms

The PRP Worldwide Census effort has already chronicled the onset symptoms for 477 patients. The range of symptoms and where they appear underscores how each case of PRP is as unique as a snowflake.

Words used to described the onset symptoms:

- A total of 294 patients used the term *rash* (201), *spot* (97) or *blemish* (19)
- A total of 70 used the term *itchy*, and 57 used *patches*, *shedding*, *dandruff*, *bumps*, *sunburn* and *peeling*.

Words used to describe location of symptoms:

- A total of 283 patients indicated the location of the symptom.
- Head (168) which includes: *scalp*, *face*, *forehead*, *head*, *eyes*, *ears* and *nose*
- Upper torso (86) which includes *chest*, *back* (36), *shoulder* and *torso*
- Upper extremities (66): *hands*, *arms* and *fingers*
- Lower extremities (38): *feet* and *legs*

Misdiagnosis

The timely diagnosis of PRP has always been a front-burner issue for me. I was misdiagnosed, mistreated for three months, and hospitalized before a proper diagnosis based on clinical observations and a supporting biopsy of a dermatopathologist. A total of 280 PRP patients confirmed one or more misdiagnoses before their “official” PRP diagnosis. The most prevalent misdiagnoses included *psoriasis* (125), *atopic dermatitis* (71) and *allergic reactions* (39). Other misdiagnoses included *pityriasis rosea*, *lupus*, *hives*, *Grover’s disease*, *pemphigus vulgarism* and even *scarlet fever*. There is work to be done by the PRP community to ensure a more timely diagnosis of PRP.

Status: Active vs. Remission

The PRP Worldwide Census effort has confirmed 206 active PRP patients, 430 in remission and 19 deceased. Of the 206 reporting “active”, only 133 (64%) are in the U.S.

DEMOGRAPHICS

Based on a country's total population ¹ and a prevalence rate of one in 400,000, the estimated number of PRP patients ² can be calculated. The fourth column compares the PRP patients found ³ with those who are actually active. ⁴



Forty countries are represented in the following table. The United Kingdom, Australia, Canada, and the Netherlands account for 74.4 percent of the International PRP Community included in the PRP

Community Database. These four also represent 72.2 percent of the active PRP patients identified to date. It is hoped that the PRP patients and caregivers in these countries will continue to seek out kindred spirits.

	Population ¹	PRP Est ²	All ³ / Active ⁴
Australia	23,393,773	58	93/13
Barbados	285,000	1	1/0
Belgium	11,132,269	28	1/0
Bulgaria	7,282,041	18	1/1
Canada	35,295,770	88	61/9
Chile	16,634,603	42	1/1
China	1,360,720	3	1/0
Colombia	47,478,000	119	1/1
Costa Rica	4,667,096	12	1/0
Croatia	4,290,612	11	1/0
Denmark	5,627,235	14	5/0
France	65,844,000	165	4/1
Germany	80,619,000	202	4/0
Iceland	4,593,100	11	4/0
India	1,240,810,000	3,102	3/1
Ireland	4,585,400	11	4/2
Israel	8,134,100	20	8/0
Italy	59,943,933	150	4/1
Japan	127,180,000	318	1/0
Jordan	6,551,600	16	1/0
Macedonia	2,062,294	5	1/0

	Population ¹	PRP Est ²	All ³ / Active ⁴
Malaysia	30,017,000	75	1/0
Mexico	118,395,054	296	3/1
Micronesia	101,351	0	1/0
Morocco	33,183,800	83	1/0
Netherlands	16,839,500	42	27/11
New Zealand	4,514,770	11	13/2
Niger	17,129,076	43	1/0
Norway	5,109,056	13	4/2
Peru	30,475,144	76	1/0
South Africa	52,981,991	132	13/2
Spain	46,609,700	117	1/0
Sweden	9,644,864	24	5/2
Switzerland	8,112,200	20	3/2
Turkey	76,667,864	192	2/0
U.A.E	8,264,070	21	1/0
United Kingdom	63,181,775	158	99/19
England	53,012,456	133	57/16
Scotland	5,295,000	13	6/2
Northern Ireland	1,810,863	5	1/0
Wales	3,063,456	0	2/1
TOTAL INT'L			376/72

Where are they hiding?

To date, only 134 or 16.9 percent of the estimated active PRP patients in the U.S. have been identified. From this point on, the counting of active PRP patients will require the support of individual dermatologist, clinics, teaching hospitals, the American Academy of Dermatology as well as the 92 state and local dermatology societies/associations.



