

Minutes of DNA repair and photosensitivity disorders Gp Meeting
on 11 Decembre 2025
during ERN skin Board Meeting

Present

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Paul Ulrich from Regensburg (Mark Berneburg)
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Guidelines:

Xeroderma pigmentosum
Translation of the french recommandations and proposal of the creation of a common document with the team from London (UK)
Document has been created and has to be sent to the group.

Other guidelines to be developed or update
TTD, albinisms, congenital poikiloderma

Photoprotection

Collaborative work with Suzanne Pasmans, presentation during the last meeting on DNA repair in Regensburg.

Questionnaire distributed among participants of the congress in Regensburg.

A draft has been written (S Pasmans and N Vidojkovic) and shared among the members of the group

Evaluation of photoprotection advice given by medical teams for nucleotide excision repair defects: an international, cross-sectional questionnaire study

Review:

First step : TTD meeting held in 2023.

A phenotype-genotype study of TTD patients is being conducted based on a literature review and the collection of TTD cases.

The collection of patients from across Europe is ongoing.

A draft document will need to be shared among the group members.

Registries:

Data on the epidemiological and dermatological features of **albinism** are limited.

Discussion on the feasibility of a collaborative, registry-based epidemiological and clinical study on albinism.

Interest of translational collaboration for this purpose (ophthalmologists, neurologists)

Training :

Didactic clinical presentations have to be prepared → need specific discussion during a next meeting to choose specific situations

Organisation of meetings

Next International meeting on DNA repair disorders will be held in Rotterdam (2025)