XP SUPPORT GROUP NEWSLETTER

Issue 14 August2003

XP and Babes in the Shade

We are delighted to announce that funding for our activities this year has been assured following a donation of **£7,281.87** from the Babes in the Shade Trust.

The Trust was set up by the Cahill family of Skelmersdale originally to build an extension to the home of Saicha and Dale Cahill who both have XP. For reasons beyond the control of the Trust they were unable to realise this dream and so when the Trust was closed, the Trustees agreed to pass the funds to us so that it could benefit not only Saicha and Dale but other families with XP.

We are particularly grateful to Vera and Billy Cahill, who have worked so hard to get these funds to us.

The Cahill family have continued to support our group and in May they organised a fundraiser evening which so far has raise a further **£1,000**. We would like to express our further thanks to Sonia Cahill and Steve Mitchell for all their hard work.

Sonia Cahill & Steve Mitchell with Angela Lue at the recent fundraiser

Barbecue & Fireworks

8 November 2003

The next meeting of the Support group will be on **Saturday 8 November 2003** at Holy Trinity Church, Wycombe Road, Prestwood, Bucks starting at 16.00. This will be our 4th Annual social event with a barbecue followed by a short walk to a local firework display. There will be plenty of opportunity to meet and talk to others.

To help us with our catering arrangements, please let us know if you plan to attend by **Monday 3 November.**

For those travelling to Prestwood, please note that we can make a contribution to your travel and accommodation expenses. If you need overnight accommodation, please contact Sandra Webb, at XP UK Headquarters.

Charity Auction and Dinner

11 October 2003

Our second Auction of Promises will take place at St Katharine's Parmoor, home of the Owl Patrol. Proceeds from the Auction help to run the Camp.

The ticket price is £30 which includes a 3-course dinner and welcome glass of sparkling wine. Bed and Breakfast accommodation at £20 per person per night (half price for children) is available We shall be running a crèche, so no need to book the babysitter. We've already sold half the tickets available, so book yours now! To book please contact Sandra Webb at XP UK Headquarters

This is a short list of some promises and gifts. We still need a lot more to make the event successful:

2 nights hotel accommodation in New York with Dinner for 2 (Flights not included)

A promise to cook a Chinese Dinner Party for 6 in your own home

Signed England Shirt from 1990 World Cup

Fundraising

Donations

We would like to express our thanks to the following for their recent donations:

Prince Albert Junior and Infant School, Birmingham who raised **£683** at a circus themed fun day. The staff and children enjoyed dressing up as clowns. The day started with a cake stall for parents. Throughout the day all the children had 2 hours of 'Fun' activities ranging from face painting, mendhi, tombola, name the Ted and splatter the Head. The school is working very hard on raising awareness of a range of disabilities at the school. They have a student, Shah, with XP who attends the school.

St Bartholomew's Penn Ladies Group, Wolverhampton for **£100**.

Largesse Publishing for **$400 (£25**2) for the Owl Patrol

Radio City Foundation, Liverpool for **£500** for the Owl Patrol

Cynthia Shelley, Wolverhampton for **£50.**

Barry & Maureen Chamberlain, London for **£100.**

Prestwood Evening WI for **£155** for the Owl Patrol

We are truly grateful to all of you who have made donations and held fund-raising events on our behalf.

100 Club

We have now reached our 100 members and our first £100 draw took place on 5th May 2003.

The winner was Mukesh Anil of Wolverhampton, who donated back £50 of his winnings, Thank you Mukesh!

June : D Gerard

July : M Trueman

Numbers are becoming available each month. If you would like be part of the 100 Club, please contact Sandra Webb at XP UK Headquarters.

Flora Light Challenge for Women

14 September 2003

The Flora Light challenge for women will take place on Sunday 14 September in Hyde Park, London and Birmingham City Centre .