	Population ¹	PRP Est ²	All ³ / Active ⁴
Alabama	4,822,023	12	11/1
Alaska	731,449	2	3/0
Arizona	6,553,255	16	19/2
Arkansas	2,949,131	7	6/1
California	38,041,430	95	83/19
Colorado	5,187,582	13	10/3
Connecticut	3,590,347	9	4/0
Delaware	917,092	2	1/0
DC	632,323	2	3/1
Florida	19,317,568	48	47/4
Georgia	9,919,945	25	17/1
Hawaii	1,392,313	3	3/0
Idaho	1,595,728	4	5/2
Illinois	12,875,255	32	21/6
Indiana	6,537,334	16	3/1
Iowa	3,074,186	8	4/1
Kansas	2,885,905	7	7/1
Kentucky	4,380,415	11	9/1
Louisiana	4,601,893	12	8/1
Maine	1,329,192	3	3/1
Maryland	5,884,563	15	9/2
Massachusetts	6,646,144	17	10/2
Michigan	9,883,360	25	22/7
Minnesota	5,379,139	13	10/2
Mississippi	2,984,926	7	22/2
Missouri	6,021,988	15	13/4

	Population ¹	PRP Est ²	All ³ / Active ⁴
Montana	1,005,141	3	10/1
Nebraska	1,855,525	5	2/0
Nevada	2,758,931	7	7/1
New Hampshire	1,320,718	3	4/1
New Jersey	8,864,590	22	8/1
New Mexico	2,085,538	5	5/2
New York	19,570,261	49	26/5
North Carolina	9,752,073	24	18/3
North Dakota	699,628	2	0/0
Ohio	11,544,225	29	17/7
Oklahoma	3,814,820	10	8/1
Oregon	3,899,353	10	8/0
Pennsylvania	12,763,536	32	21/9
Rhode Island	1,050,292	3	0/0
South Carolina	4,723,723	12	8/6
South Dakota	833,354	2	1/0
Tennessee	6,456,243	16	12/3
Texas	26,059,203	65	46/14
Utah	2,855,287	7	3/2
Vermont	626,011	2	2/1
Virginia	8,185,867	20	16/7
Washington	6,897,012	17	15/3
West Virginia	1,855,413	5	1/0
Wisconsin	5,726,398	14	15/4
Wyoming	576,412	1	3/1
50 States + DC	316,769,000	792	586/134

The above table is based on a state's total population ¹ and a prevalence rate of one in 400,000, to calculate the estimated number of PRP patients ². The fourth column compares the PRP patients found with those who are actually active. ⁴

We are not alone and I can prove it!



On Sunday, January 19, 2014, Lindsay Sprick and Virginia “Ginny” Maxwell met for brunch at the 116 Espresso Wine Bar in Columbia, South Carolina. A month later the duo met on Friday, February 21 and shared lunch at the Blue Fin, another restaurant in Columbia. At both gatherings, Ginny’s husband, Jeffrey and their one-year-old daughter, Lauren, tagged along.

To the waitress and fellow diners, the table of four wasn’t out of the ordinary. Probably family or friends enjoying a meal together.

Hold on there. The odds of having PRP may be one in 400,000, but the odds of having a juvenile type of PRP range from one in 1.6 million to one in 8 million. Now, what are the odds of Lindsay and Ginny being our “official” Meet & Greet? It was a sure thing!

M&G *How was the first Meet & Greet arranged?*

Ginny: Bill McCue sent us an email without disclosing either our names or email addresses. He asked us if we wanted to meet a fellow PRP patient nearby. We both said, “Yes.” The next thing I knew I got a call from Lindsay.

Lindsay: It was far too simple. The hardest part was just making the phone call to reach out to Ginny. I had all of these emotions swimming around in my head. I really wanted to meet her, but I was also wondering if we would relate. Were her problems like my problems?

M&G *Besides PRP, what did you talk about?*

Lindsay: We spoke for over two hours about friends and family. We shared stories. We felt like long-lost sisters and talked about everything you’d expect sisters to talk about!

Ginny: She told me about NoDa Brewing Company where she works in marketing. *Her Hopness*, an official title, turns 25 in May. And she loves cigars and watching Netflix on the couch!



Clockwise: Lindsay Sprick, Ginny and Lauren Maxwell

M&G *Have you ever met an PRP patient?*

Lindsay: I’ll be 25 in May and have never met another PRP patient prior to meeting Ginny.

Ginny: I was on a roll. A few weeks earlier I had helped a PRP patient from rural South Carolina get to an ER for help in Columbia. Lindsay makes my second!

