

PITYRIASIS RUBRA PILARIS (PRP)

A RARE SKIN CONDITION



www.prp-support.org

QUESTIONS and ANSWERS about Pityriasis rubra pilaris

• INTRODUCTION

You are here because you have either been recently diagnosed with PRP or someone you love and care about has received this diagnosis. We are here because we have experienced this disease, first hand; and we want to lend support, reassurance and counsel to you.

Because PRP is a rare or "orphan" disease, it is difficult to gather information in one place, so we have attempted to remedy that problem by reviewing common questions and answers to help you and your loved ones cope with this new diagnosis.

Although these questions and answers were carefully researched using many medical sources, these are not intended to take the place of your dermatologist's or internist's advice and counsel. This information is based on researching medical publications. More importantly, it is also based on the everyday experiences of our Support Group members who have personally been dealing with PRP.

Wherever possible, medical terminology has been explained in parenthesis or non-technical language has been substituted for medical terms. We included some medical terminology so that you could be familiar with it as you will encounter it if you read any professional articles on PRP.

In addition to this information, always consult with your dermatologist and/or other physicians on matters relating to diagnosis and treatment of PRP. It is also suggested that you make a printed copy of this information for physicians, employers, family, friends, and anyone else who needs to be educated about PRP.

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• **DESCRIPTION of PRP**

WHAT IS PRP?

Pityriasis Rubra Pilaris (PRP) is a non-fatal rare skin disorder of unknown etiology (origin). It was first observed by the medical community in the 1800's. Its name is broken down into three parts and derives from their definition:

- pityriasis: characterized by fine, small husk-like scales;
- rubra: red;
- pilaris: pertaining to the hair follicle.

It is a chronic papulosquamous (eruption) disorder of both papules (small circumscribed superficial solid elevations of the skin) and scales (thin flaps of tissue).

It is characterized by reddish-orange scaling plaques and palmoplantar keratoderma (thickening of the palms and soles as a result of excessive keratin formation).

The disease may progress to involve erythroderma (intense and often widespread reddening of the skin from dilation of blood vessels) with distinct areas of uninvolved skin or "islands of sparing." Erythroderma is not a specific disease but a description of a visible symptom.

Most cases of PRP are sporadic (randomly occurring), however there is a familial form of the disease, inherited in an autosomal dominant (chromosome not involved in sex determination) form.

TYPES OF PRP

There are currently six classifications of PRP. It is important to your diagnosis and subsequent treatment to know which classification your disease represents. Your dermatologist should be able to inform you.

Type I: Classic Adult: This is the most common form of PRP, accounting for more than 50 percent of all PRP cases. Most patients are adults who are over 50 years of age. Onset is acute, and the features are classic, including erythroderma with islands of sparing, palmoplantar keratoderma and follicular hyperkeratosis. This type of PRP carries the best prognosis. It has been reported that about 80% of patients will have remission within two to four years.

Type II: Atypical Adult: This form accounts for about 5% of all cases of PRP. It is characterized by dry scaly lesions, areas of eczematous change (itching, swelling and scaling of the skin), alopecia (loss or thinning of hair) and long duration (often 20 years or more).

Type III: Classic Juvenile: This form accounts for about 10% of all cases of PRP. It is very similar to Type I. However, its onset is within the first 2 years of life. Remission can occur sooner than Type I, with an average of one year.

Type IV: Circumscribed Juvenile: This form accounts for about 25% of all cases of PRP. It occurs in pre-pubertal children and is characterized by sharply demarcated areas of follicular hyperkeratosis (thickening of the skin around the hair follicle) and erythema of the knees and elbows. The long-term outcome is unclear, with some reports of improvement in the late teens. This form of PRP rarely progresses.

Type V: Atypical Juvenile: This form accounts for about 5% of all cases of PRP. Most cases of familial PRP belong to this group. It has an early onset and runs a chronic course. It is characterized by prominent follicular hyperkeratosis, scleroderma-like (collagenous fibrosis) changes on the palms and soles and infrequent erythema.