Sandra Webb will lead a team on behalf of the XP Support Group in the London Run and we hope some of you will join her. You can register online at **www.activeeurope.com** . Registration is until 15 August or until the required number of entrants are reached, whichever is sooner. The cost for registration is £12, of which £5 goes to your nominated charity. It costs £1 extra to register online, but if you add up the cost of telephoning and stamped addressed envelopes, you will only save yourselves a few pence by telephoning the hotline on **0207-902-0819**.

The XP Support Group has now been added to the B Section on charities, so just search for XP Support Group. Once you have your transaction receipt, please let us know what size T shirt you would like (S,M,L,XL) and we will send you a sponsor form.If you don't feel up to running but would like to sponsor the team, please contact Sandra Webb at XP UK Headquarters.

Football Prediction Competition

Enclosed with this Newsletter is a copy of our football competition. Using your skill and knowledge of the English Football league can you predict which team will be premier champions or who will be the first premier league Manager to be sacked? The cost for each entry is £2 and the pool will be shared as follows:

1st Prize 30%
2nd Prize 15%
3rd Prize 5%
50% to the XP Support Group

The closing date for entries is **16 August 2003.** We shall announce how big the pool is in the next Newsletter and keep you informed throughout the season as to who is in the lead. You can enter as many times as you like but each entry must be accompanied by £2. Photocopy it and pass it on to your friends. Cheques should be made payable to the XP Support Group

Giving Donations on-line

We are now able to accept donation by credit card on-line, please see our website at www.xpsupportgroup.org.uk

Future Events

Skin Information Days

The Skin Care Campaign will be running Skin Information Days as follows:

13 September 2003: Percy Building, Newcastle upon Tyne University
25 October 2003: Renaissance Hotel, Manchester

For further information, please contact Sandra Webb at XP UK Headquarters.

Other News

XP and the European Space Agency

In June, Sandra, Alex and Holly Webb attended the Paris Air Show at the invitation of the European Space Agency to present the first prototypes of the protective clothing for XP patients. Alex had been testing out the face mask for two weeks prior to the show, so was able to give his views. The new mask does not yet meet all the requests that we put to the Space Agency, but we have been told at each stage of the prototypes one or more of our requests will be tested out. At the Press conference we were able to see for the first time the proposed undergarments which would offer full protection of the body. The undergarment could be an all in one or 2 piece suit. A cooling mechanism was incorporated into the garment which was controlled by small back pack which would weigh a maximum of 1.5kgs depending on the size of the child. The device could operate for two hours continuously, thus allowing a child to play outside for a substantial time without getting too hot. We feel very positive that the Space Agency has as its main objective to have a production suit ready in 2004 and the funding to provide a suit to every XP child in Europe.

Alex looking at the prototype face mask and suit with Mme Haignere, French Minster for Research.
(Photo courtesy of the European Space Agency)

Disneyland Paris

In the last issue of the Newsletter we advised that we can organise visits to Disneyland Paris at a special rate for patients and their families for up to 2 nights. The accommodation costs will be met by the support group and bursaries for travel may be available.

At the "Owl Patrol" camp it was suggested that we should organise a group trip to the resort. If you are interested, either going as a group or with your family, please contact Sandra Webb at XP Headquarters.

Please note this offer is only open to patients and their families.

Open for discussion

This is a new section to the Newsletter to which we would like you to add your views. We have two subjects on which we would like to hear from you.

I have been recently contacted by the Lupus group for photo-sensitive patients. They have started a campaign and we would like to have your views: Below is a copy of an article in By Brenda Ryder taken form their last Newsletter:

Recognition and Provision for Light-Sensitive Patients:

Request for safe premises for hospital and surgery appointments:
Several members have commented on how they dread a hospital or doctor's appointment and are fearful of a stay in hospital because the fluorescent lights and unscreened windows will damage their health. These experiences are shared by patients with Xeroderma Pigmentosum (XP) and other light-sensitive sufferers for whom a hospital, doctor's or dentist's appointment can be a grim ordeal.

In this age of disabled access to public buildings, it seems inconsistent with the tenets of the Disability Discrimination Act that light-sensitive patients should have their condition aggravated by accessing basic health care.

