XP SUPPORT GROUP NEWSLETTER

Issue 7 February 2001

UK Night-time Camp will be called The Owl Patrol

The Owl Patrol will meet for the first time from **8-11 February 2002**, at St Katherine's Parmoor, Frieth in Buckinghamshire. St Katherine's is a former convent now run by the Sue Ryder Foundation, and we are delighted to be working with them to provide this facility for XP patients and others with light sensitive conditions.

The Camp will run from Friday evening to Sunday night with campers departing on Monday morning. Rooms will be made safe with UV protective films or blinds as appropriate, which means that after the Camp, St Katherine's will be available as a permanent respite facility should any family wish to use it.

There will be indoor daytime activities as well as workshops and talks for interested parties. Night time activities will begin at approximately 5pm and finish at midnight.

The winner of the competition for the name is Claude Verley of Wolverhampton, a bottle of champagne is on its way to him.

The first camp committee meeting has been held and a programme drawn up. To help us in our planning, we need to know how many of you are likely to attend. We therefore enclose with this issue of the Newsletter an application form for the Camp. The camp is free to all XP patients or those with light sensitive conditions and to one parent for each patient under 16. For non XP campers we ask for a contribution of £10 per person towards the cost. Demand is likely to be high and we would like to accommodate everyone who would like to come if possible, so please let us have you forms as soon as possible. We shall not ask you to make a firm commitment until September 2001.

We also need a number of Volunteers to act as Counsellors. An application form is also enclosed

AGI DERMATICS Announces Study results!

From a press release sent to the XP Society:

SUBJECT: T4N5 Liposome Lotion

After fifteen years of hard work, three phase levels of clinical trials, and nothing short of a small fortune and a lot of prayers, AGI Dermatics (formerly Applied Genetics) of Long Island NY is able to reveal the results of its T4N5 lotion. Using XP patients, (the most sun sensitive in the world population) they were able to study from a "worst case scenario basis".

"In a clinical study, about to be published in the Lancet (end of Feb. 2001) and Scientific American (March 2001), a DNA repair lotion reduced the occurrence of the most common form of skin cancer, basal cell carcinoma, by 30% and a pre-cancerous form of skin cancer, actinic keratosis, was reduced by 68%.

The study was conducted among patients with the rare genetic disease Xeroderma Pigmentosum ... who lack DNA repair and develop skin cancer in childhood. XP is a disease that accelerates the effects of the sun. For example, they have seen 8-year-old patients with cancers that would take decades to develop in otherwise healthy individuals.

The new drug, T4N5 Liposome Lotion - trade name DimericineT –was developed by the New York biotechnology company Applied Genetics Inc. Dermatics. It delivers a purified DNA repair enzyme in liposomes to skin to reverse sun damage to DNA and thereby prevent skin cancer. The drug supplements the missing enzyme in this disease and reduces the rate at which cancers develop.

The study leader is Daniel Yarosh, Ph.D., president of Applied Genetics. He will be presenting his findings at the March American Academy of Dermatology Meeting. AGI will also be asking the FDA for approval in March."

This is very good news for all XP patients. Some of you who are reading this participated in this study and we all thank you for doing so.

Please see www.agiderm.com/dermaceuticals/testing.html for additional information.

Skin Cancer or not- can you tell the difference?

The next meeting of the Support Group will be held on **Saturday 17 March 2001** at Holy Trinity Church, Wycombe Road, Prestwood, Bucks starting at 14.00. A buffet lunch will be served from 13.00. A creche will be available at XP Headquarters. Our speaker will be Denise Hancock, Skin Liaison Sister, Wessex Cancer Trust's Marc's Line. Enclosed with this issue is a notice of meeting.

Response so far to this meeting has been low, so that if you would like to attend and haven't already done so, please Contact Sandra Webb as soon as possible otherwise the meeting will be cancelled.

Competition

Design a christmas card

We have now been a group for almost three years and feel it's time to have our own Christmas card. The competition will be divided into three age groups: Under 10's, 11-18 and over 18. So this is a competition for everyone. A prize and runner up prize will awarded in each category. All winning entries will remain the copyright of the XP Support Group.

The closing date for entries is **30 April 2001**.

Fundraising

Miller fundraising catalogue

Sales for Christmas 2000 raised £25.65 for the group. Thank you to all of you bought goods from the catalogue.

Donations

We would like to express our thanks to all the many individuals who donated money over the Christmas period. It is wonderful of you to think of us.