Type VI: HIV-associated: These patients may have nodulocystic and pustular acneiform lesions. There have also been reports of the presence of elongated follicular plugs or lesions. Patients tend to be resistant to standard treatments but may respond to antiretroviral therapies.

WHAT CAUSES PRP?

The specific underlying cause of PRP is unknown. Researchers indicate that the condition may be hereditary or acquired. In many cases, PRP appears to occur randomly for no known reason (sporadically). However, in some affected individuals, evidence suggests that the disease may be inherited as an autosomal dominant trait. Human traits, including the classic genetic diseases, are the product of the interaction of two genes for that condition, one received from the father and one from the mother.

In dominant disorders, a single copy of the disease gene (received from either parent) will be expressed "dominating" the other normal gene and resulting in the appearance of the disease. The risk of transmitting the disorder from affected parent to offspring is 50 percent for each pregnancy regardless of the sex of the resulting child.

There may be a "trigger" factor involved in the appearance of PRP. Some theories suggest that a viral or bacterial infection; antibiotics; trauma to the body, such as major surgery or sun exposure; or emotional stress and trauma. Any or all of these factors may contribute to the appearance of the disease.

HOW RARE IS PRP?

The precise incidence of PRP is unknown, but it has been reported to occur with 1:3500 to 1:5000 patients presenting in dermatology clinics. This classifies it as a rare or "orphan" disease and it is listed among other orphan diseases at [NORD \(National Organization for Rare Disorders, Inc.\)](#).

PRP occurs equally among male and female patients and any race can be affected. The familial form of PRP typically begins in early childhood. The acquired form of PRP has an age distribution with peaks in the first and fifth decades of life but can also begin at any age.

IS THERE A CURE?

At the present time there is no known cure for PRP but there are treatments which will be discussed later on in this article. Since PRP is an "orphan" disease, there is not as much research being done into its cause and cure as there is in the more prevalent diseases among our population. However, some of the research into other papulosquamous diseases, such as psoriasis, have benefited those with PRP in finding successful treatments.

WHAT ARE THE SYMPTOMS OF PRP?

In the majority of cases, PRP begins on the upper part of the body and moves downward. PRP is initially characterized by skin lesions described as mildly itchy or burning, sharply pointed, horn-like, brownish-red to rosy yellow-colored papules. These papules usually occur on the back of the wrists, the outside of the forearms, underarm folds, elbows, knees, backs of the hands, and fingers. When the papules grow together, they produce dry, scaly, rough, red plaques over large areas of the skin.

Gray, brittle nails and excessive oiliness of the glands on the scalp (seborrhea) and face may also occur. Loss or gradual thinning of hair is common. Often the edge of the eyelids are turned outward (ectropion).

Patients with PRP can have painful and disabling thickening of the skin on the palms of the hands and soles of the feet. There may also be nail dystrophy and shedding. Most of the morbidity associated with PRP, however, is associated with erythroderma (reddened skin). Erythroderma is a reaction pattern of the skin that can occur in the setting of several different skin disorders, most commonly including psoriasis, eczema, lymphoma, drug reactions, and PRP. It is characterized by generalized erythema and scaling, hair loss and loosening of separation of nails from their beds.

Shedding of skin (exfoliation) is continuous in most cases and can cause extreme itching and burning sensations.

Systemic symptoms of PRP may include malaise (feeling of being unwell or indisposed), fatigue, anorexia, fever and chills, inability to regulate body temperature. Patients with erythroderma illnesses may also develop lymphadenopathy (disease of the lymph nodes), hepatomegaly (enlarged liver), splenomegaly (enlarged spleen), electrolyte abnormalities due to increased fluid loss and possible cardiac failure in patients with pre-existing heart conditions.

