

Light for Everyone – Please make the only treatment for the rare light intolerance disease EPP available!

The ultra-rare genetic defect EPP forces us to a life in darkness and pain. We EPP sufferers demand access to the only treatment for our condition, which was already approved over two years ago!



A genetic defect, in which light is an enemy

In EPP (erythropoietic protoporphyria), only a few minutes of light exposure are sufficient to trigger a phototoxic reaction which causes severe burns inside the blood vessels, leading to excruciating pain which does not respond to any known painkiller and can persist for days. EPP sufferers therefore avoid all light sources, which leads to massive restrictions for them and their social environment. However, living completely without light is not possible: EPP sufferers would only be safe in a dark cellar! We therefore endure not only light deprivation but also frequent episodes of excruciating pain since childhood, leading to social isolation, depression and despair. As if that weren't bad enough, about 5% of patients develop potentially fatal liver failure as a consequence of the genetic defect.

Light at the end of the tunnel

Until recently, no treatment for EPP existed. As EPP symptoms are triggered by the visible light spectrum, sunscreens and other UV-protection measures are useless in this condition. 2014 however, the new active substance «afamelanotide» was approved in the EU for treatment of adult EPP sufferers. EPP patients receiving the treatment during the clinical trials and special access schemes were able to spend hours in direct sunlight and started an almost normal work and social life! Very importantly, the approval for adults will also enable the development of a formulation to treat children, the most vulnerable and severely affected group of EPP patients.

Waiting in the dark


In Germany, patients affected by rare diseases with no alternative treatment are typically granted access to newly developed drugs for their condition right after approval. In EPP however, the access to «afamelanotide» has been delayed and experienced all kinds of obstacles over and over again. As the treatment is available on a regular basis in the Netherlands since June 2016, we know that no fundamental obstacle exists to treat patients. Of additional concern is the fact that the three medical EPP centres in Germany will only be able to treat a small portion of the 400 German sufferers.

Germany is one of the reference nations for orphan-drug availability. Therefore, we hope that access in Germany will also have a positive impact regarding accessibility of «afamelanotide» in other European countries, who are facing similar obstacles.

The German patient organisation «Selbsthilfe EPP e.V.» therefore requests an investigation by the appointed member of the German parliament for patient relations of the Ministry of Health, Karl-Josef Laumann, to clarify the reasons for the continued delays and with the aim to make the treatment available by next spring – the most challenging time for EPP patients. In order to make our voice count, representatives of «Selbsthilfe EPP e.V.» should be actively involved as equal stakeholder in every step of the investigation.

Please support us to bring light in our life!

Living in the dark and in pain knowing that a treatment exists is unacceptable. Please support us to live the normal and rich life we deserve.



Elke Hauke

1. Chairwoman Selbsthilfe EPP e.V.



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Link to the petition: «Licht für Alle - Therapie für die seltene Lichtkrankheit EPP endlich zugänglich machen!»:

https://www.change.org/p/patientenbeauftragter-der-bundesregierung-karl-josef-laumann-licht-f%C3%BCr-alle-therapie-f%C3%BCr-die-seltene-lichtkrankheit-epp-endlich-zug%C3%A4nglich-machen?recruiter=39596823&utm_source=share_petition&utm_medium=copypink

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Homepage of the German EPP association: www.epp-deutschland.de

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www.aufdermauer.photo