May 1, 2014 Volume 1, Number 3

The PRP Community

It’s time to challenge the status quo and dramatically improve the diagnosis and treatment of pityriasis rubra pilaris. Now.

CONTENTS

This issue of the PRP Community newsletter takes a closer look at the challenges facing the PRP Community, projects and programs to "dramatically improve the diagnosis and treatment of PRP" and alliances that should be nurtured and a path forward.

Challenging the status quo

After 17 years there are opportunities that could dramatically improve the timely diagnosis and effective treatment of PRP.

- Open Letter or PRP Community (PRPC)
- Challenging the status quo

  PRPSG website ✻ PRPC newsletter ✻ PRPC events ✻ PRP-related medical research ✻ PRPC efficacy research ✻ PRPC polls & surveys ✻ PRPer profiles ✻ PRPC forums (email & Facebook) ✻ PRPSG archives

- Building channels of communication

  PRPers ✻ Surrogates ✻ American Academy of Dermatology ✻ AAD societies ✻ Teaching hospitals and major clinics ✻ National Institutes of Health ✻ National Organization of Rare Diseases ✻ Coalition of Skin Diseases ✻ Foundation for Ichthyosis and Related Skin Types

PRP Community Projects

Projects or initiatives to support the PRP Community

- The PRP Census should include all PRPers
- Every PRPer should meet and greet another PRPer in 2014
- The PRP Community can be an effective catalyst for PRP research
- It's time for PRPers to come out of hiding
- The PRP Community can build a bridge with dermatologists

PRP Community Alliances

There is no reason to reinvent the wheel when organizations are willing to provide guidance, and support. It will be important, however, to make these relationships reciprocal. We cannot just be takers.

- National Organization of Rare Diseases (NORD)
- Coalition of Skin Diseases (CSD)
- Foundation for Ichthyosis and Related Diseases (FIRST)

PRP Community Path Forward

It takes effort to challenge the status quo. The status quo likes to win. It takes more than wishful thinking to prevail.

- PRP Community Calendar
- PRPer and PRP Community Checklist
- Newsletter Policies & Procedures

May 1, 2014

Fellow PRPers and Surrogates—

November 28, 2012 was an eventful day for me. First, Dr. Michael Golden confirmed my diagnosis of *pityriasis rubra pilaris* and I officially joined the ranks of the PRP Community. Next, I found the PRP Support Group and immediately subscribed to the PRP-L mailing list. The following day was Thanksgiving. About all I had to be thankful for was getting on the PRP-L list and being able to access the archives. I knew I was not alone.

On April 8, 2014 I was declared to be in remission by Dr. Arturo Dominguez at the University of Texas Southwestern Medical Center's dermatology clinic in Dallas. My journey from onset to remission had taken 20 months.

I know I am one of the lucky ones. Lucky to be among the 50-plus percent who have Type 1, Classic Adult PRP and even more lucky to be among the 80 percent who reach remission within three to four years.

I know I was lucky that Soriatane (acitretin) worked without any deleterious side effects other than cracked lips.

I know I was lucky that the combination of Triamcinolone®, Clobetasol®, urea lotion (40%), and Desonide® worked. I know I was lucky that hydroxyzine and Ambien® helped me sleep at night.

I also believe that sticking to the treatment plan outlined by Dr. Dominguez improved my lucky streak.

Along the way I have invested my own time, talent and limited treasure in projects that included:

- The PRP Worldwide Census with over 400 respondents
- A PRP Community database listing over 1,400 PRPers with more than 800 valid email addresses
- A PRP Community database with over 600 PRP-savvy dermatologists, clinics and teaching hospitals
- Three PRP Community newsletters

Now that I am in remission I understand why many PRPers don't want to be reminded of the agony wrought by this disease we share. I can certainly find something to do in retirement that will make PRP a distance memory.

However, that's not me. I'd rather reinvest 40 years of experience in publishing, advertising, public relations, grass roots organizing, non-profits, marketing communications and legislative advocacy within the PRP Community. My decision:

To challenge the status quo and dramatically improve the diagnosis and treatment of pityriasis rubra pilaris.

The May 1st issue of the PRP Community newsletter represents both a needs assessment and action plan.

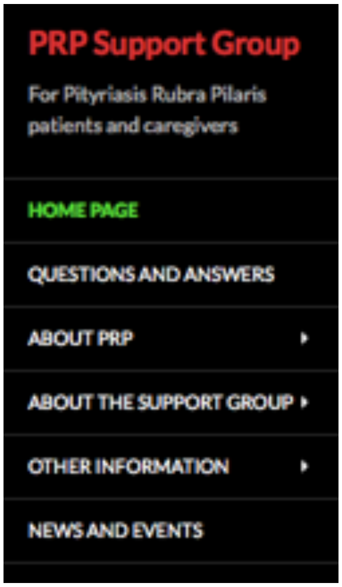
Bill McCue
Plano, TX

“It’s time to challenge the status quo.”

The PRP Support Group (PRPSG) does not compete with either the PRP Facebook Support Group or with the PRP Alliance. We are all part of the same PRP Community. With limited resources, it’s time for the PRPSG to become more inclusive, more creative and more proactive. It’s time to challenge the status quo.

PRPSG Website

Kudos all around for the new website design. It sparkles!


PRP Support Group

For Pityriasis Rubra Pilaris patients and caregivers

The PRPSG website routinely comes up among the first 10 websites displayed in any Google search of *pityriasis rubra pilaris*. A Newbie is now going to feel a sense of relief when he or she first arrives at the website.

The challenge with any website is keeping content fresh. Too much of the current content goes back nearly a decade. PRPers need to see content with dates in the 2012 to 2014 range.

