



# *Nodular Prurigo International*

*Information and support for anyone affected by nodular prurigo*

Dear Doctor,

We are a worldwide support group, with over 1000 contributors, hosted on the Facebook social media site. As the members of this group, we ask that you take a moment to read the following so that you may be able to better help your patients and anyone else diagnosed with nodular prurigo/prurigo nodularis (NP), who may come under your care.

We are sure you understand that NP is a very difficult condition to diagnose and treat. After 117 years since Montgomery and Hyde first described this condition, we are no further forward in fully understanding its aetiology or able to find effective treatments or a cure.

On a day-to-day basis within our group, we read of the devastating effect that NP has on people's lives. Most suffer with this chronic condition for many years and a significant number have to wait a considerable time before they even acquire an accurate diagnosis. We put this down to the difficulties some physicians have in diagnosing this somewhat rare condition. This leads to a degradation of the physical, psychological, social and economic status of many individuals.

The stigma created by any skin conditions is well reported in the research, and it is therefore unsettling that some of this stigma is reinforced by the very medical staff that is charged with supporting patients. We are clear that many doctors downgrade the symptoms and effects of NP and in some instances put the responsibility on the patient for the continuation of symptoms because of their desire to scratch. In some rare instances the term 'Picker's Disease' is still stated, the very early root of this stigmatisation.

We consider this unfair, unhelpful and anachronistic. Let us be clear from practical knowledge, that the itch associated with NP is on a scale which far exceeds the 'normal' types of itch resulting from skin irritation or trauma that are commonly experienced by most of us. Added to this, the relentlessness of irritation has a profound psychological impact. We need every physician to accept and recognise this fact and treat patients with consideration and compassion. With the effectiveness of most of the available classical treatments being poor to ineffective, it is even more appropriate that psychological support for patients should take high priority.

As with many rare conditions which do not point to a profitable end result for the pharmaceutical industry, there is little reason to engage in the research and development of more effective treatments. Neither, it would appear, do academic researchers seem to have much interest in the subject. Although we applaud the research that has and is being done, we consider we are being failed by both industry and the medical profession.

As a self-funded organisation receiving no financial or charitable support, we can do little to redress this balance. We can only hope that with understanding you may at least use whatever standing you have within your professional life, to influence an agenda which may take things forward. We are sure that you have the best interests of your patients at heart and hope that you can help us in this regard.