

Care.
Share.
Teach.
Learn.
Checklist.

PRP Community on RareConnect



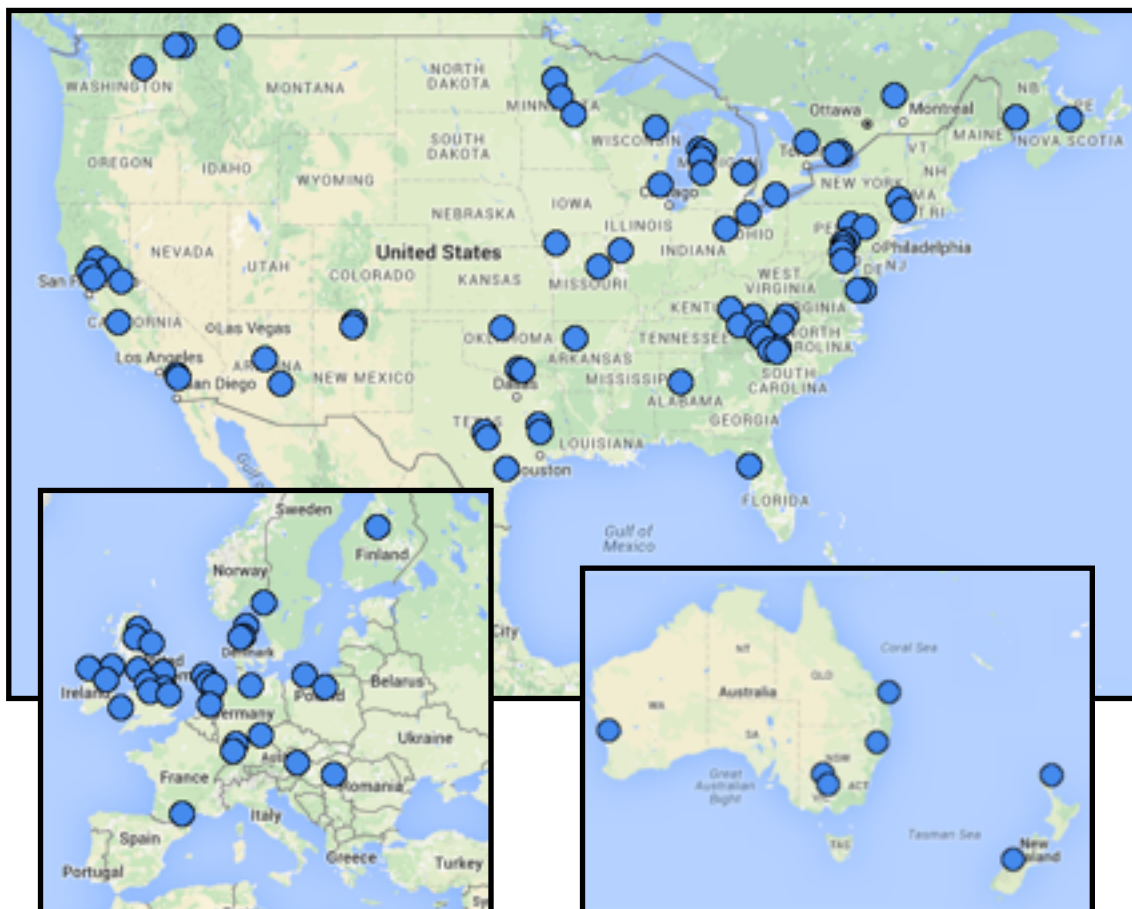


Confirm Your Blue Dot

Members of the PRP Community on RareConnect, should enjoy a degree of solace knowing that they are not alone. Your PRP journey need not be a solitary hike through unfamiliar terrain. Others are traveling from onset to either remission or long-term management. The *location* of each member is signified by a blue dot on the Worldwide PRP Map.

- * As a member of this PRP Community, your blue dot may inspire a member with a neighboring blue dot, to reach out to you or respond to your confidential email.
- * Blue dots facilitate the coordination of face-to-face PRP Meet & Greets.
- * Parents with children diagnosed with juvenile onset PRP may discover a kindred spirit “just down the road”, “the next town over”, or “within driving distance.”
- * The blue dots on the Worldwide PRP Map may also inspire FaceTime, Skype, Oovoo and other outreach opportunities.