The PRPSG website belongs to the PRP Community and should be used for the common good. We need to be proactive in using this resource in ways that build awareness, develop understanding and involve PRPers.

PRP Community Newsletter

The PRP Community newsletter is bona fide PRP news. To date, the PRPSG has been reticent to post links on the PRPSG website for the following issues: The Pilot Issue (April 1), the special AAD Annual Meeting issue (April 15) and even this issue (May 1). Newbies, in particular, would find the newsletters a respite from medical jargon, abstracts and the redundancy of the Internet.

PRP Community Events

There’s nothing more damaging to a website’s credibility than a newsroom without news or a calendar without events. Efforts to build mutually beneficial relationships with NORD, CSD and FIRST would be greatly enhanced with a robust calendar of events. Moreover, PRPers should be aware of kindred spirits just a click away.

PRP-related Medical Research

The PRP Alliance has undertaken a 90-day effort to recruit 500 PRPers (active and in remission) to participate in the Thomas Jefferson University PRP Phase 2 Research Project. The PRPSG could be supporting that effort by posting appeals that have been published in the PRP Community newsletter. In addition, PRPers may prefer contacting a fellow PRPer for more information. This option should be made available. We should all be on the same page.

PRP Community Efficacy Research

The PRPSG should also endorse and support the gathering of information from PRPers that might constitute a catalyst to whet the appetites of bona fide medical researchers. For example, why not poll 800-plus PRPers to determine how many have taken a particular drug, the resulting side effects and outcomes and the inevitable comments that would be shared by PRPers.

- Efficacy of Stelara
- Efficacy of Retinoids
- Efficacy of Methotrexate

PRP Community Polls & Surveys

A total of seven surveys/polls are in the queue through December 2014. The PRPSG should endorse these efforts, allow updates in NEWS & EVENTS and post the final results on the PRPSG website, e.g., SURVEYS.

- Biopsies as a Diagnostic Tool
- Living in Remission
- Maintenance Survey: Hands, Fingers & Palms
- Maintenance Survey: Feet & Soles
- Maintenance Survey: Ears
- Quality of Life: Energy & Fatigue
- Working with PRP

PRPer Profiles

There is a need for the PRP Community to read about the courage of fellow PRPers as they journey from onset to remission. The 3,000-word profiles of ***Barbara Kossler***, ***Patricia Ullman Hayward***, ***Bill Mahler*** and ***Darren Costello*** were posted on the PRP Alliance website but never seemed to be "picked up" for inclusion in the PRPSG website. The status quo must change.

Emailer-based Forum

The PRP-L List has been the cornerstone of the PRPSG for 17 years. Over the years its traffic has ebbed and flowed. Most recently it has been ebbing. As the table below indicates, there was an average of 19 posts per month and an average of 67 comments during the first Quarter of 2014. Even more disconcerting should be the fact that less than 12 percent of the PRP-L List subscriber participate.

There should be a within the PRP Community to concerted effort to "prime the comment pump", perhaps with a weekly question that results in an article posted on the PRPSG website. Or perhaps the comments spark a poll to 800-plus PRPers. The status quo must change.

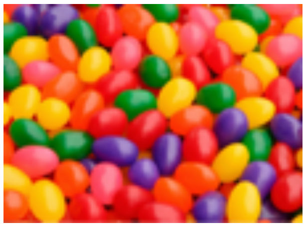
Facebook-based Forum

With over six times the number of "posters" and over 18 times the number comments, the statistics for the PRP Facebook Support Group reflect a new mode of communication. It's not a contest with winners and losers.

Over 85 percent of the PRPers who consider themselves "Facebookers" are also "Emailers" who subscribe to the PRP-L list. It's vital that visitors to the PRPSG website learn about both forums and are invited to participate *in both*. The status quo must change.

PRP Worldwide Census

It took over eight months to acquire over 1,300 email addresses prior the launch of the PRP Census effort on November 6, 2013. It took three months and thousands of emails to actually acquire 400-plus completed census forms. There are still 286 non-responders who possess important information of value to the PRP Community. The PRPSG could play a major role by endorsing the effort. and posting appeals for participation.



A second target related to the ongoing PRP Census will be the identification of PRP-savvy dermatologists. The PRPSG website. could have a role to play here.

PRP-L Archives

No one disputes the fact that there is gold in the PRP-L archives. One can make a case, however, that the list's technology is not conducive to research. Query "Soriatane" and get 4,488 documents, "acitretin gets 461, query both and get 239. Even if you refine the search, you might inadvertently lose the factoid for which you search.

The PRP Community should undertake the extraction of all the gold from the archives mine. Every jot and tittle. It needs to be sucked into a database without all the extraneous and repetitive formatting. Repetitive messages must be exorcised. Once the archives have been cleansed, then the remaining information may be parsed. It will be a monumental project, but 30,000-plus documents shared over 17 years cannot be ignored. It is our legacy.

PRP Support Group Emailers

Month	Posts	Comments
Jan '14	30	104
Feb '14	16	66
Mar '14	11	30
1Qtr 2014	57	200
	19 avg	67 avg

PRP Facebook Support Group

Month	Posts	Comments
Jan '14	161	1,418
Feb '14	101	1,328
Mar '14	106	979
1Qtr 2014	368	3,725
	123 avg	1,242 avg

“Building channels of communication.”

The PRP Alliance was never envisioned to be a support group. It has a singular focus: to build channels of communication within the PRP Community and between the PRP Community and other entities.

Over the years I have been a member of the Public Relations Society of America. The following definition of public relations was adopted by PRSA in 2012:

> “Public relations is a strategic communication process that builds mutually beneficial relationships between organizations and their publics.”