With this in mind I consulted my MP Andrew Turner who very kindly visited me in my home because there are fluorescent lights in the venue used for his local surgery. I explained the difficulties of doctors' surgeries and hospitals to light-sensitive patients and how some modest alterations (elimination of fluorescent lighting, screening of windows) would ensure a safe appointment or stay in hospital. Andrew Turner thought that the existing legislation of the Disability Discrimination Act should cover this provision but that the providers need to be made to realise this. He advised that I write to the Health Secretary with my concerns and has asked to be kept informed of Mr Milburn's reply.

A quest for disability grants in the future:
Because of the rarity of our condition we need to raise awareness to get the same recognition and provision given to people with other disabilities and impairments. Some members have asked what they can do to protect themselves and overcome their restrictions on a limited income. (There are sufferers who have to stay indoors with closed curtains to prevent themselves from becoming really ill). It seems evident that patients with extreme light sensitivity are at least as disabled and restricted as, for example, many wheelchair-users and should be given financial

assistance with the screening of home and car windows on the same basis as help is given to other disabled persons.

There is clearly much work to be done to gain recognition and provision for light-sensitive patients. Please take every opportunity you can to raise the profile of severe light sensitivity.

Sandra Webb heads the XP group and approved my letter to the Health Secretary. Lobbying has had to take second place to Sandra's work of running the support group. However her members share similar difficulties with the lighting in public buildings, which they are keen to have addressed.

Sandra is called upon to offer support to families with an XP sufferer and to even greater numbers of patients with other light-sensitive conditions because they have nobody to represent them. There are about 40 diagnosed cases of XP in this country. The XP group currently has registered with them 55 children and 106 adults with XP or light-sensitive conditions.

Sandra suggested that I send a copy of my letter to Bruce George MP, Chairman of the All Party Parliamentary Group on Skin, who is very aware of XP and light sensitivity following Sandra's talk to the Group last November.

STOP PRESS!

Response to request for safe hospital provision: I sent a copy of my letter to the Health Secretary to the Chief Executive of my local hospital with a covering letter, enquiring whether they were aware of severe light sensitivity and would be able to accommodate a patient with this condition.

My letter passed through various hands until it reached the Occupational Therapy Department. A therapist who deals with disability provision has contacted me and I was most impressed by her interest in the implications of our difficulties and appreciative of her efforts to make suitable provision.

These are the measures being taken:
The ambulances have been checked and already have UV screening. My file will be marked for the requirement to be kept from light, so this need can be responded to in any department. There will be a single hospital room with screened windows available for the use of a light-sensitive patient.

The therapist mentioned that in some cases it is possible to have a home visit but I would prefer not to take more time of an overstretched professional. We discussed the option of a first appointment so there would be no need to wait under fluorescent lights. I commented that there was one department with very understanding staff who let me sit in an empty room with heavy curtains drawn and I was always grateful for this.

However I know this is not always possible and unfortunately some patients have had to contend with doctors who know about their condition and think it is just something they have to put up with.

This therapist has a commitment to ensuring that all disabilities and impairments, no matter how rare or individualistic, are catered for. She is going to have a meeting with another professional involved with disability management and has offered to write a guide for offering safe hospital provision for light- sensitive patients which can be posted on our Eclipse website (which will soon be up and running).

This should prove helpful to those members who are not being listened to, so you can take the guide to your local hospital to show what can and should be done.

The second topic for open discussion is more sensitive and some of you may feel unable to take part but we want to hear your views particularly:

Professor Alan Lehmann was contacted earlier this year by P J Brooks who is the only researcher of which he is aware that is working on neurological abnormalities in XP. In his studies he is trying to understand the cause of the neurological abnormalities and would really be helped if he could obtain some post-mortem brain biopsy material.

Do you think we should assist by asking for families to give consent for body parts to be used in research?

Office Closure

The office will be closed from **25 July to 3 August** and **16-31 August** inclusive. If you need to contact us, please leave a message on the answer machine or send an e-mail to **info@xpsupportgroup.org,uk** . We shall be collecting messages on a regular basis.

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