



Emergency contacts

Name: Phone:
Name: Phone:

Medical contacts

Name (GP/pediatrician): Phone:
Name (specialist): Phone:
Rare disease reference center: Phone:

ERN SKIN
logo

RARE DISEASE

Patient
photo

Emergency card

Xeroderma Pigmentosum

Patient first name: family name:
Date of birth:

! Caution: my skin is very sun sensitive

Reference Center logo

XERODERMA PIGMENTOSUM (XP)

XP is a disease characterized by a very high sensitivity to ultraviolet (UV) and a 10 000-fold increased risk of skin cancer.

Sun-exposition might be followed by severe burns (50% of patients) and damage to exposed surfaces of the eyes with loss of vision and ocular cancer. The combination of an inherited inability to repair UV-induced DNA damage and environmental exposure to UV must occur for cutaneous and ocular symptoms to develop.

Progressive neurodegeneration is present in 25% of patients

There is no cure for XP, but many of its manifestations may be reduced or prevented through consistent UV protection

Measures/acts to be avoided:

Sun exposure

UV exposure

Recommended care measures

- Use of low UV lighting:
- Shield florescent, incandescent or LED bulbs

- Special UV-blocking clothing

- Sunscreens UVA and UVB blocking

- Using UV meters to determine safe areas in new environments

See also **DISEASE-SPECIFIC EMERGENCY CHARTS**