Using the word “publics” doesn’t come easy to folks who are not in the PR business, but it is what it is. Here are the “publics” where channels of communication are essential.

PRPers

The PRP Community Database currently maintains information on 1,302 PRPers of which only 829 have a valid email address. The breakdown by location: US, 395; International, 259 and unknown, 175. More information needs to be “pushed” to PRPers rather than expect to have them “check in periodically.”

Surrogates

For database purposes a surrogate “stands in” for the PRPer, most typically representing the PRPer among the ranks of PRPSG emailers or “Facebookers.” Surrogates face unique challenges and deserve their own channel of communication, e.g., section in the PRP Community newsletter.

American Academy of Dermatology

The AAD boasts 16,000 members in the U.S. and another 1,000 outside the U.S. The top priority for the PRP Community should be to develop effective channels of communication between with AAD leadership and members. Attending the AAD Annual Meeting in San Francisco, CA (March 21-24) with a small delegation of PRPers would be a worthy goal.

State & Local Dermatology Societies

There are 92 state and local AAD-affiliated societies. A separate and distinct communication channel should be fostered between PRPers and their state and local societies. In Texas, for example, there is is the Texas Dermatology Society and local chapters in Dallas/Fort Worth, Houston, Austin and San Antonio.

Each one different.

Each one special.

Teaching Hospitals & Major Clinics

The PRP Alliance will build a comprehensive database of teaching hospitals with robust departments of dermatology. The database will also include high-volume dermatology clinics where the potential of identifying PRP-savvy dermatologists will be greater.

National Institutes of Health

It is time for the PRP Community to understand what is going on at the Office of Rare Disease Research (ORDR) and the Genetic and Rare Disease Information Center (GARD). What do we need to know that might have a positive or negative impact?

Rare Disease Organizations—Non-Profits

The PRP Community should become more visible to the National Organization of Rare Diseases (NORD), e.g., Rare Disease Day 2015 and Handprints Across America. NORD is trying to cover our back.

Skin Disease Organizations

The Coalition of Skin Diseases (CSD) and the Foundation for Ichthyosis and Related Skin Diseases FIRST) are kindred spirits where a “mutually beneficial relationship” could easily grow. Their members may have a different disease, but they often share the same pain in the same places as any PRPer.

Building channels of communication is not rocket science. It does require, however, a willingness to listen and understand PRPers, surrogates, the AAD and the state/local societies, teaching hospitals and major clinics, ORDR and GARD, NORD, CSD and FIRST. The hard part is over—we already started…and know the acronyms.

"The PRP Census should include ALL active PRPers."

I'm a Newbie in Dallas"
On February 7, 2013—over 10 weeks since my PRP diagnosis—I sent my first email to the PRP-L list. I eagerly awaited an online Welcome Wagon. Not a single response.

One month later on March 12th, I sent another message with the subject: "People with PRP in TEXAS". By this time I had ventured into the PRP-L archives and identified ***Bonnie Sue Luft*** (Waco), ***Ralph Gilmore*** (in remission in Arlington) and ***Stephen Gimenez*** (Houston). Not a single response to my post.

Then I asked myself: How many PRPers should there be in Texas? How many in the Dallas/Fort Worth area?

The answer was in the Dowling Oration given by Dr. Andrew Griffiths in March 2003. According to Dr. Griffiths the prevalence rate for "active" PRP is one in 400,000. That means there should be 65 "active" PRPers in Texas and 16 in the Metroplex. Unfortunately, the only "active" PRPer I could find in North Texas was me.

I became fixated on finding local PRPers. The American Academy of Dermatology confirmed that there are 130 dermatologists in the Dallas/Fort Worth area. I knew then I could contact all the dermatology departments and clinics and confirm every active PRPer.

But the focus of my local search for PRPers inexplicably expanded to the 65 in Texas. Along the way I discovered ***Abbie Cotrell*** (San Antonio).

By mid-summer I had commenced a PRP Biopsy Poll that documented the biopsy experiences of 258 PRPers. More often than not the biopsy data was accompanied by unsolicited comments about the PRPer's road from onset to remission. The comments were fascinating. I was hooked.

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		

Source: PRP Census Database

The next thing I new I was calculating the number of "active" PRPers in the U.S. (972).

Somewhere along the line a voice from Temple University advised me that any PRP Census should not exclude the International PRP Community. "Easy for him to say," I thought, "I'm the one who is going to do all the work."

The PRP Census was now the 2014 PRP Worldwide Census and North Texas was on my back burner.

The Path Forward
With over 400 PRP Census forms received, there are still another 420-plus PRPers who have not responded. An appeal will be made to the non-responders on the pages of PRP Community newsletter, in a a series of emailed PRP Census requests and hopefully on the PRPSG website.

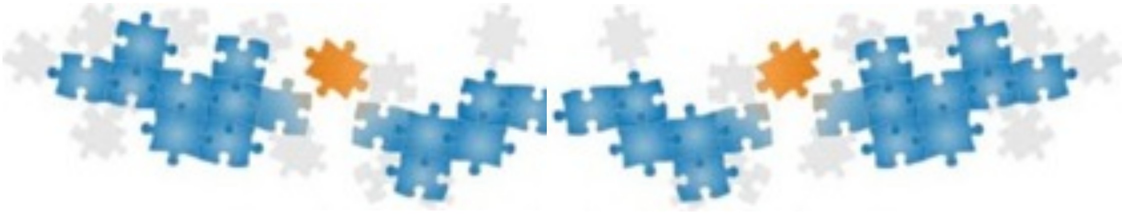
As PRP-savvy dermatologists are identified and added to the Registry of PRP-savvy Dermatologists, PRPers who diagnosed and/or treated PRP will be discovered. Working within HIPAA and HITECH guidelines, these PRPers will have the opportunity to make themselves known to the PRP Community.

