# The Ultimate PRPer: PRP with PRP

# **Pre-Emergent & Emergent Phases**

It is a year ago this month that I started on my medical treatment for PRP.

The following is a brief summary of my PRP experience and the acitretin drug Neotigason.

I have used Richard Greene's admirable guide to the <a href="Phases of PRP">Phases of PRP</a> to help structure/document my experience.

I have included some of the photo's taken throughout my journey in order to help you compare the severity, or otherwise, of my condition and its response to the treatment, with your own.

## **PR-EMERGENT PHASE**

I am a 69 year old male. I live in England. My PRP is typicalish, I assume Classic Adult Onset (Type I), triggered by stress? My only known skin problem prior to PRP had been a nasty heat rash if I exposed my arms/torso to a lot of sun when on holiday. For many years therefore I had used sun screens and/or covered up.

## **EMERGENT PHASE**

#### October to December 2010 (3 mos)

A small rash started on my chest, gradually worsened and eventually spread over my entire body.

I was misdiagnosed by four different doctors. First it was eczema, then pityriasis rosea, then possible allergic reaction, then infected eczema before PRP was eventually diagnosed on January 4, 2011.

#### TREATMENT(s):

Not all at once

- \* Betnovate
- \* Dermol Lotion
- \* Antihistamines
- \* Prednisone steroid tablets
- \* Daktacort
- \* Hydrocortisone cream, chloramphenical eye drops BP
- Emulsifying creams
- \* Vaseline

#### **OUTCOME:**

The condition continued to get worse.

## **Editor's Note:**

The following PRP Profile has been authorized for publication by Philip Richard Popham (PRP) to chronicle his journey with PRP. Kudos to Philip.



12/2010 - The rash is spreading



01/2011 - Getting red all over



01/2011 - Red spreads downward



01/2011 - Fewer islands of sparing

# INTENSE PHASE January to March 2011

During this two-month period, I experienced many of the symptoms familiar to you all, i.e., islands of sparing slowly disappeared, my whole body was turning red, my skin shed continuously – I was raw and so very itchy, legs/ankles were swollen, nails thickened and yellow, thick/cracking skin on soles of my feet, some hair loss, no body temperature control, etc. PRP diagnosis confirmed by a second Dermatologist on 8 February 2011.

### TREATMENT(s):

Neotigason – 10mg tablets (a retinoid drug that contains the active ingredient acitretin)

My treatment started on 8/2/2011. Initially set for a period of 8 weeks. Dosage during this phase was:-

8/2/11 - 22/2/11 (2 weeks) – 10mg per day

23/2/11 - 7/3/11 (2 weeks) – 20mg per day

My other medication/treatment consisted of:-

- \* Antihistamines: Fexofenadine hydrochloride (180mg max.) for day; Hydroxyzine (20mg) for night;
- \* Hair shampoo: Nizoral (Ketoconazole) 2%;
- Emollient: Aveeno Body Lotion; Aveeno Intensive Body Wash;
- ★ Chloramphenical Eye Drops BP.

### **OUTCOME:**

Alcohol was to be avoided. I was told I would see an improvement in six weeks. Shedding of skin continued and increased even more after starting the Neotigason. Scale shedding in my eyes continued as did the itch and rawness. I was initially applying emollients five times a day/night but reduced this to three after changing to the Aveeno products. I also used Aveeno Lotion around my eyes instead of Vaseline.



02/2011 - It's all red and rash



01/2011 - Skin sheds continuously



01/2011 – Soles harden and crack



01/2011 - Palms harden and skin sheds

# **EARLY RESOLUTION PHASE**March to April 2011

During this two-month phase, I started to see and feel some improvement. The red skin on my upper body lightened in colour, the rash and the itching reduced slightly, but the shedding continued unabated. The hard skin on my hands and feet had gone, and soon I was only applying the emollient once a day. The swelling of my feet and ankles reduced, but the red colour, rash and shedding continued its movement downwards.

TREATMENT(s): My course of Neotigason continued as follows:-

- \* 8/3/11 30/3/11 (3 weeks) 20 mg per day
- \* 31/3/11 3/5/11 (5 weeks) 10mg per day \*\*

Other treatment/medication remained unchanged.

#### **OUTCOME:**

\*\* Possible Neotigason side effects - I noticed that my eyes became dry and scratchy first thing in the mornings and watered more in bright light. My daily dosage was therefore reduced to 10mg.

Despite this minor side effect, I was extremely pleased in the way my condition began to improve. As a result, only two months after starting treatment, I was able to have my first haircut in over four months and resume a number of outdoor activities, i.e., gardening and golf. My dermatologist prescribed Sun Sense Ultra SPF50 for protection against the sun and I experienced no major problems with cautious sun exposure.



# **CONTINUING RESOLUTION PHASE:** May to August 2011

Throughout this four-month phase, the initial improvement in my condition continued unabated. My skin colour became more normal, the skin rash almost disappeared, and as result, the itch and shedding stopped. The only minor set back was an ankle rash that would occasionally appear after wearing close fitting socks.

- May 2011 The rash reduced considerably and my skin regained a more normal colour by June 2011
- \* July 2011 An occasional ankle rash would last a few days whilst ... August 2011 some face rash persisted

# TREATMENT(s)

My course of Neotigason continued as follows:-

- \* 4/5/11 26/7/11 (12 weeks) 10 mg every other day
- \* 27/7/11 3/9/11 (6 weeks) 10 mg per week then medication stopped completely.

Other medication/treatment now mainly consisted of Aveeno wash for showering, occasional use of the Nizoral hair shampoo and some Aveeno Body Lotion to my upper body and face, as and when required.

