

MEMORANDUM

TO: Her Majesty's Courts and Tribunal Service
FROM: Bill McCue, President, PRP Alliance, Inc.
SUBJECT: Stewart Ian Littlejohn
DATE: January 21, 2019

The following information is submitted to Her Majesty's Courts and Tribunal Service in support of Stewart Ian Littlejohn's assertion that he "be assessed as having a limited capability for work." Consequently, until he is able to return to the workplace, Mr. Littlejohn should be awarded Employment Support Allowance.

1. On the issue of perspectives

As the founder of the PRP Alliance, editor of the *PRP Survival Guide*, an Administrator of the 1,453-member PRP Facebook Support Group, and a PRP patient in remission, I have been asked by Mr. Littlejohn to provide a third-party perspective regarding the challenges to body, mind, and spirit associated with pityriasis rubra pilaris and his re-entry into the workplace.

- * The "*first-party*" perspective would be Mr. Littlejohn's own words – his personal commentary on the daily ravages and rigors of PRP already shared with the Court and panel in the form of documents. It should also be noted that virtually no quality-of-life research has been published by dermatologists regarding PRP and the capacity of employable PRP patients to work. Therefore, the insights and observations of Mr. Littlejohn should be given appropriate consideration. He is, in fact, a subject-matter expert when it comes to living with PRP.
- * The "*second-party*" perspective" reflects the periodic observations of specific healthcare professionals who have treated Mr. Littlejohn since the onset of symptoms in May 2017. These observations include his ever-evolving treatment protocol and unpredictable progress, a perspective consistent with Mr. Littlejohn's patient narrative.
- * The "*third-party*" perspective is that of the PRP Global Community as represented by the PRP Alliance, Inc., the PRP Facebook Support Group (1,454 members), the PRP Community on RareConnect (308 members), and the PRP Global Database which currently maintains 1,782 PRP patient profiles.

2. PRP is not psoriasis

With a prevalence of one in 400,000, there are an estimated 164 patients under treatment for PRP in the United Kingdom. In contrast, there are 1.8 million patients in the UK currently diagnosed with some form of psoriasis. It should be noted that the most common misdiagnosis of pityriasis rubra pilaris is, in fact, psoriasis. What should this mean to the Court and panel?

- * Care must be taken not to conflate the specific PRP-related challenges impacting Mr. Littlejohn with the more generic challenges of psoriasis. With such a limited global patient population, PRP suffers from a dearth of research focusing on the impact of PRP on the daily challenges of body, mind, and spirit. Mr. Littlejohn's testimony should, therefore, be given appropriate consideration.

3. PRP is a journey – unique to each patient

When the symptoms of PRP first appear, there is no test to predict the severity and progression of symptoms, elapsed time between onset and remission (if and when remission occurs), the appropriate treatment protocol, and when the capacity to work is possible. Today, Mr. Littlejohn and the other 163 PRP patients in the UK must proceed one day at a time. Each patient – and their carers – await a series of healing milestones to indicate progress, e.g., the cessation of pain and itch, the ability to walk, sleep through the night, and even sweat. And for those who can – the capacity to work. The loss of income has a profound impact. What should this mean to the Court and panel?

- * The global PRP community has a mantra regarding treatment options: "What works for one doesn't work for all." It is important to view Mr. Littlejohn's PRP journey as unique rather than common.

4. The impact of PRP on the capacity to work

According to the PRP Global Database, two-thirds of the PRP patient population report onset between the ages of 16 and 65 – the age range of employment in the UK. Conversely, patients with onset before the age of 16 and after the age of 65 account for only one-third of the patient population. What should this mean to the Court and panel?

- * PRP and employment are incompatible until the symptoms sufficiently resolve. With rare exception, the onset of PRP heralds the loss of income and the incapacity to work.

5. PRP is a full-time job

Prior to the onset of pityriasis rubra pilaris (PRP) in May 2017, Mr. Littlejohn was self-employed as a chauffeur. As the severity of the symptoms progressed, he had to abandon his successful business and focus on the day-to-day management of his inflamed skin and its escalating impairments to mobility (feet), dexterity (hands), vision, hearing, energy, and mental wellness. Add to those challenges the side effects of oral medications and daily regimen of ointments and other topicals. What should this mean to the Court and panel?

- * Skin is our largest organ. The average adult carries 3.6 kilograms and two square meters of skin. Please do not under-estimate the auto-inflammatory impact of PRP on Mr. Littlejohn. The debilitating impact of PRP cannot be overstated.

6. PRP is an ultra rare skin disorder

The Genetic and Rare Disease (GARD) information Center has identified over 7,000 rare diseases of which 597 are rare skin disorders. PRP is just one of the 597. What should this mean to the Court and panel?

- * It is estimated that 19 out of 20 dermatologists will never diagnose and/or treat pityriasis rubra pilaris during their career in medicine. Conversely, the one in 20 who do diagnose and/or treat a PRP patient will see a unique version.
- * Statistically, there are 109 PRP patients in the UK who are in the age range of 16 to 65. Those who were employed prior to the onset of PRP stopped working for an indeterminate period of time. For most PRP patients diagnosed with Adult Onset PRP, their journey ends in less than five years. There are some, however, where the inflammation lingers or returns.
- * For the present, Mr. Littlejohn's PRP journey continues. One day, however, his PRP journey will be over and he will no longer need Employment Support Allowance assistance. He will once again drive passengers from Portsmouth to London Heathrow.

I respectfully ask the Court and panel to determine that Mr. Littlejohn has a limited capacity to work.