Census Deadline
The official deadline for the 2014 PRP Census is December 31, 2014. The "Interim" PRP Census Report will be published in the January 1, 2015 issue of the PRP Community newsletter. The word "interim" refers to the fact that the PRP Census will be an ongoing effort.

It is hoped that the PRP Census will eventually gather information on the efficacy of a pharmaceuticals as well as techniques to manage stress, pain and itching.

The latest revision of the 2014 PRP Census is available now.

“Every PRPer should meet another PRPer face to face.”



My third PRP Meet & Greet took place on April 27th. Linda Walls and her 21-year-old son, Bryan and I met at a Steak ’n Shake near DFW in Dallas, midway between North Richland Hills and Plano.

We spent over two hours chatting up a storm. Bryan has had PRP since birth. He is a fine young man with a very proud and supportive mother. You will be reading much about Bryan in the months ahead.

I uncovered Linda’s email address from message she had posted on August 4, 2005. On December 5, 2013, she responded to my ***third*** PRP Census appeal by submitting a census form on behalf of her son. I invited her a PRP Meet & Greet and she accepted. After trading a few emails we confirmed a time and place.

That’s all it takes. Interested?

Learn more about PRP PRP Meet & Greet.

Meet & Greeters (counterclockwise,upper left): ***Lindsay Sprick*** (Charlotte, NC) and ***Ginny Maxwell*** and her daughter ***Lauren*** (Columbia, SC); Bill McCue and ***Michael Funk*** (Abilene, TX), Bill McCue and ***Linda Walls*** and her son ***Bryan*** (Richland Hills, TX), ***Patricia Ullman Hayward*** and ***Lisa MacDougall*** (Halifax, Nova Scotia) and *Bill McCue* (Plano, TX) and ***David Young*** (Aurora, CO).

“The PRP Community can be a catalyst for research.”

As of Wednesday, April 30, 2013, I have received questionnaires and signed authorizations from 28 PRPers (U.S. 22, International: 6 (UK: 5, Australia: 1).

With 61 days remaining until the deadline for accepting questionnaires and forms (June 30, 2014), it’s time for you to allocate five minutes of your time and a 49-cent stamp and participate. This is the PRP research the PRP Community has spent 17 years wishing for. It’s here. It’s now. It’s time to step up.

Tracking Participants

Why is it important to track the participants in the TJU PRP research project?

To determine the amount of effort necessary to recruit 500 participants. These are the numbers I need.

- 838—PRPers with a valid email address
- 28—number of PRPers who have confirmed submitting questionnaires and authorization forms to TJU
- 472—number of PRPers needed to reach the 500 participant goal
- 810—number of PRPers in the PRP research pool

About HIPAA guidelines

The Health Insurance Portability and Accountability Act (HIPAA) includes privacy guidelines that specifically prohibit anyone associated with the Thomas Jefferson University PRP research project from disclosing what is termed “Protected Health Information”. PHI includes your name.

I jokingly told all fellow PRPers that I need to hire an administrative assistant named Claire Voyant. While she can’t type worth a lick, her psychic powers could enable her to tell me who has submitted their questionnaire and authorization forms to TJU.

But alas—there is no administrative assistant with such psychic powers. Only you can tell me.

Take a stand—inspire other PRPers

The only way to know who is participating is to ask participants directly. I did this on Saturday April 26th with posts to the PRPSG emailers and the PRP Facebookers.

Please take a moment to review the current list of PRPers who authorized me to memorialize their participation in the TJU PRP Research Project.

“There’s serious ferreting at 9 and Chestnut.”

When you send your completed questionnaire and authorization forms to Nick Ross at 833 Chestnut Street in Philadelphia, that’s the end of your active participation. Now the PRP research may begin.

Getting your PRP-related medical records from your dermatologist is the next step. Clinical notes, biopsies, lab results—everything goes to Philly.

The verb ferret has many definitions:

- to search for something by asking asking many questions
- to find by persistent investigation. (often followed by out): to ferret out the facts.
- active and persistent searching
- to search out,
- to discover
- to bring to light
- to search intensively

I think the PRP Community should consider the ferret as the unofficial mascot of all PRP Research. We should have coffee mugs for the researchers. In fact, I have just made the yet-to-be-named ferret the official mascot of the PRP Worldwide Census.

We really appreciate the PRP researchers in Philly.

“It’s time for PRPers to come out of hiding.”

Sometimes I just don’t get it. Please help me with this.

I see a very real difference between NAMES and NUMBERS?

For example, anyone who is mentioned in the PRP Community newsletter by name, sees the article in which their name appears ***before*** it is published or posted.

I have had only two PRPers (both will remain NAMELESS) who request that there names be presented as a complete first name with only the first letter of the surname, e.g., Bill M. No problem there either.

But what do I say to someone who doesn’t want to share even the most ***basic numbers*** and ***core data*** associated with our disease.

- Onset date: *August 8, 2012*
- Onset age: *66*
- Onset symptoms: *Rash on right forehead*
- Misdiagnoses: *Seborrheic dermatitis*
- Biopsy experience: *five, last supported PRP*
- Diagnosis date: *November 28, 2012*
- Diagnosing dermatologist: *Dr. Michael Golden*
- Treating dermatologist: *Dr. Arturo Dominguez*
- Status: *Remission as of April 8, 2014*

Why would a PRPer withhold such core data that could benefit the PRP Community?

For those concerned that such core data might be used for nefarious purposes, the PRP Census database is hosted on a HIPAA-compliant server.

Quick frankly, I think that claiming “privacy” is a cop-out. To non-responders: here’s why.