DIAGNOSIS

WHO CAN BEST DIAGNOSE PRP AND HOW IS IT DIAGNOSED?

Most cases of PRP are either initially diagnosed by a dermatologist or referred to a dermatologist by a primary physician. Only a dermatologist is trained to diagnose this type of disease.

On initial examination, PRP is often mistaken for psoriasis or one of the other erythrodermal diseases. For that reason, skin biopsies should be taken and diagnosed by a competent pathologist with experience in diseases of the skin. Many dermatologists serve this function as well, or in conjunction, with a pathologist.

There are no specific lab tests to confirm the diagnosis of PRP.

Since dermatologists see so few cases of PRP, it is often best to go to a large teaching hospital, if possible, for a firm diagnosis.

AFTER DIAGNOSIS, WHAT SHOULD BE ANTICIPATED?

Your dermatologist should inform you of the type or classification of PRP you have (see Types of PRP) and your treatment options will be based on this classification. This specialist should fully explain the treatment options and help you make a decision as to which, if any, to choose. There are several treatment options but basically your dermatologist will either put you on one of two oral medications or take a "wait and see" attitude, again, depending on the type of PRP with which you present. Many patients with PRP do not choose to take medication and many of those have successfully cleared on their own.

WHAT ABOUT POSSIBLE MISDIAGNOSIS?

Misdiagnosis or delayed diagnosis is always possible with a rare skin disease such as PRP. Dermatologists classify many conditions under the general heading of erythroderma or exfoliative dermatitis. PRP is only one of these conditions while other conditions are different, distinct diseases requiring entirely different methods of treatment.

Some of the other diseases that come under this heading are psoriasis, seborrheic dermatitis, atopic dermatitis, PRP, contact dermatitis, photosensitive conditions, pemphigus foliaceus, mycosis fungoides, bullous pemphigoid and cutaneous t-cell lymphoma.

It is always wise to consider a second opinion whenever seeking a diagnosis to any disease, particularly a rare one, and most physicians should encourage that option.

WHAT SHOULD BE DONE FOLLOWING DIAGNOSIS?

The best thing you can do is find a physician/dermatologist that you trust and follow his/her advice. Do not hesitate to ask questions and explanations about any aspect of the treatment regimen or the disease itself.

Try to learn all that you can about your disease. This is why our PRP Support Group is here . . . to share our experiences with the disease and its diagnosis, and our methods of comfort and treatment during the course of the disease.

Please do not hesitate to email the group for advice or encouragement...both are readily available and freely offered. Only through helping others do we best help ourselves.

MEDICATIONS and TREATMENT

ARE THERE ANY TREATMENTS?

There are medications used to treat PRP. The success of treatment outcomes vary from person to person. PRP appears to be a very individualistic disease when it comes to both symptoms and degree of involvement of the skin. Only upon examination can a dermatologist decide on the appropriate treatment for each individual.

Remember that some patients do not choose to take medication and many of them (primarily with Type I PRP) have successfully cleared on their own.

WHAT ARE COMMONLY PRESCRIBED MEDICATIONS?

There are different classifications of medications considered by physicians. Results have often been mixed. There are cautions associated with many of these medications. (With the lack of well-designed clinical research studies, patients should fully review and discuss these options with their physicians.)

Retinoids: These are oral medications which contain a synthetic form of Vitamin A (etretinate). These are the most commonly prescribed drugs used in the treatment of PRP. Examples include Soriatane and Accutane.

Immunosuppressive agents: Another oral agent is methotrexate (Folex, Rheumatrex). These are antimetabolite drugs that impact on cell reproduction.

Vitamins: An increased dosage of Vitamin A has been used by some. However, some consider oral retinoids to be more effective than oral Vitamin A.

Topical: Corticosteroids may provide some patient comfort but are believed to have little long-term if any effect on PRP.

