

Painful Light Intolerance since Childhood?



Think

Erythropoietic Protoporphyrin (EPP)!



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Hello! My name is Heme! I am also known as the red blood colour.

I transport the oxygen in your blood!

Unfortunately, I have a lazy brother...

His name is Pret O' Porphyrin.

Too much Pret* in your blood means you suffer from the disease EPP.

Only 1 person in 100'000 is affected.

*Protoporphyrin

...which turns him radical...

Burn! Oxygen, burn!

and makes him a nasty pyromaniac.

When Pret gets too much blue and red light, he thinks of himself as enlightened ...

After a few minutes in the light, neuropathic pain develops ... which however usually does not lead to immediate visible symptoms.

Pret really is a big pain in the ... nerves

Therefore, every EPP patient tries to avoid visible light...However, 100% protection and living completely without light is impossible.

An efficient and safe drug for EPP was approved in 2014.

However, due to excessive regulatory requirements, it has not reached the sufferers yet.

April 11th, 2016: EPP patients protesting in Canary Wharf, London

The patients therefore organize demonstrations, start online petitions, get media attention and hopefully soon will convince the regulators to enable them to live a normal life.

...to be continued.

Pictures by: Jasmin Barman-Aksözen

Dr. Jasmin Barman-Aksözen
Molecular biologist, did her PhD by investigating gene regulation in EPP, the disease she is affected from.

Elke Hauke
Dedicated patient advocate. Has a now adult daughter affected by EPP, who was able to complete her studies thanks to the treatment.

Dr. Rocco Falchetto
Started an online petition to make the drug available to sufferers in Switzerland. He was one of the first patients receiving the treatment in 2006.