To make this work, please confirm that you have a blue dot. If not, contact a Moderator.





Confirm Your “My Profile” Image



Many of the 80-plus rare disease communities already on RareConnect seem to be satisfied with a simple gray, cartoon-like, cookie-cutter silhouette image as a member’s placeholder. The PRP Community, however, marches by the beat of a different drum. A very small percentage of our new members upload a personal image during registration.

State flag buttons

To enhance the visual appeal of the [member list](#), the appropriate state “flag button” is uploaded for all new members of the PRP Community on RareConnect residing in the United States. A member may, at anytime, replace their state flag button with an alternate image of their choosing.

Country flag buttons

To illustrate the international scope of the PRP Community on RareConnect, the appropriate country “flag button” is uploaded for all members residing in a country other than the United States.

How to upload images to “My Profile”

Here are the simple steps to replace your “Flag Button” with a personal photo.

- * Return to your PROFILE
- * CLICK Edit “My Profile”
- * CHOOSE File. The image must be 120 x 120 pixels with a resolution of 72 pixels per inch
- * CLICK the blue button labeled “Update your information”

It’s your decision — a “flag button” or personal photo.





Confirm Your Introduction

When someone joins the PRP Community and goes to the Member List and clicks on your Profile image (flag button or personal photo), your Profile Introduction will appear. Make sure that you have filled out “Your Introduction”. Remember — only fellow members will be able to read your introduction.

PRP Summary

While not a requirement, we strongly recommend that your introduction begin with a brief snapshot of your PRP experience to include the following

- * Role: Patient or caregiver
- * Onset date and age
- * Diagnosis date
- * Diagnosis: Adult vs Juvenile, Type (1-6) if known
- * Current status: Active vs. remission;
- * If applicable, remission date and duration (onset to remission)

What should you write in your introduction?

When a member of the PRP Community reads your introduction, let them know that you are a fellow traveler who understands the challenges of body, mind and spirit facing PRP patients and their caregivers. A good place to start is to answer the the question: Why did you join the PRP Community? Please don't leave your introduction blank. Remember, since it's easy to edit whatever you write — write something.

Bill McCue's Page moderator



« >>>> Role: Patient; Onset date: 08/2012; Onset age: 66; Diagnosis date: 11/2012; Type: Adult Onset; Current status: Remission; Remission date: 04/2014; Duration: one year, 10 months <<<< In August 2012 a red spot appeared on my forehead. Three months later I was diagnosed with PRP. My journey has continued beyond remission (April 2014) as the founder of the PRP Alliance, editor of the PRP Survival Guide and advocate of the

Christine G.'s Page moderator



« <<<< Role: CG (Molly); Onset date: 08/2013; Onset age: 4, Diagnosis date: 10/2013, Type: Juvenile Onset, Status: Active >>>> Mein Kind leidet seit nun fast 3 Jahren an der Hauterkrankung Pityriasis Rubra Pilaris. Ohnmächtig mussten wir zusehen, wie die Krankheit den kleinen Körper fest in Besitz nahm. Als deutschsprachige Europäerin bemerkte ich rasch, dass die wenigen Informationen und Selbsthilfe-Gruppen alle auf Englisch waren





Start Your Testimonial

Living with PRP is your story to tell, whether you are the patient or the caregiver. We all learn from the shared experiences and insights of others in the PRP Community. It is more important to START your testimonial and PUBLISH what you have than to wait until

Give your testimonial a working title

The working title may just be your name, e.g., Mary Jone's Story or Jack Kasper's Story. You can indicate that there is more to come by addend a version number, e.g., Mary Smith's Story (v.1) or Jack Kasper's Story (v.1). Somewhere along the way a more meaningful title may evolve.