A new classification of topical ointments called TIMS (topical immunomodulators, which work directly on the t-cells of the skin, have been shown to be effective in mild cases of PRP. Protopic Ointment is one of these drugs and there are new ones in development now. These were first developed for use in eczema and later shown to be effective in treatment of psoriasis and PRP.

Unlike steroid creams, there is no limitation on the length of time that they can be safely used.

Antihistamines: Prescription strength antihistamines can be a great relief from the itching that accompanies PRP. The severe itching often causes interruption of normal sleep or insomnia. Your doctor can work with you to come up with the best combination of antihistamines and perhaps a sleeping medication. Rest is critically important for PRP patients so don't hesitate to make your physician aware of anything that interrupts your sleep.

Antidepressants: Whenever one has a disabling and appearance-altering disease, depression is

normal. Your lifestyle has been altered and you can no longer find the energy to do the things you once enjoyed or even work effectively. Antidepressants can help you cope. Talk with your physician about antidepressants and do remember that they often take 3 to 4 weeks to take effect.

ARE THERE CAUTIONS OR CONCERNS ABOUT MEDICATION?

There are cautions and concerns about all medications. Depending on the medication, it is imperative that your doctor prescribe frequent, usually monthly, lab tests. If you are taking a retinoid or immunosuppressant, your liver function and your cholesterol and triglyceride levels may change dramatically so these need to be carefully monitored.

Since many of these medications, as well as the disease itself, may cause you to shed large amounts of skin cells, you should be vigilant about staying well hydrated and also be concerned about the electrolyte levels in your blood.

Your physician can best determine which lab tests you should have and on what type of recurring schedule.

WHAT TREATMENTS SHOULD BE AVOIDED?

Some of the UV treatments that have been successful in psoriasis have shown no benefit for patients with PRP and might, in fact, make it worse. Long-term steroid use, both topically or orally, should be avoided as it only provides comfort measures but can result in very dangerous side effects.

Avoid all newspaper and television claims about "miracle" salves, creams or lotions. If they were that good, your dermatologist would be the first to know.

If you are taking a prescribed retinoid, do not take any additional vitamin supplements which contain Vitamin A. This is extremely important! You are already receiving a near toxic dose and additional Vitamin A could be very harmful.

OTHER CONSIDERATIONS

WHAT LIFESTYLE CHANGES SHOULD I CONSIDER WITH PRP?

Watch out for infections! This is one of the most crucial things to be concerned with. Many of the medications that are prescribed for PRP are either immunomodulators or immunosuppressants. These can make you far more vulnerable to serious life-threatening infections like cellulitis as they slow down the reaction of your immune system. In addition, the vast amounts of skin you are losing have compromised your first line of defense against infection...your skin. Should you see any redness or swelling or begin running an elevated temperature, seek medical help immediately.

Exposure to the sun should be avoided as the damaging UV rays of the sun can only irritate and worsen your PRP.

Avoid all alcoholic beverages! These are contraindicated if you are taking any of the retinoids and will be for a long period of time after you cease taking them. In the case of Soriatane, it is three months. This is because alcohol increases the effect of the retinoid and can cause serious liver damage.

Drink plenty of fluids! You are losing skin cells at an tremendous rate. This means that you are losing considerable body fluid as well. Ask your doctor if you should be drinking a mineral-enhanced bottled water but, whatever you do, be sure that you DRINK!

Get plenty of rest! Exhaustion is a common trait among PRP patients and it is often hard to explain to loved ones how a skin ailment can sap your strength. Just remember that your body is working overtime to produce skin cells at an enormous rate, plus the side effects from your medication factored in, can easily explain why you don't have the energy you once had. If your family cannot understand this, have your dermatologist or primary physician explain it to them.

Eat healthy! Your body is undergoing quite a bit of energy loss through both fluids and electrolytes. A well-balanced diet has never been more important.

