ANNUAL
REPORT
2001-2002

XP SUPPORT GROUP
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WHAT IS XERODERMA PIGMENTOSUM

Xeroderma Pigmentosum (XP) is a rare genetic disorder that causes extreme sensitivity to the sun's ultraviolet rays. Unless patients with XP are protected from sunlight, their skin and eyes may be severely damaged. This damage may lead to cancers of the skin and eye. XP has been identified in people of every genetic group all over the world. There are about 100 cases in the UK, many of which are undiagnosed.

Causes

Ultraviolet light damages the DNA in cells and disrupts normal cell functioning. DNA (deoxyribonucleic acid) within in our genes contains all coded information needed to direct cell functions.

Two factors combine to cause the abnormalities in XP. First, a person inherits traits from each parent which, when combined, lead to an unusual sensitivity to damaging effects of ultraviolet light. Second, exposure to the sun, which contains ultraviolet light, leads to changes in the skin and eyes.

Damaged DNA is mended by the DNA repair system. But the DNA repair systems of people with XP do not function properly. As a result, un-repaired DNA damage builds and causes cancerous cell changes or cell death.

Symptoms

Many persons with XP get an unusually severe sunburn after a short sun exposure. The sunburn will last much longer than expected, perhaps for several weeks. This type of sunburn will usually occur during a child's first exposure, and it may be a clue to the diagnosis of XP. However, some people with XP will not get a sunburn more easily than others, and the disease will be undetected until unusual skin changes appear over time.

Most patients with XP develop freckles at an early age. Continued sun exposure will lead to further changes in the skin, including irregular dark spots, thin skin, excessive dryness, rough-surfaced growths and skin cancers. These skin changes will resemble those of elderly people who have spent many years in the sun. In people with XP, these changes caused by sun damage often begin in infancy and almost always before the age of 20.

The eyes of a person with XP are often painfully sensitive to the sun and may easily become irritated, bloodshot and clouded. Non cancerous and cancerous growths on the eyes may occur.

Treatment

There is no cure for XP, but much can be done to prevent and treat some of the problems it causes:

- Protection from ultraviolet light, by a combination of physical and chemical means. These include sun avoidance, shade, clothing, hats, optical filtration and sunscreens.
- Frequent skin and eye examinations.
- Prompt removal of cancerous tissue.
- Neurological examination in some cases

Text extracted from "Understanding Xeroderma Pigmentosum" published by US Department of Health & Human Services

AIMS OF THE SUPPORT GROUP

- To relieve the need of persons with Xeroderma Pigmentosum (XP) and UV-related conditions and their families;
- To advance the education of the public in Xeroderma Pigmentosum;
- To promote research into Xeroderma Pigmentosum.

OBJECTIVES OF THE GROUP

- To raise funds for the XP Research fund set up by the XP Society;
- To assist families to attend Camp Sundown (a night-time camp held in New York State, USA) or to attend "The Owl Patrol", our own UK night-time camp held in February;
- To give grants for UV protective products;
- To raise public awareness by means of an educational campaign.

ACHIEVEMENTS DURING THE YEAR ENDED 31 MARCH 2002

The membership of the Group continues to grow and is now over 400. Members consist of patients and their families, the medical professions, other professions who work with XP patients such as social services and education, volunteer helpers and those who have given donations. We support 32 XP patients in the UK and 19 abroad, we also support 46 patients with other light sensitive conditions

Over the last year we have received over 150 enquiries by e-mail, and over 500 telephone calls. Enquiries mainly come from Patients, Hospitals and the Press.

We sent a family to attend Camp Sundown in July 2001.

We held our third Fireworks and Fun social evening in November.

Our web site at www.xpsupportgroup.org.uk continues and to date we have received 3,800 hits. We take this opportunity to thank Rick Tattersfield, our Webmaster, who set up and maintains our site.

Sandra Webb was once again a finalist and this time a winner of a Windrush Award in the Arts and Community category. These awards are made to black British and Asians who have made a contribution to the community or business and celebrates the arrival of HMS Windrush with the first immigrants from the Caribbean to the UK.

Following the £10,000 grant from BBC Children in Need, three of our families were featured in a short film shown on Children in Need night.

The Support Group and its families have received Press coverage in the following publications: Bucks Examiner, Bucks Free Press, Disability NOW, Wycombe Star, TV Choice, Woman Magazine, Home and Country, The Weekly News and The Scottish Daily Mirror. Sandra Webb also gave a live TV interview on the Well Being channel.

Sandra Webb has continued to give talks to the Woman’s Institutes in the Buckinghamshire and Hertfordshire area, as well as Lions and Rotary Clubs. In July Sandra was invited to be a speaker at the annual conference of the British Dermatological Nurses Group, thus continuing our aim of educating the public.

Finally, we are extremely proud of the achievements we have made since the group was set up and we shall continue to strive to achieve our targets for next year.

Our biggest achievement was the establishment of "The Owl Patrol", our first night-time camp held at St Katherine's in Frieth. We welcomed 23 children which included brothers and sisters along with their parents and in some cases grandparents. Campers travelled from Cuba, the United States and Germany. The camp was a true family event. We were also pleased to welcome Caren and Dan Mahar, the founders of the XP Society and Camp Sundown.

Along with fundraising we received grants from the following organisations to set up the Camp:
Lloyds TSB
BBC Children in Need
The Roald Dahl Foundation
ITT Charitable Trust
The Buckinghamshire Foundation
The Roger Vere Foundation
Radio City Give a Child a Chance Foundation (received in 2000-2001)

We are also particularly grateful to Bonwyke Ltd, who provided all the protective film for St Katherine's free of charge. Because they have been so generous we know we have the funds to run next year's camp, which will be held from 14-17 February 2003. We do of course thank The Sue Ryder Prayer Fellowship at St Katharine's for providing us with a home for the "Owl Patrol" and a permanent respite facility.

The camp was filmed by the "Tonight with Trevor MacDonald" Team for a documentary yet to be shown .

AIMS FOR 2002-2003

To send at least one family to Camp Sundown 2002

To appoint an official medical advisor – we currently have an informal arrangement.

To increase the number of people actively involved in running the Support Group.

Finally, we hope to secure a patron. Any ideas for a suitable person should be passed to the Secretary at the XP Support Group Office.

HOW YOU CAN HELP

DONATIONS	All donations gratefully received. We are eligible for Gift Aid so remember for every £1 you give we can reclaim 28p if you fill in the Gift Aid declaration form available from the Office.
FUNDRAISING	Organise an event, such as a sponsored event, coffee morning
VOLUNTEERS	We currently need an Editor for the Newsletter and a fundraising Co-ordinator. We also need volunteers to help with meetings
SPREAD THE WORD	Show this report to friends and colleagues

TRUSTEES

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