







## XERODERMA PIGMENTOSUM (XP)

Xeroderma Pigmentosum (XP) is a rare genetic disorder that causes a problem with the body's ability to repair DNA damage in cells. In XP the primary source of cell damage comes from exposure to ultraviolet (UV) light. Most UV comes from sunlight, but damage can also come from toxins, such as cigarette smoke. In XP patients, this damage is not repaired and builds up over time.

#### How common is XP?

XP is rare. It affects about 1 in a million people; approximately 350 Americans live with XP. It is more common in Japan and some other isolated populations.

#### What happens when people with XP go into the sun?

In some types of XP, even minimal exposure can cause serious burns. People with XP are 10,000 times more likely to get skin cancer. They do not "melt," and being exposed to the sun does not trigger death.

#### What are some other problems associated with XP?

Some people with XP have problems with vision. Others experience hearing loss or cognitive delay. Dry skin and freckling are common.

Can exposure to sunlight shrink the brain of a person with XP? No. Some types of XP include neurological decline, but these problems are not associated with exposure to sunlight, and the loss of function happens slowly over time.

### Can you catch XP? Is it contagious?

No. XP is a genetic disease that is inherited. Both parents carry a copy of an XP gene in their DNA, but do not have XP themselves. Most parents do not know they are carriers. The child of 2 XP-carrier parents has a 25% chance of being born with XP.

#### Is XP fatal?

If diagnosed early, individuals with XP can protect themselves from UV exposure, which will limit deadly skin cancers. Some types of XP (particularly those with neurological complications) do have a shortened life expectancy.

# Do people with XP have to be locked inside all day? No! People with XP have to be careful to protect themselves from sunlight, but with protection like a hat, gloves, and hood, are

able to go outdoors and

do most activities other

Can I support people with XP?

people do.

Yes! Consider supporting the XP Family Support Group, which strives to create awareness and educate the public about XP, as well as to raise funds to promote research. create collaborations with international XP partner organizations, and provide family grants for UV protective equipment and travel assistance for attending the annual XP national convention.



XPFamilySupport.org