Summary

The summary is an efficient snapshot to present your PRP timeline to fellow members:

Role: Patient; Onset Date: 08/2012; Onset Age: 66;

Diagnosis Date 11/28/2012; Type: Adult Onset (Type 1);

Current Status: Remission; Remission Date: 04/08/2014; Duration: 1 year, 8 months

Story Contents

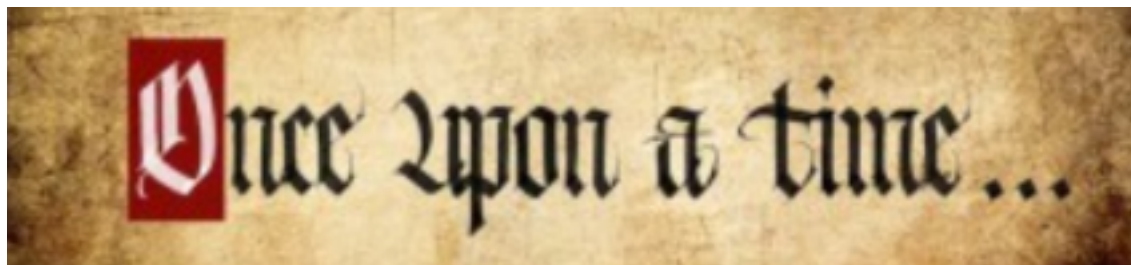
The best advice we can offer is to imagine writing a letter to a friend or family member who REALLY wants to know what has happened to you. Write your letter to someone who cares — someone like a fellow member of the PRP Community.

Photo

There are no rules. We suggest that you use your Profile image. And remember — you can easily change the image you use.

Publish your story

Click the blue button and your story is published for friends and fellow members of the International PRP Forum to read. And remember — you can easily edit your story.





Send an email to a fellow member

The PRP Facebook Support Group has become the most active support group serving the worldwide PRP community. With more than 630 members and thousands of posts and comments each month, it has earned the moniker: The Land of Chat. The technology of Facebook is a double-edged sword. On one hand it's easy for members to start a conversation (post) and then participate in — or watch from afar — a spirited dialog as PRP Facebookers routinely:



- * Vent and lament. Some call it barking at the moon
- * Offer updates to members of the PRP family
- * Share milestones of healing and provide hope
- * Extend hugs and prayers to those in need.

There are others who want nothing to do with Facebook. The patients with PRP and caregivers want to read posts, make comments and communicate with other patients and caregivers via email.

Email — a bridge between members

There are two features of the RareConnect email program worthy of note:

- * **Only friends can email each other.** You must be friends before you can email. Only moderators can email any member without being friends first.
- * **Email addresses are hidden from view.** When you send and receive emails, neither the sender nor the receiver can see each other's email addresses. All you will see is webmaster@raredisease.org.

Your email address was required when you first registered with RareConnect. If you see a message "Confirm Email", please click the message. You will receive an email from webmaster@rareconnect.org with an embedded link. Please click the link.





Post a question or make a comment

A FORUM is a place or opportunity for discussing a subject. In the case of the International PRP Forum, the subject is pityriasis rubra pilaris.

Meet

POST

Ask questions. This is a simple process that begins on the [MEET](#) webpage and clicking the blue START button.

- * Topic — Get to the point. Ask the question or make a statement
- * Discussion — While there is no word count limit, brevity is recommended.
- * Privacy Setting — Checking this privacy box and only signed-in members may view
- * Language — You have the option to post in one of six languages: English, French, German, Italian, Spanish and Portuguese
- * Add Tag — A tag is a label or keyword which best describes what you are trying to say. Tagging content makes it easier for other users to find the subject of your post.

COMMENT

Provide answers. The COMMENT has even fewer options:

- * Your Reply — As with the original POST, there does not appear to be any limit on word count, brevity is recommended.
- * Language — You have the option to COMMENT in one of six languages: English, French, German, Italian, Spanish and Portuguese
- * Share — Click the blue button labeled SHARE

READ

Observe. Not everyone wants to POST or COMMENT. Less than half of the 600-plus members of the PRP Facebook Support Group are POST, COMMENT and/or LIKE.



Pityriasis rubra pilaris is an
ultra-rare skin disease.

We know neither cause nor cure.
Each journey begins with the
unanticipated onset of PRP
and continues to remission or
long-term management.

The PRP Community on RareConnect
is an opportunity for each of us to
reach out from the darkness
and find fellow travelers.

We care. We share. We learn.
We are not alone.

We are in this together.

We survive as a community.

