

Q6: How do you treat Erythropoietic Protoporphyrin (EPP) patients with ultraviolet phototherapy?

A: Generally treat as if for Polymorphic Light Eruption (PLE) - although because the treatment does not cause the photodermatosis, as it so often does with PLE, patients usually continue on higher increments for longer. In some circumstances longer courses (20 treatments instead of the "standard" 15 for PLE) appear to give enough extra benefit that the longer course is worthwhile.

There is no greater risk of burning than in other conditions. Many with EPP are worried that it might cause EPP phototoxicity. The small amount of visible light that unavoidably accompanies the ultraviolet-B (UVB) from a narrowband (NB)-UVB lamp is rarely sufficient to cause a problem. Individuals with EPP have increased levels of Protoporphyrin-IX which absorbs long wavelength ultraviolet-A and visible light and not ultraviolet-B (UVB).

As with UVB for other conditions, ordinary UVB sunburn can occur but this is not a particular problem: in fact EPP patients experiencing sunburn can be almost pleased as they have never had normal sunburn before because the pain of EPP phototoxicity (caused by the larger proportion of accompanying visible light and long wavelength UVA with sunlight) has usually prevented them ever having been exposed to sufficient UVB from natural sunlight to cause an ordinary sunburn. Sometimes they have assumed that people experiencing "ordinary" sunburn must feel something like they themselves do with EPP phototoxicity and have wondered how other people don't find a sunburn so bad. If EPP patients experience "ordinary" UVB sunburn for the first time they understand how mild the symptoms of an "ordinary" sunburn are compared with the severe, and longer lasting, pain of EPP phototoxicity.

It is recommended to wear appropriate clothing during treatment as it seems wise not to treat body sites not requiring treatment. This also reduces the theoretical risks of long term adverse effects from ultraviolet therapy. Try to schedule therapy appointments early or late in the day when visible and long wavelength ultraviolet-A light levels are lower.