#### **OUTCOME:**

My condition improved considerably over this period. Neotigason dosage was reduced and in September was stopped altogether. The only signs that I had ever had a skin condition were a few small, round dry areas on my face, upper arms, chest and back and a number of small plugs over skin pores/hair follicles. Nails to hands and feet were back to normal but body temperature control was not – still no sweating.



May 2011 - The rash reduced considerably and my skin regained a more normal colour by June 2011









July 2011 - An occasional ankle rash would last a few days whilst ... August 2011 - some face rash persisted



# **FULL REMISSION/CLEARING PHASE**September 2011 to February 2012

During this six-month period, there has been a continuing, if slight, improvement. The only signs of any skin problem are a few blemishes/rash on my chest and face, an occasional itchy scalp and, strangely enough, itchy sideburns. The rest of me looks and feels normal, and I even started sweating again.

#### TREATMENT(s)

No medication, Aveeno Oil for showers, occasional Nizoral shampoo for my hair if my head feels itchy, and Sun Sense Ultra SP50+ lotion if I'm out in the sun for any length of time.

#### **OUTCOME:**

I look and feel normal. My only negative experience during this period has been during a recent holiday to the Middle East when the slight rash on my chest reacted to the heat and sunlight. My legs, arms and face, however, were far less sensitive.

#### **CONCLUSION(s):**

I do not believe that I am completely cured yet. I do, however, believe that I am fortunate enough to be in the 50% of PRP patients who "respond to systemic retinoids" (see Dr Andrew Griffiths' paper/Dowling Oration 2003 on our PRP website). This paper also states that "in those who do respond, reducing or stopping the retinoid is not followed by a relapse, so it appears that retinoids do shorten the course of the disease." In my case, Neotigason relieved the symptoms, improved my condition within two months, led to a substantial improvement within six months from starting treatment and, since stopping the treatment five months ago, has not yet resulted in any significant relapse. I hope, therefore, that it will have truly shortened the "course of the disease" for me.



02/11/2011



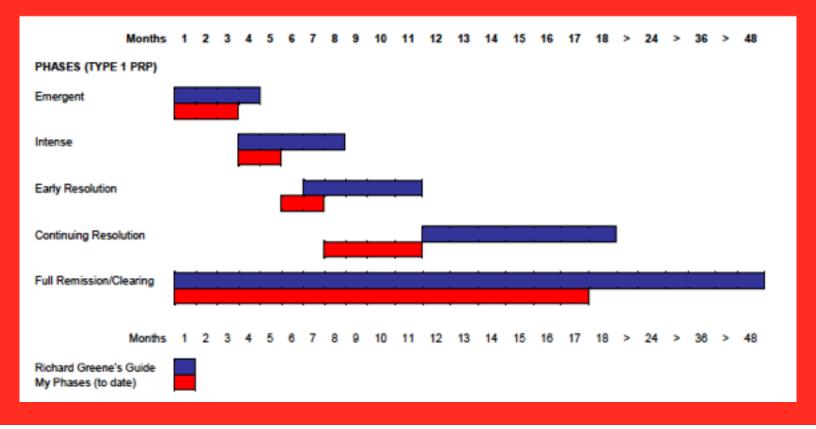
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In the diagram above I have tried to compare the timescale of my phases with those given in Richard Greene's guide. It is subjective but I hope it graphically conveys my 17-month journey to date.

I am also aware that, in my case, I was fortunate enough to be treated by a dermatologist who had some experience in treating PRP. He believed that the treatment timescale and the dosage should suit the individual patient (i.e. age, weight, general health etc.) and not just be based on the drug manufacturer's guidelines. He also felt that the treatment program should be flexible and give the patient some form of control. He said that if I wanted to reduce dosage, or stop taking the drug, for a day, two or more, he had no problems with it. It was not necessary to consume as much of the drug as possible within a specified time limit. If the daily dose is reduced the overall timescale can easily be increased to compensate (it's a marathon not a sprint).

As a result, during what turned out to be a six month course of Neotigason, I actually took the drug on 125 out of the 205-day period. My total dosage was some 1,700 mg which gives an average of 8.3 mg per day. If the six-week period when I was slowly coming off the drug is excluded, the period is 163 days, the dosage is 1,640 mg which gives an average of approximately 10 mg per day.

Compare this with the 35 - 50 mg discussed in Dr. Griffiths' paper, and the 25 to 30mg starting dose and 75 mg per day maximum permitted dose as given in the Neotigason literature. My low dosage may be one of the reasons why I only had some very minor side effects.

My dermatologist also said at the outset that the disease/ treatment cycle could be likened to a bouncing ball, (i.e. treat the PRP, it can bounce back, treat the PRP, it can bounce back again but less severe, treat it again, etc. etc. until the bounce is no more, the ball rolls smoothly and hopefully one is cured). Given that an indicative overall timescale for Type 1 PRP in Richard Greene's Phases guide is two to four years, I am very mindful that in the 17 months since my PRP reared its ugly head, I have really only had one bounce to date and that my PRP could therefore return. If it did, I would have no hesitation in resuming my Neotigason treatment, as I firmly believe that it has had a beneficial impact on the overall timescale and speed of my healing.

Like other members of our support group, I am most grateful for all the suggestions and advice that is offered, be it medical or non-medical. I use baby shampoo on my hair and avoid applying deodorants, after shave etc. to my skin. My diet has not changed and I'm glad to say that I have not lost the taste for a wee dram. I wish you all the very best in your respective journeys and hope that our collective attempts to deal with this orphan disease will one day prove beneficial.

I will certainly try to continue and play a part.

Philip Richard Popham (PRP with PRP)