Avoid stress! Your body is already stressed and, as in any disease that causes cosmetic changes, your emotions are also stressed. You have been told you have a rare disease and that is frightening as well. Use any relaxation techniques that work well for you...yoga, solitary meditation, music, reading or just take a nap every day. Should the stress seem to be making you depressed, talk to your doctor about antidepressants and let him decide if they are appropriate for your individual case.

Stay warm (or cool)! Your body temperature regulating system is being overworked by losing all those skin cells that are your insulation. You will suddenly be more aware of drafts and find yourself shivering when others are perspiring...and vice versa! Dress accordingly and take all the comfort measures you can. Wear long sleeves in the summer, keep a sweater in the car. You'll soon get used to finding ways to keep yourself comfortable.

WHAT DO I TELL FAMILY AND FRIENDS?

This is often a difficult disease to explain to people because it would be very rare for anyone in your circle of friends and family to have ever heard of PRP. And most people look upon a "rash" as a minor inconvenience. Yours represents a major and debilitating disease.

You must decide what to tell each individual in your circle, based upon how much they need to know and how much they can understand. If you have small children, you need to tell them that you have a disease of the skin and you may not feel like playing with them all the time because you tire easily...tell them that you need some "quiet time" each day and see if you can get them to join you in a nap or quietly read a book. It's very hard for children to understand this change in you but they are amazingly adaptable creatures and most will find satisfaction in doing small chores to help relieve your burden and help them feel more "grownup."

When telling adults or employers, be candid and tell them that it is a rare disease but it is NOT contagious and that you are undergoing treatment and hope to return to your full health soon. But for now, you may need to cut back your activities, even change your working habits or hours, to suit your level of energy.

DISABILITY AND EMPLOYMENT CONCERNS

This is a serious matter that you must take up with your employer. He must understand your limitations and it may require a letter from your physician to convince him of your need for a lighter workload.

If you find that you cannot continue in the type of work you do, check into Social Security Disability Insurance and your employer's disability plan, if you have chosen that option. There will be many forms to fill out but physicians are familiar with them and can do that for you. You may even want to find legal help in the form of a lawyer who specializes in disability claims.

WHY DON'T DOCTORS KNOW MORE ABOUT PRP?

As we noted earlier, this is a very rare condition and this means some dermatologists will never even see a case of PRP during their careers. Because of this, little research is being done on it.

Unfortunately, drug companies have to put their research dollars into diseases that affect a large number of the population or they will not be able to redeem their investment.

But medicine is a constantly changing science and not all therapies are clearly established. New research changes drug and treatment therapies daily and that is to our benefit as often a drug for some other, more common, form of skin disease will show beneficial results in treating PRP.

DAY-TO-DAY CARE and INFORMATION

SKIN

There are many comfort measures and cosmetic measures you can take to help your skin during this time when it's under siege by PRP. Moisturizers are the first line of defense and comfort. Cream moisturizers work best as they can be used twice a day with good results. Lotions need to be applied more often. Some moisturizers contain ingredients to relieve itching and your druggist can help you find just the right one for you. Many dermatologists recommend Cetaphil cream, which can be purchased at places like WalMart. Avoid "perfumed" lotions as they often contain alcohol which has a drying effect.

Again...good fluid intake can help with your skin care. Take lukewarm to cool showers to prevent further drying and avoid long soaks in the tub...they may feel good at the time but they will dry out your skin.

INFECTIONS

Infections, specifically of the skin, are common with PRP because your skin is your first line of defense against germs. The peeling and inflammation leave microscopic cracks in the skin that allow in infection. Your immune system, if you are taking any of the immunosuppressant drugs, no longer has the ability to fight off serious infections, like cellulitis, on its own. At any sign of redness, pain, swelling or fever, contact your doctor immediately or go to your nearest Emergency Clinic.

If you have pierced ears, you may want to take the safe route and not wear earrings during this time or switch to clip-ons. Also be wary of potentially infective chores like cleaning the cat's litter box or cleaning the bathroom toilet. Wear gloves if you must tackle these chores and wash hands frequently.

