

Lundi 16 octobre 2017  
12h15 - 13h30 | Hôpitaux Universitaires de Genève  
salle 3-797, 3ème étage (Bât. C, biblio ORL)

## 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.*

Dr Jasmin Barman  
Stadspital Triemli, Zürich

Carole-Anne Baud, MLaw  
Doctorante à l'Université de Genève

the photograph: Daniel Aufdermayer [www.aufdermayer.photo](http://www.aufdermayer.photo)