There is simply too much at stake to hide under a rock.

1. Of the 7,000 rare diseases, *pityriasis rubra pilaris* is among the rarest of the rare. You make us even more rare by not participating in the Census, polls, surveys and bona fide medical research projects.
2. Too many dermatologists are befuddled. How can we enlighten them if you are hiding under a rock?
3. The diagnosis of PRP is too often preceded by misdiagnoses and mistreatment. How can we quantify patterns of misdiagnosis if you are hiding under a rock?
4. To date only 47 of 838 PRPers have completed the required forms for the Thomas Jefferson University PRP Phase 2 research project. On what basis would someone NOT want to participate?
5. Over 420 PRPers have not identified their PRP-savvy dermatologists. Perhaps you don’t remember—I sincerely hope that’s the reason.
6. And this is the one that bugs me the most—an unwillingness to help determine the efficacy of drugs based on your experience. You are a data treasure!

The beauty of the Census is that no one knows who is hiding under the rock. I do, but I can’t tell. As you know, privacy is the cornerstone of the PRP Census. Weird, huh?

No one is asking you to be interviewed on the Today Show by Dr. Nancy Synderman. You are only being asked to share your PRP experiences. Share the love. Share the data.

To anyone I may have offended with this diatribe—complain to the next PRP Newbie who was misdiagnosed by a dermatologist who was not PRP-savvy.

"The PRP Community can build a bridge with the AAD."

The Rare Diseases Act of 2002, Section 2 (a)(1) classifies a rare disease as any disease or disorder "which affect small patient populations, typically populations smaller than 200,000 individuals in the United States."

With a prevalence rate of one in 400,000 there are an estimated 792 "active" PRPers in the U.S. We are among the rarest of the rare. No wonder we get less respect than the late Rodney Dangerfield.

For 17 years the PRP Community has been lamenting the never-ending befuddlement dermatologists. Now is the time to no longer lament. The time is to "un-fuddle" the befuddled.

Let's start with a simple mission: Increase awareness of PRP among dermatologists. We can accomplish this mission through the Online Registry of PRP-savvy Dermatologists (Registry Project).

Step One:
Verify existing data in the Census database

485 PRPers have identified the dermatologist(s) who diagnosed and/or treated their version of PRP. This is the low-hanging fruit in building the online registry. We have a direct link between a PRPer (me) and two PRP-savvy dermatologists (Dr. Michael Golden and Dr. Arturo Dominguez). The contact information for each would be entered into the Registry.

Step Two:
Mine the Census database

Once a dermatologist is in the Registry, we simply confirm if other dermatologists in the same clinic or hospital are PRP-savvy. Again, the connection with the first dermatologist should help identify more PRP-savvy dermatologists.

Step Three:
American Academy of Dermatology

The AAD has very effective channels of communication with their members. [Publications] include:

- Magazines: Dermatology World, Journal of the American Academy of Dermatology (JAAD) and Aspire
- E-Newsletters: Dermatology Advocate, Dermatology Daily, Member to Member and Skin E-News, Society Insider and Young Physician Focus

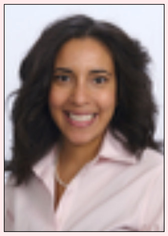
The ADD also supports 92 state and local societies. Many of these local organizations have newsletters that could carry our message of enlightenment as well.

The Online Registry of PRP-Savvy Dermatologists will begin after the registration deadline for participating in the Thomas Jefferson University PRP Phase 2 Research Project.

A more detailed overview of the Registry Project will appear in the May 15th issue of the PRP Community newsletter. The overview will detail how PRPers can "nominate" their own dermatologist for inclusion.

A sample listing for Dr. Nana Duffy appears to the left.

Nana Duffy, MD



Genesee Valley Laser Centre
300 White Spruce Boulevard
Rochester, NY 14623
Office: (585) 424–6770

Organizational affiliations: Member of the American Academy of Dermatology, the Society for Investigative Dermatology and the Women's Dermatologic Society.

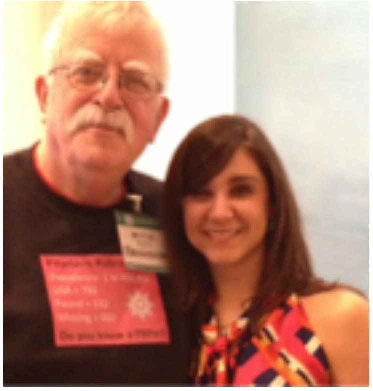
Website: gvlasercentre.com

“Networking with dermatologists at their Annual Meeting.”

Dr. Jouni Uitto

Dr. Arturo Dominguez

Dr. Shadi Kourosh



Dr. Brooke Eastham

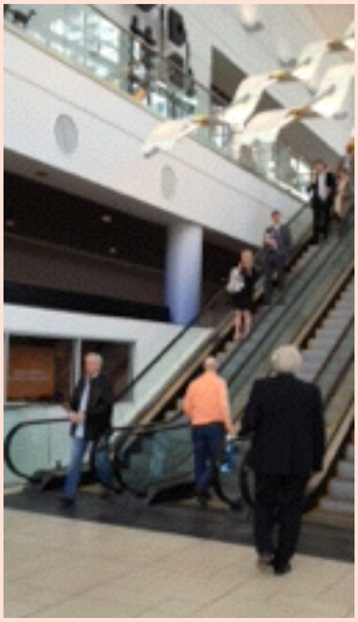
Thank you Lt. Col. John P. Kraynak, Commanding Officer of 7th Engineer Battalion (circa 1970). As the CO of First Bridge Company I heard Col. Kraynak’s Mantra more than once:

> *The wrong course of action is better than no action at all. You can correct a mistake, but you can’t re-create a lost opportunity.*

Granted—there are some serious caveats to his advice. However, when I learned that I could fly to Denver roundtrip for $128 and have the opportunity to meet TJU’s ***Dr. Jouni Uitto*** in person to discuss the TJU PRP Research Project it was a no-brainer. I also saw a fabulous opportunity to rub elbows with over 8,000 dermatologists attending the American Academy of Dermatology Annual Meeting (March 21-24) at the Colorado Convention Center in Denver.