M&G *What has Meet & Greet meant to you?*

Lindsay: It’s been an experience I can’t unravel from my life now. I feel so lucky that we finally got to meet. To think we’ve been living an hour and a half from each other all this time was unbelievably mind blowing.

Ginny: I made a life-long friend. We’re definitely planning on seeing each other again! It’s hard to stop once you meet someone who has been through similar trials and tribulations. It makes you stronger in the long run.

(continued from page 6)

M&G *Who made the first call?*

Lindsay: That would be me. The second Ginny answered the phone and found out who I was, it was immediately clear to me that she was just as excited as I was. We talked on the phone for about 20 minutes and I couldn't wait to meet her.

M&G *Any regrets about sharing with a stranger?*

Lindsay: Responding to the Meet & Greet invitation was absolutely one of the best decisions I've made in a long time. It was like meeting a long-lost sister.

Ginny: It is crazy I swear she is my cousin or something! Even Lauren bear-hugged her!

M&G *What did you learn about yourself?*

Lindsay: I wasn't alone out there. We both face hardships and challenges. Now, though, we wouldn't have to be alone. We could talk about it together.

Ginny: You can't have too many PRP friends. We are all different and bring our own version of PRP with us. Only a fellow PRP patient really knows what it means to have PRP. We are family.

M&G *What happened after your Meet & Greet?*

Lindsay: Leaving that first meeting, I was just so jazzed up about the whole situation. It was crazy. We both couldn't wait to meet again. Now we talk, text and Facebook each other constantly!

Ginny: I remember thinking that I need to bring my twin boys, Nathan and Joey to a Meet & Greet. They are going to love Lindsay!

M&G *Should PRP patients Meet & Greet?*

Lindsay: I would highly recommend reaching out to other PRP patients. It was great to finally get rid of that isolated feeling PRP gives you.

Ginny: I can't speak for others, but I already asked Bill to send a Meet & Greet invitation in Nashville where I visit family. Might as well include my growing PRP family too.

Editor's Note: A third Meet & Greet is in the works for Lindsay and Ginny.

Meet & Greet

The PRP Community Database makes arranging a Meet & Greet a no-brainer. Remember, nothing happens unless at least one PRP patient or caregiver requests that a Meet & Greet invitation be sent.

The PRP Census has identified the location of 793 PRP patients with a valid email address. That's where the coordination begins.

1. An email is sent to all PRP patients on a state, region or metropolitan basis. For example, a PRP Meet & Greet invitation for the Dallas-Fort Worth area would include the PRP patients in Arlington, Dallas, North Richland Hills, Plano and Watauga.
2. All invitees have five business days to reply.
3. Those who reply in the affirmative are sent an email that includes the email addresses of the other respondents.

4. It is up to the participating PRP patients to schedule the time and place of their PRP Meet & Greet.
5. Meet & Greeters are asked to provide a photo memorializing the occasion.

Spread the Word

Lindsay and Ginny have shared the details of their two Meet & Greet encounters with fellow members of the PRP Facebook Support Group. When you "Meet & Greet", don't keep it a secret.

Spread the Word

Want to see if a Meet & Greet in your area is possible in your state or country—just email Bill McCue at bill.mccue@prpAlliance.org

HELP!

PRP Support Group

My phone rang on November 28, 2012 and the voice at the other end confirmed the diagnosis: *pityriasis rubra pilaris*. That evening I researched PRP. In less than ten minutes I found the PRP



Support Group. Within an hour I had subscribed to their daily digest. One week later I was sniffing around the PRP-L archives reading 10-year-old messages.

The PRP Support Group has an email-based communication system with advantages and disadvantages. For most, the former outweigh the latter.

Anyone recently diagnosed with PRP should subscribe to the their list serve. Check “Yes” to receive the daily digest and post an “I’m a Newbie” message. Then see what happens.

There is gold in the PRP-L archives, but it can be a challenge to mine it for data. The PRP-L archives are simply not designed for easy research. But if you are willing to put in the time, it is possible to learn a great deal about PRP from the 30,000-plus documents shared between fellow PRP patients going back to 1997. I did.

PRP Facebook Support Group

When I began the PRP Worldwide Census in early November, 2013, Tierney Ratti recommended that I join the PRP Facebook Support group. At that point in my life, my experience with Facebook had been



limited to occasionally viewing my children and grandchildren on my wife’s iPhone and iPad. But Tierney was persistent.

When I reluctantly opened a Facebook account and became a PRP “Facebookers”, I witnessed energetic bantering between PRP patients. Post a message and 30 people see it in 20 minutes. Comments flow. It doesn’t take long to get hooked.

