Access to orphan drugs

The case of the ultra-rare light intolerance erythropoietic protoporphyria (EPP)
EPP is a very rare genetic condition in which even brief exposures to sunlight and artificial light sources trigger severe
and extremely painful phototoxic reactions in all exposed skin areas. Unlike in most other rare diseases, an approved
therapy exists which enables patients to live an almost normal life. Swiss patients were the first EPP sufferers testing
«afamelanotide» in clinical trials and played a crucial role in the EU approval. Until 2016, most Swiss EPP patients
had access to the treatment at a subsidised price, reimbursed by health insurers. However, as a commercial price was
introduced last year, many health insurers stopped treatment reimbursement, forcing patients back into a life in pain
and darkness.
The seminar will address scientific, legal and ethical aspects of the case as an illustration of the challenges in orphan
drug access.

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