For the record the “best elbows” in Denver belonged to ***Dr. Jouni Uitto***, ***Dr. Hye Jin Chung*** and ***Nick Ross*** (TJU PRP Research Project), ***Dr. Brooke Eastham*** (Quality of Life research), ***Dr. Shadi Kourosh*** (MGH, Boston), ***Dr. Arturo Dominguez***, UT Southwestern, Dallas) ***Jean Pickford*** (executive director, FIRST) and ***Sue Thornton*** (vice president, CSD)

Most PRPers missed my visual humor in the April 15th issue. Let me try again. What’s the difference between asking a dermatologist—descending the escalator during the AAD Annual Meeting—if they have PRP patients versus a bear eating salmon swimming upstream to spawn? Answer: the dermatologists aren’t trying to spawn.



I had three places to engage dermatologists in Denver: (a) at the bottom of the main *down* escalator, (b) in the open areas near classrooms where dermatologists chatted in small groups and (c) in the Mingle Zone where phones and laptops were recharged. I was able to ask 783 dermatologists if they had ever diagnosed or treated a patient with pityriasis rubra pilaris? ***Dr. Bob Durst*** (Topeka, KS), ***Dr. Alise Curry*** (Boulder, CO) and ***Dr. Jennell Nelson*** (Manassas, VA) were among the 22 dermatologists who answered “Yes.”

For more about the AAD Annual Meeting read the April 15th issue of the PRP Community newsletter.

"The PRP Community should build a pathway to NORD."

The National Organization for Rare Diseases pulls out all the stops to promote Rare Disease Day. It was in the wake of Rare Disease Day 2013 that I was inspired to mine email addresses from the PRP Support Group archives—30,000-plus messages going back to November 1997.

There were a handful of PRPers who participated this year, but in general, the PRP Community was in a state of status quo.

Just a little personal background. When NORD was founded on May 4, 1983, my seven-year-old daughter had been dealing with phenylketonuria (PKU) since birth. Three weeks later my son would also be born with PKU. The prevalence rate for PKU is one in 10,000—rare by federal standard.

Over the years as a parent I learned about the importance of rare disease support groups, parent-to-parent communication and national and regional conferences. So much energy was expended by so many people. The support was effective and appreciated.

Now the shoe is on my foot—I have PRP. Perhaps I was spoiled by my experience with PKU. While I easily empathize with my fellow PRPers, I continue to be frustrated knowing PRP Community's great potential.

Physician Database

As previously reported (page 9), the identification of dermatologists who have diagnosed and/or successfully treated PRP should be a high priority for the PRP Community. When completed, the Online Registry of PRP-savvy Dermatologists database would be offered to NORD for inclusion in their Physician Database. They need the following information:

- Medical expert's name
- Institution
- Disease of Expertise (PRP)
- Specialty: dermatology
- Email address
- Phone number

If NORD accepts the offer, each PRP-savvy dermatologist would be contacted by NORD before having their information add to the NORD physician database.

Rare Disease Database

NORD maintains a partial database of 1,200 of the nearly 7,000 diseases considered rare in the U.S. The full description of PRP available to online visitors lists seven references, all between 1984 and 1999. There are four organizations related to PRP listed: the PRP Support Group is the last. Seems to be a missed opportunity

Patient Stories

The combination of video and story is terrific. Take a peek at what NORD has done and imagine a mother with a newly diagnosed PRP child watching a video about a family of PRPers, ***Ginny Maxwell***, ***Lauren***, ***Nathan*** and ***Joey***, and then reading their story in print. I can think of a dozen more PRPers who could share their stories.

Build & grow an organization

NORD promote best practices in governance and management, and and experience with innovations in patient/family services. The PRP Community would be well advised to develop a relationship with NORD. A great place to start would be Rare Disease Day 2015 and things we can do right now.

- Check out Handprints Across America
- Put the "Countdown to Rare Disease Day 2015" on the PRP Support Group website.

Even though we are small in numbers (792 "active" in the U.S.), we can still make a contribution.

NORD

"The PRP Community will work more closely with CSD."

While rubbing elbows with 8,000-plus dermatologists at the American Academy of Dermatology Annual Meeting in Denver (March 21-24), I met Sue Thornton, the vice president of the Coalition of Skin Diseases. CSD had a 20-foot booth in the exhibit hall and displayed stacks of brochures and fact sheets hoping to educate passersby with blue badges—the dermatologists.

I asked Sue questions, collected brochures and promised to get back to her. I did. It wasn't long before I got a call from Kristi Burr, president of the CSD and the executive director of the Basal Cell Carcinoma Nevus Syndrome (BCCNS). We talked for nearly two hours and I realized that Kristi's experience with BCCNS and CSD would become an important asset for the PRP Community.

Based on my initial conversation with Kristi, I see three important areas of further discussion:

[Physician's Referral List]

The BCCNS website has an interactive Physician Referral List that would be a great start for the Online Registry of PRP-savvy Dermatologists. Take a look and let your mind wander.

Non-profit status

The PRP Support Group should begin to consider the value of becoming a 502(c)(3) non-profit organization or finding a way to position the organization under the umbrella of a bona fide non-profit. This will not happen overnight and may not happen at all. But the discussion should begin.