Adoptions

Wolverhampton Benefits Agency – Temple St. Branch and Owen Williams Railways, Birmingham - who with their Bonus ball scheme have raised £999 during this financial year.

A Christmas Carol

14 December 2000

The Ubiquitous Touring Company of High Wycombe presented a wonderful performance of "A Christmas Carol" in aid of the group. The evening raised £276 and £40 for Crisis at Christmas. Our special thanks go to Nick Andrews and his company for a truly splendid evening.

Our thanks also go to Hyde Heath WI, Holmer Green WI, Chesham WI, Prestwood Monday Group, Prestwood WI and one anonymous group, who provide the mince pies for the evening.

Give a child a chance

We are delighted to announce that the Support Group has been awarded £1,000 from the Liverpool charity "Give a child a chance". This is specifically for our night time camp in February 2001. Our special thanks go to Sonia Cahill and her family who helped in our application for the grant from their local Radio station.

Does your local station offer grants? If so please contact Sandra Webb as soon as possible.

Future Events

Skin information days

The Skin Care Campaign will be running two Skin Information Days. Details are as follows:

Saturday 12 May
The Glasgow Quality Hotel Central, Gordon Street, Glasgow.

Saturday 16 June
The Phoenix Art Centre, Exeter.

For further information, please contact Sandra Webb at XP Headquarters

Charity auction

The Syndicate of Wolverhampton will be another Black Tie Ball with live entertainment at the Park Hall Hotel, Goldthorn Hill, Wolverhampton on 5th May 2001. the evening will include a charity auction, proceeds of which will be donated to the Group.

Tickets priced at £25 , which includes dinner are available from Rodney Dillon, Tel: 01902-787507 or Mobile 0421-875223. The event in October was a sell out so do contact Rodney early for your ticket.

Quiz supper

Saturday 30th June 2001

A quiz supper will be held at Prestwood Village Hall. Tables for up to 8.

Tickets are £7.50 to include Fish and Chip Supper. Last year this was sell out so get your tickets early.

For tickets, please contact Sandra Webb at XP headquarters or Val Corteen. Tel 01494-863810

Family profile

Our family profile is from Helen, who is still awaiting diagnosis of her children's condition:

My name is Helen and I live in Cheshire, I am a single mum to Chelsea, 9, Stephanie 2 and Daniel 1. My younger two children both suffer from light intolerance and in the process of investigations. When Chelsea was 6, I met my partner at the local gym,. I became pregnant about a year later with Stephanie. After a long pregnancy and probably too many doughnuts, I gave birth to a beautiful baby girl weighing a whipping 10lb 3ozs! Everything seemed well for the first few months.

When Stephanie was 12 weeks old we went on holiday to Tenerife. After two days her eyes became infected and despite antibiotics her eyes were completely closed and swollen for a week. She suffered 7 of these eye infections in 8 months. The doctors said she had a blocked tear duct!

During that first summer I noticed her exposed skin becoming red even though she was always under a sun canopy and in the shade. We bought a pair of sunglasses which seemed to protect her for a while, but then the skin on her face began to burn also the lower part of her arms which had been exposed. As winter crept in things became a little easier.

I gave birth to Daniel in December, thankfully he was a little smaller at 8lb 5ozs. Spring arrived, along with bright days and the summer sun. A time that many people wish for. For the early part of that year (2000), Stephanie would be in her paddling pool with a UV body suit, factor 60, sunglasses, hat, under a parasol and in the shade! She could tolerate 2—30 minutes before her skin would become red and we would come back indoors. It was one of those days that Daniel burnt. He was asleep in his chair, 6 feet away from the patio doors, the garden was all in shade. After 20 minutes, I noticed his face bright red. I thought he must be too hot, even though he only wore a cotton T-Shirt and a nappy. That night when I removed his T-Shirt he had a large red V on his chest where his arms had been. All his face and chest was blistered and peeling. It was the I realised something wasn't right with my babies.

Ironically I saw the article about 2 children in Liverpool who had XP. After a call to the television studio, they put me in touch with the XP Support Group. Shortly after that I received the special visor material*. I couldn't wait to take the children out. Our first trop was to Toys R Us. We walked through the doors into the lights and headed towards the outdoor equipment. After 5 minutes Stephanie began screaming. I looked at her face under the visor. Her eyes were swollen and all her skin was red raw. We drove home with Stephanie screaming the whole way. We bathed her skin with ice water. Her cheek was blistered. From there we went to see a photo-biologist at Hope Hospital who sent my children for biopsies. We now have to sit and wait. We spent the rest of that summer behind curtains.