One thing is for sure — you can’t feel alone with PRP Facebookers who love to chat, share, offer advice, and vent.

How to join

Simple. It starts with a Facebook account. First, click on “Search for people, places and things”. Next, type in “Pityriasis Rubra Pilaris (PRP)” and ask to join. Finally, Tierney will “Accept” and you will be welcomed. Like I said: simple.



PRP Alliance

The PRP Alliance is not a support group. It is quite simply *a very independent resource to advance the goals of the PRP Community*. Currently, the PRP Alliance is a one-man operation...sort of. No board of directors. No committees. No employees. No kidding.

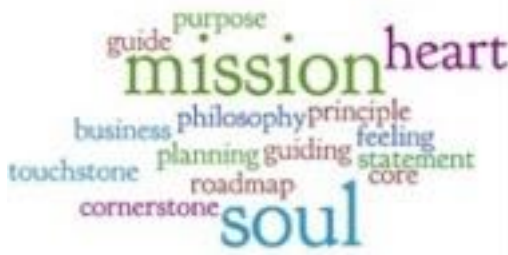
What I have are “friends” from within the PRP Community who graciously share their experience and give me their two cents.

Unlike the PRP Support Group, I have no subscribers or an archive of documents going back to 1997.

Unlike the PRP Facebook Support Group, I have no members who banter 24/7.

So what does the PRP Alliance actually do as of April 2014?

- First, I count PRP patients in an unrelenting search for the 792 who are active in the U.S.
- Second, I search for PRP-savvy dermatologists who have diagnosed and/or treated PRP over the years.
- Third, I advocate the Meet & Greet program for PRP patients worldwide.



Eleven Reasons to Join a Support Group & Share

1. To better understand pityriasis rubra pilaris through the collective, first-hand experiences of those who have been afflicted.
We are in this together.
2. To provide — and to receive — hope, encouragement, and emotional support. This is especially important in the absence of an existing support system. *We are in this together.*
3. To minimize loneliness and feelings of isolation. To know that we are not alone. We are a community of kindred spirits. *We are in this together.*
4. To effectively manage expectations and maximize hope. We want more than our fair share of good news and are willing to work for it. *We are in this together.*
5. To lighten the burden placed on loving family members by sharing that burden with the PRP community. *We are in this together.*
6. To recognize that everyone has their own version of PRP and what works for one may not work for another. We can find effective ways to cope with pain, anxiety, stress, depression and frustration. *We are in this together.*
7. To promote a better understanding of our disease within the PRP community by sharing our personal experiences with treatments, dermatologists and other healthcare professionals. *We are in this together.*
8. To promote participation in bona fide research projects designed to improve the diagnosis, treatment and understanding of PRP by the medical community. We must find ways to enlighten dermatologists and other healthcare professionals. *We are in this together.*
9. To maintain a core value of acceptance, understanding and empathy.
We are in this together.
10. To vent to each other when our pain is too great, our frustrations unbearable and our fear overwhelming. *We are in this together.*
11. To meet a fellow PRP face to face, in the flesh. Isn't it about time we hugged? *We are in this together.*



Members of the PRP Facebook Support Group were asked the question: Why should a PRP patient or caregiver join a support group and share? The 11 reasons to the left were the result of the 19 PRPers or surrogates below.

- ▶ Amber S
- ▶ Andy W
- ▶ Brenda M
- ▶ Charlene F
- ▶ Dan McG
- ▶ Ginny M
- ▶ Gena H
- ▶ Joanne L
- ▶ Krista V
- ▶ Laurel A
- ▶ Leslie G
- ▶ Michael Fk
- ▶ Mona C
- ▶ Pat N
- ▶ Sharon T
- ▶ Sherry R
- ▶ Stephanie Me
- ▶ Tierney R
- ▶ Vijay N
- ▶ Violet T

Thank you for sharing your opinions, and insight. You have demonstrated that we are in this together. Kudos to each of you.

Reaching out to Dermatologists



There are too many PRP patients and caregivers who have had a bad experience with a dermatologist who was befuddled by PRP. Mine was a specialist in MOHS surgery. She misdiagnosed me with *seborrheic dermatitis* and then mistreated me with prednisone. For eight weeks the “wrong” meds took their toll resulting in technicolor hallucinations of biblical proportions, e.g., tropical fish and a giant 20-foot rubber duck. Based on PRP Census observations, I would suggest there are two types of PRP diagnoses:

1. Timely

At one end of the “timely” diagnostic scale is the dermatologist who instantaneously recognizes the symptoms with no biopsy required. At the other end, it may take additional clinical observations, biopsies and even a patient progressing to full bloom. Perhaps I should not have expected a diagnosis based on a dime-size spot on a forehead—although it happens.