Most PRPers think that the PRP Community is doing a good job, but there is an expression that comes to mind: "In the Land of the Blind, the one-eyed man is king." There may be better ways to better serve the PRP Community.

Man the Booth

Over the next year the PRP Community must figure out a way to participate an an exhibitor at the AAD Annual Meeting in San Francisco. Exhibitors have better access to dermatologists than a lone PRPers wearing a sweat shirt stalking attendees with blue badges as they descend escalators, congregate in small groups and recharge their phones and laptops in the Mingle Zone. The CSD may be the way.

VITILIGO SUPPORT INTERNATIONAL

ippf

BCCNS

NATIONAL Eczema ASSOCIATION

debra Care, Research, Cure

SWF

C.A.R.F.

National Foundation for Ectodermal Dysplasias

XP Family Support Group

NATIONAL PSORIASIS FOUNDATION

National Alopecia Areata Foundation

FIRST Foundation for Ichthyosis & Related Skin Types™ Educate • Inspire • Connect

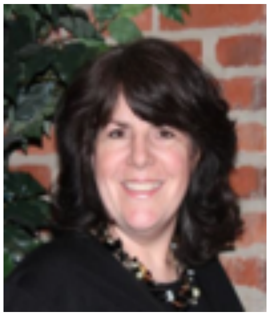
CUTANEOUS LYMPHOMA FOUNDATION

"The PRP Community should join FIRST."

While attending the American Academy of Dermatology 72nd Annual Meeting, I had the opportunity to meet *Jean Pickford*, executive director of the Foundation for Ichthyosis & Related Skin Diseases (FIRST) a coalition with whom we share a great deal. We chatted long enough for me to recognize that I had found a kindred spirit. Jean has graciously agreed to this interview.

Jean Pickford
Executive Director

Maureen Neville
Communications Director



Moureen Wenik
Program Director

General Questions

Q. What is the most important benefit FIRST could offer the PRP Community?

A. Being part of a unique community that understands what it's like to deal with a chronic skin condition that affects you both medically and psychologically.

Q. FIRST gets calls from PRPers via NORD. Do you have statistics regarding PRP-related inquiries?

A. Yes. We have contact information from 99 PRPers. Each caller is referred to the PRP Support Group.

Q. Can the 99 be queried to ensure that they are either subscribers to the PRP Support Group or members of the PRP Facebook Support Group?

A. Yes.

Q. Can they be queried to verify their participation in the 2014 PRP Census?

A. Yes.

FIRST to KNOW

Q. FIRST hosts a topic-specific conference call twice a month. Have you ever featured PRP?

A. No. The Conference call on June 1st at 8:00 PM (EST) will be the first.

Q. Is there a special number to call?

A. We have a dedicated conference phone line for FIRST to Know calls. To participate in the call, simply dial: 862.902.0250. An automated system will prompt the caller to enter the pin# 261618915.

Q. How does the PRPer ask questions? It's not like you can raise your hand.

A. Questions may be emailed before or during the call to FIRST program director ***Moureen Wenik*** at mwenik@firstskinfoundation.org. Callers can also just jump in. FIRST staff are moderators.

Q. How do you know who else is on the line?

A. Only the moderator knows how many callers are on the line. Attendance is taken for those who want to announce their presence.

Q. Can PRPers who miss the call hear a recording?

A. The call will be recorded and the podcast will be distributed to anyone who requests it.

Legislative Advocacy

Q. How can the PRP Community become more knowledgeable about legislative issues that impact PRP?

A. Join the Coalition of Skin Diseases. The CSD is closely linked to the AAD and their government offshoot, AADA. Members of the CSD are kept abreast of the latest legislative issues and invited to their hosted conference in DC every year.

Path Forward

NORD, CSD and FIRST represent an untapped resource for the PRP Community to dramatically improve the diagnosis and treatment of pityriasis rubra pilaris.

“There are things to do, places to go and people to meet.”

Advancing the interests of the PRP Community requires involvement. Let’s start by knowing who to call “friend”, what our “friends” are doing, ways to work together.

CALENDAR 2014

May 8

—Portraits of Courage, Washington, D.C. The National Organization of Rare Diseases (NORD) will honor patients, parents and caregivers at its annual gala in Washington DC. I wager that the PRP Community has more than a few “Portraits in Courage” that we should share with the PRP Community. *learn more...*

June 1

—FIRST to KNOW conference call at 8:00 PM (EST). PRP Community has been invited to participate in a special event hosted by FIRST and program and research director ***Moureen Wenik***. Details about the FIRST to KNOW program and and what to expect will be shared in the May 15th issue of the PRP Community newsletter. *learn* more...

June 30

—Deadline for participating in the TJU PRP Phase 2 Research Project. Mailing the 3-minute questionnaire and signing the 30-second authorization forms must be postmarked by midnight, June 30, 2014. *learn more...*

November 6

—PRP Worldwide Census Day. On the anniversary of the passage of the Rare Diseases Act of 2002, a 56-day blitzkrieg begins to collect as many PRP Census forms as possible. *learn more...*

November 13

—Online Registry of PRP-savvy Dermatologists goes live. This date also commemorates the first “official” post placed in the PRP-L Archive by PRPSG founder Jean-Luc Deslauriers. *learn more...*

CALENDAR 2015

February 28

—Rare Disease Day, February 28, 2015. PRP is among the rarest of the rare. There is a cornucopia of activities coordinated by the NORD that the PRP Community should consider. *learn more...*

March 21-24

—American Academy of Dermatology 73rd Annual Meeting, San Francisco, CA. If anything like the 72nd Annual Meeting in Denver, the PRP Community needs a game plan. *learn more...*

June 8-13

—World Congress of Dermatology, Vancouver, BC, Canada. The conference will cover areas including diagnosis and management of specific disorders. *learn more...*

The PRP Community needs it’s own Awareness Day

We may be a rare disease, but who said we don’t deserve a PRP Awareness Day? I propose November 13, 2014...exactly 17 years from the day that Jean-Luc Deslauriers posted the first message to an audience of 16 PRPers. Read message.