EYE CARE

Both PRP and many of the medications to treat it can cause severe dryness of the eyes. It's more important than ever to see your ophthalmologist and inform him of your disease and its treatment. Most likely, he will never have had a patient with PRP but he can check your eyes for any side effects like severe dryness and inflammation and vision changes and prescribe accordingly.

EAR CARE

Buildup of shedding skin in the ears is a common problem, along with itching. Sometimes, hearing loss can occur with blockage from the buildup of skin. Do NOT use Q-tip-like swabs of any kind to clean your ears. There are many safe and appropriate ear washes on the market and they come with

safe applicators. If those don't work, a trip to an Ear Nose Throat specialist should be your next step.

FOOT CARE

PRP causes thickening of the nails and it may become difficult for you to adequately manage trimming them yourself. Do avoid ingrown nails or trimming too close because of the risk of infection (cellulitis).

Thickening of the soles of the feet is common and can be very painful. Wear the most comfortable footwear you can find...even if it means bedroom slippers! Keep feet warm and dry at all times. Do not go barefoot and risk infection! Wear white and not colored socks. Apply creams and lotions liberally and use foot soaks to relieve discomfort and help slough off excess skin cells and calluses.

HAIR

PRP can cause thinning of all the hair anywhere on the body. This is both appearance altering and depressing. In addition some medications, such as retinoids and immunosuppressives, can cause hair loss to one degree or another. It differs with each individual. Some only have mild thinning; some lose all their hair, including eyelashes and eyebrows. Just remember, our collective experience suggests that it will grow back!

Keep your hair clean and, if you lose a large amount, look into the possibility of purchasing a wig for those times when you must go out in public. Wigs can be found online in almost every style and color and the prices are very reasonable... anywhere from US\$29 to US\$79 for a washable fully styled wig.

NAIL CARE

You may find that your nails have a tendency to split and shred and feel weak and thin, both because of PRP and the medications you may be taking. Keep your nails trimmed close to the tips of your fingers...once they grow beyond, they are more vulnerable to damage from doing everyday chores.

Find a good nail hardening polish like Sally Hanson's Hard As Nails. Use it often to help prevent further damage. Do NOT use artificial nails at this time in your life, even though the temptation is great. You would be very vulnerable to infection from the type of grinding and treatments necessary to have artificial nails.

EMOTIONAL CONCERNS

There are so many to cover under this heading. Our emotional health is every bit as important as our physical well-being and you cannot separate the two. When you are dealing with any disease, it is difficult to be your natural optimistic self, but when you are dealing with an appearance-altering and physically debilitating disease like PRP, it's many times more difficult.

Find your support system...it may already be in place. Talk with the friends and family members you can trust to best understand your ordeal. Watch for signs and symptoms of depression and have others watch for them also. Seek counsel from your doctor about medications if the feelings of depression cannot be shaken off and become a burden to you.

Always remember that you are not alone. There are many of us out here with PRP and we are all going through the same experiences that you are. Joining this support group and sharing the pain and the problems is of utmost importance. Only someone who has walked in your shoes, can understand how you feel.

SWEATING

You may suddenly notice that you are not perspiring anymore, even in hot weather! This is a symptom that many PRPers experience and the cause is not certain but is probably tied into the fact that you are already losing much of your body's moisture because of the shedding of your skin. Perspiration keeps the body's temperature regulated and so not perspiring can make you less heat tolerant. And the amount of skin and "insulation" you've lost can make you less tolerant to cold.

With the loss of sweating, please use appropriate caution if you exercise or if the air temperature is very warm.

BODY TEMPERATURE CONTROLS

As stated above, this is a difficult balancing act with PRP. Most PRPers complain of cold. Many cannot tolerate air conditioning in stores and theaters and even develop chills when exposed to it. Dress accordingly and always have an extra sweater or jacket with you and keep a blanket in the car. Even on a hot July day when the rest of your family is enjoying the a/c in the car, you may find yourself wrapped in a blanket!