We are now in January and things have deteriorated a lot in the last few months. Stephanie burns with UV and visible light. Even a 40 watt light bulb burns her little face. We spend our days behind blacked out glass with only a 10watt light bulb, the television is dimmed very low. If I go to the shops the children travel in a blacked out buggy, which gets very hot and stuffy underneath.

We have raised enough money to buy the space-suits from the HED Foundation in the USA. Stephanie still has the burns on her face and chins, 5 months after the event, despite course of steroid and hydrocortisone creams. Thankfully Daniel's skin will not be as sensitised as Stephanie's as he went into the dark at a younger age.

I have to deal with the ignorance of people in the Health service who have said that because they haven't seen the children burn, then they found it hard to believe what was happening!!! When are these people, who are supposed to work in a caring profession, begin to start listening? Just because they haven't dealt with it before, doesn't mean it doesn't exist! I now have a fantastic occupational therapist called Lorraine who helps with the support that we need as a family.

Even though Stephanie and Daniel suffer with the illness, it affects Chelsea too. She ahs lived in a light world for eight years and now has to live in the dark.

I don't know what is around the corner for us or what the future holds, but when I wake in the morning to these three smiling happy faces it makes life a little easier.
"Chelsea, Stephanie and Daniel, you are my three special stars who shine bight enough to light the dark skies"

* *The protective film blocks out UV, but if someone is sensitive to visible light as well, it cannot on its own , give sufficient protection.*

Gift aid declaration

On the back page of this issue is a Gift Aid Declaration form. If you are a taxpayer and have donated to the Support Group since April 2000, please complete the form and return to us. This will enable us reclaim the tax on your donation which is currently 28p for each £1 that you give.

You can cancel this declaration at any time by notifying us.

If in the future your circumstances change and you no longer pay tax on your income you can cancel your declaration.

If you pay tax at the higher rate you can reclaim further tax relief in your Self-Assessment tax return

If you are unsure whether your donations qualify for gift aid tax relief, please contact us or ask your local tax office for the leaflet IR65.

Please notify us if you change your name or address.

Other News

Camp Sundown 2001

The XP Support Group aims to send at least one family to Camp Sundown each year. In 2000 we were able to send three. If you would like to attend, please write to the Trustees at XP Headquarters saying why you would like to attend. If you applied last year and were unsuccessful, please re-apply.

Camp Sundown will run for two sessions this year: **9-13 July and 16-20 July.**.

Photos from Camp Sundown 2000 can be seen on the XP Society website at www.xps.org.

Office Hours

The office is normally open from **9am till 9pm**.However on weekdays calls will not be answered between **2.45 and 5pm**

The office will be closed from **25th May to 3 June**

If you need to contact us, please leave a message on the answer machine as we shall return your call.

Next issue

The next issue of the Newsletter will be July 2001. Please let us have details of any places that you have visited that are light sensitive friendly. Items for sale or news that would be of interest to the group. More family profiles are required.

XP Support Group

The XP Support group is a charitable Trust founded in 1999 by parents of a child with XP. It aims to relieve the needs of persons and their families with Xeroderma Pigmentosum and other related conditions. The Group raises funds for research, gives grants for UV protective equipment and products, assists families to attend Camp Sundown or respite in a protected environment.

This Newsletter is published by :
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Web site : **www.xpsupportgroup.org.uk**
Registered Charity No: 1075302

Gift aid declaration –

If you have donated to the Support Group during the last year or intend to and are a taxpayer – would you please complete and return the following form which will enable us to reclaim the tax on your donation (currently 28p for each £1 that you give).

Name of Charity : XP Support Group (Registered Charity no 1075302)

Title………..**Forename(s)**………………………………………………….**Surname**……………………………………………

Address………

……

……………………………………………………………………………….**Postcode**……………………………………………

I want the charity to treat

- the enclosed donation of £……………
- the donation (s) of £…………………..which I made on …………/………./………
- all donations I have made since 6 April 2000, and all donations I make from the date of this declaration until I notify you otherwise

as Gift Aid donations.

Signed……………………………………………………………………….**Date**………………………………………………..

Please return to : XP Support Group, 2 Strawberry Close, Prestwood, GREAT MISSENDEN, Bucks HP16 0SG