Any PRPer or surrogate who would like to discuss the feasibility of a PRP Awareness Day should contact ***Tierney Ratti*** via email at tratti@cox.net or via Facebook. The ponderings, cojitations and reflections of these folks will be shared in the next issue of the PRP Community newsletter.

"A checklist for PRPers and the PRP Community."

On August 8, 2014 I was told by my dermatologist that I was officially in remission after only 20 months. He reminded me that I still have PRP. The truth be told, I look in the mirror whenever I step out of the shower

I have basically come out of retirement with absolutely nothing to prove…but apparently much to do.

Challenging the status quo may make some folks feel uncomfortable. Change has that effect. You have read three issues of a PRP Community newsletter that did not exist before April 1, 2014. The status quo is already changing.

- ☐ Propose that the PRP Community newsletters be posted in the NEWS AND EVENTS section of the PRPSG website and archived in RECENT POSTS.
- ☐ Propose that events detailed in the PRP Community newsletter be included in the NEWS AND EVENTS section of the PRPSG with links to the appropriate PDFs that detail the events from the PRP-perspective.
- ☐ Propose that the appeals for PRP participation in the Thomas Jefferson University PRP Research Study be included in the PRP RESEARCH section of the PRPSG website.
- ☐ Propose that the upcoming Efficacy Surveys regarding Stelara, Retinoids and Methotrexate be included in the PRP RESEARCH section of the PRPSG website.
- ☐ Propose that the upcoming polls and surveys regarding biopsies as a diagnostic tool. living in remission, working with PRP, energy and fatigue, etc., be included in the PRP RESEARCH section of the PRPSG website.
- ☐ Propose that links to PRP Profiles, e.g., Bill Mahler, et. al) and future PRP "personal stories: be listed with links in the PERSONAL STORIES section of the PRPSG website.
- ☐ Propose that the PRP Facebook Support Group be included in the a section of the PRPSG website renamed ABOUT THE SUPPORT GROUPS. Instructions relative to (a) subscribing to the PRP-L List and/or (b) joining the Facebook group should co-exist.

- ☐ Propose that a link to the PRP Census "Numbers" be included in the SURVEYS section of the PRPSG website.
- ☐ Propose that the Meet & Greet program be explained in the OTHER INFORMATION section of the PRPSG website.
- ☑ Continue to develop a mutually beneficial relationship with the American Academy of Dermatology AAD State and local societies
- ☑ Create a database of teaching hospitals, major clinics and other venues where PRP-savvy dermatologists might be found.
- ☑ Research and report back to the PRP Community the specific ways that Institutes of Health (ORDR and GARD) may help our fellow PRPers.
- ☑ Continue to develop a mutually beneficial relationship with the National Organization of Rare Diseases. They have a wealth of information.
- ☑ Continue to develop a mutually beneficial relationship with Kristi Burr, president of the Coalition of Skin Diseases (CSD) and staff. A door was opened in Denver at the AAD Annual Meeting.
- ☑ Continue to develop a mutually beneficial relationship with Jean Pickford, executive director of the Foundation for Ichthyosis and Related Skin Diseases (FIRST).

On May 15th the fourth issue of the PRP Community newsletter will be posted, I can only do the tasks over which I have control. Let's see how the checklist looks on the 15th.

"Our newsletter has a name...On the Road"

Nearly a month ago I began using the phrase "yet-to-be-named newsletter". In the past few weeks it has been upgraded to PRP Community newsletter. Then I had a creative "burp" and **On the Road… The journey from Onset to Remission** was born.

Some random thoughts to share:

1. On the Road is a metaphor with lots of potential. In my mind's eye I see a series of city limit signs for towns like
    - Onset
    - Diagnosis (a wrong turn will take you to the town of Misdiagnosis)
    - There are the twin cities of Hell and Agony. Remember Detroit of the future (RoboCop) and Los Angeles of the future (Terminator)?
    - The road to Remission has off-ramps to Relapse, Flare-up and an off-ramp I took: Blood Clot

    The journey from onset to remission properly frames the scope of having PRP.
2. Every front cover will have a scenic view of a road to Remission. The newsletter will offer hope.
3. The front cover will always identify the four major topics for that issue.

Attribution policy
Both direct quotes and indirect quotes will be attributed. PRPers need to know the source of the information they receive in order to weigh its usefulness.

Personal Identification
There are two elements regarding identification:

1. Name
    - BEST: ***Lindsay Sprick***
    - Acceptable: Lindsay S.
2. Location
    - BEST: Charlotte, NC
    - Acceptable: NC

On the Road...
The Journey from Onset to Remission

This issue:
- **TJU Research Packets find their way to Philly**
- **Derm Registry reaches 1,000**
- **PRP Awareness Day Set for November 13th**
- **Spotlight on PRPers "Down Under"**

Use of Likeness Policy
Whenever the image or likeness of a PRPer appears in an issue of On the Road…, the PRPer will receive a draft copy of the page prior to posting. No image will appear without the prior consent of the PRPer.

Schedule for May 15th issue
For the foreseeable future On the Road… a new issue will be posted on the 1st and 15th of each month.

- Layout Mockup (May 7th)
- First draft (May 12th)
- Proofing (May 13-14)
- Posting (May 15th)

I'm always looking for proofreaders and copywriters.