ITCHING

Did you ever think of itching as being anything more than a nuisance occasionally? And now you find it quite painful? This is a common symptom of PRP. The best relief can be found in antihistamines, antidepressants, and creams and lotions that contain camphor or other ingredients to soothe the itch. Avoid scratching! It can lead to infection! Avoid long soaks in the tub! They can

dry your skin! Warm to cool showers and lavish amounts of creams and lotions, along with whatever medications your doctor prescribes, are the best relief.

PEELING

You may find yourself (or your helpmate) permanently attached to the vacuum cleaner! Some PRPers literally leave a trail of dead skin flakes wherever they go. This is not the time to wear that little black dress or that charcoal gray suit! Peeling can be an embarrassment but do remember that the peeling is helping you shed those plaques that make up PRP and it is helping you grow new, hopefully clear, skin.

DIET

Eat healthy! No dieting for now because your body needs nutrients to replenish those that you are losing through your skin. Go heavy on the vegetables and fruits and fresh foods. Avoid salty items like potato chips which can cause edema and have no nutritional value. Eat plenty of lean meat to be sure you are getting adequate amounts of protein. If you feel you need professional help and advice about nutrition, consider visiting a nutritionist. But do take along information about PRP because chances are slim to nothing that he/she will have ever heard of this disease. You might even want to print out the information in this article and mail it to both the nutritionist and your other physicians, like eye and ENT, before your next visit.

SUN AND UV EXPOSURE

Avoid the sun at all costs. The ultraviolet rays of the sun are damaging to healthy skin. Just imagine what they can do to your already reddened and thin PRP skin. Wear long sleeves if you must be outside for any length of time. Some travel catalogues even carry shirts and pants that have UV protection if you have to spend extended time outdoors. Wear a hat! If driving in the car, be sure that you have something to cover up with if the sun's rays are hitting your skin.

Always remember, if you can see the sun, the sun can see you!

CHILDREN

Children with PRP are a special concern and often misunderstood group. Their peers cannot be expected to understand the significance of their disease and their parents often need help with the pain they feel watching their child go through the trauma of this disease and its various treatments.

The first line of defense is a good pediatrician who, hopefully, has knowledge of PRP. He and your child's dermatologist can work together to best work out a treatment regimen for your child and help you deal with the problems inherent to both the disease and the treatments.

There are members of the PRP Support Group who have small children with PRP. Do let us know your situation and we feel certain that someone with similar problems will be in touch with you.

• **NOTE TO PHYSICIANS & HEALTH PROFESSIONALS**

With early PRP symptoms many patients are commonly misdiagnosed leading to possible inappropriate or useless treatments. This can be confusing and frightening for many. We have seen and heard from many PRP Support Group members about these concerns. Please do not neglect or underestimate the emotional toll of these circumstances and these symptoms.

Further, we strongly encourage that a PRP diagnosis be independently confirmed when possible. Other serious conditions mistakenly diagnosed as PRP have included Sezarys syndrome and Cutaneous t-cell lymphoma.

A comprehensive PRP bibliography is now available for your use on our Support Group web page →→
www.prp-support.org

Physicians and health professionals are also invited to benefit from the collective wisdom of our Support Group. Your questions and comments will be useful to our effort. Further, we encourage those who are interested to conduct needed basic and clinical research regarding the cause and treatment of PRP.

• **IN CONCLUSION**

Please keep in mind that this article is not intended, in any way, to replace the wisdom and advice of your physicians. It is merely an attempt to present an overview of PRP and to answer some of the most frequently asked questions about this rare disease that you have suddenly been confronted with.

You are not alone. We have all shared your symptoms to greater or lesser degree and are here to support and guide you.

We hope this information has helped to answer some of your questions and concerns, and we welcome YOUR comments and suggestions for additional topics we may have neglected to address.

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