2. Not Timely

Here the dermatologist simply does not recognize classic PRP symptoms. For some the befuddlement is temporary; for others it is terminal. We must educate both. As advocates of awareness, the PRP community must find a way to enlighten our healthcare providers ... and soon.



The American Academy of Dermatology (AAD)

Educating dermatologists about PRP begins with the AAD. Founded in 1832, the AAD boasts a U.S. membership of 16,000 with an additional 1,000 international members. The AAD has representation in all 50 states with 92 separate state and local societies. There are channels of communication and opportunities to build awareness and understanding.

However, while continuing education is important, PRP is on no one’s radar. For example, when one visits the ADD website at www.aad.org and “*pityriasis rubra pilaris*” is entered into their website’s search field, 13 documents about *pityriasis rosea* are returned. Query “PRP” and you will be offered an article about platelet-rich plasma. There is clearly much work to do here — work that has already begun.

The PRP Worldwide Census and other efforts has identified a total of 448 PRP-savvy dermatologists, clinics and teaching hospitals who have diagnosed PRP and/or provided ongoing treatment.

The immediate objective is to translate the list of 448 into an Online Registry of PRP-savvy Dermatologists. Secondly, to use the Registry as a catalyst for cooperation with all AAD members and state/local societies. It’s time for the PRP Community to bring PRP front and center.

Next Issue

DERM REGISTRY UPDATE

How has the development of an online Registry of PRP-Savvy Dermatologists progressed? Follow a link to our list of dermatologists, clinics and teaching hospitals.

STRESS AS A TRIGGER

The first installment of a three-part series. Part 1 will focus on over 200 documents found in the PRP-L Archive going back to 1998. Part 2 will report on the results of a new PRP “Trigger” Poll. Part 3 will gather insights from the medical community.

MEET & GREET IN NOVA SCOTIA

Women from Halifax (sounds like a new reality series) is the story of three PRP patients in Nova Scotia who share lunch (Meet & Greet) and the same dermatologist (Dr. Robert Tremaine).

DERMATOLOGY SPOTLIGHT

The PRP Worldwide Census effort has confirmed that seven of our kindred spirits were diagnosed and/or treated for PRP by Dr. John Koo or Dr. Timothy Berger, UCSF Medical Center. The dates of diagnoses go back to 2004.

PRP UPDATE

A regular feature of *THE ROAD LESS TRAVELED* will be to look back and see what happened in the PRP Community during the previous month, e.g., acts of kindness, acts of courage, Newbie intros, medical research updates, etc.

On the road again...with you.



In 1968 I graduated from Assumption College in Worcester, Mass and pondered how to spend my summer before going into the Marine Corps. I eventually considered four possible options:

1. I could spend the summer in Cape Cod drinking beer with my college chums. However, there would have been way too much beer. This was ill-advised given the physical rigors I anticipated at Officer Candidate School.
2. I could work. The idea of working yet another summer wasn't appealing. I knew I was Vietnam-bound and the idea of spending the lazy, hazy, crazy days of the summer of '68 in a factory was simply not going to happen.
3. I could just hang around my hometown, Bristol, CT but concluded that a summer in Bristol would be not be Cape Cod, with or without the beer.
4. Then it came to me: Go to California. No—go to *Disneyland*, California. But, walking would take too long and driving would be too fast and expensive. That's when I came up with the grand idea...a bicycle.

I convinced the Bristol Chamber of Commerce to make me a Goodwill Ambassador for our city's annual summer Chrysanthemum Festival. I convinced the Bristol Nursery to give me little packets of mum seeds.

On July 4, 1968 I traveled west as *Billy Mumseed*, handing out little packets of Chrysanthemum seeds and arriving in Anaheim, California 33 days and 3,000 miles later. It was my first public relations campaign...press releases, interviews and TV. What a hoot!

By every measurement my bicycle ride was a success. I always managed to be the guest of a local Chamber of Commerce, Elks Club or Rotary Club. I traded 30-minute stories about my travels for food and lodging.

So here I am 46 years after my *Billy Mumseed* gig, deciding how to travel my own road to remission. I want to spend my time and limited energy doing something productive. Rather than riding a 10-speed Schwinn to Disneyland again, I have decided to commit to a monthly newsletter about PRP and (a) promote timely diagnoses and (b) document successful treatment options. I plan to travel my road to remission with you.