XP SUPPORT GROUP NEWSLETTER

Issue 12 February 2003

XP at the Houses of Parliament

On 27th November, Sandra Webb was invited to give a talk to the All Party Parliamentary Group on Skin at the Houses of Parliament, chaired by the Rt. Hon. Bruce George MP. Sandra was a guest speaker along with James Partridge of Changing Faces.

The aim of the talk was to give an insight into the work of our Support Group and what it is like to live with XP. To demonstrate the life of an XP patient, Sandra gave a power point presentation called “A day in the life of Alex”. The talk was very well received and we were even asked to provide a copy of the presentation to a hospital who wishes to use it in training their nurses. Copies of the presentation and their notes can be obtained from the XP office. We ask for a donation towards the copying onto CD and postage.

The talk came at a very appropriate time as the All Party group is now looking at the Psychological and Social consequences of Skin Disease. You can be part of this enquiry. A copy of the letter sent to us is given on page 3. If you wish to take part, please send your answers to Sandra Webb at XP Headquarters and they will be forwarded along with the XP Support Groups’ views.

Owl Patrol – 2nd UK Night Camp

The next meeting of the Owl Patrol will take place from Friday 14th February to Monday 17th February 2003 at St Katharine’s, Parmoor.

Over the weekend there will be arts and crafts activities during the day and outdoor activities at night. Our speakers will include Professor Alan Lehmann who will discuss new developments and Professor Alain Sarasin who is working on gene therapy for XP. There will also be a questions and answers session with a Consultant Dermatologist. The programme is given on page 4

In addition, following the meeting with the European Space Agency, a team from the task force will be at Camp on Saturday 15th to discuss their developments of clothing and face masks for patients. We welcome your attendance to give your views. This is an excellent opportunity for you to help design equipment that will really help those with XP and other light sensitive conditions.

All residential places are now completely booked, however we are still accepting those of you who would like to come along as day campers. Please contact Sandra Webb at XP Headquarters as soon as possible.

Travel expenses to attend Camp will be met by the Support Group

New Sponsor for the Newsletter

We are delighted to announce that GlaxoSmithKline are sponsoring the production and distribution costs of the Newsletter for 2003. Our thanks to Karen Ayres who put forward our group for their “Making a Difference” scheme.

Fundraising

Donations

The Christmas period saw many donations and we would like to give a special mention to the following:
The Parishioners of Little Hampden Church for **£140** donated at their annual Carol Service.
The Colleagues of Mrs Harj Dhaliwal for **£300** raised at a charity Dinner.
The Children of Prestwood Infant School who raised **£137** with their Christmas Bauble Fund. Instead of giving Christmas presents to their teachers the children gave a donation in exchange for a Christmas bauble which was hung on a tree.
Maria Gardiner and friends who for the second year held a family New Years Party and raised **£79**
The Syndicate of Wolverhampton held a Black Tie Ball at the Park Hall Hotel, Wolverhampton. Proceeds from the charity raffle raised **£470**. Our thanks to Rodney and Molly Dillon

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

100 Club

We still need some more members to reach our 100 target. Here are the recent winners. Each winner has received £50.

October : Ms P Tyrer

November : Richard Hannant

The December, January and February draw will take place at the Owl Patrol Camp. So if you want to get into the February draw you have few days left

Help us to make the prize £100 by joining. To join, see the May 2002 Newsletter or e-mail, write, ring or text Ally Fraser - see details below – perhaps your friends and family would be interested too? Numbers can be chosen by you as soon as you contact me, so, if you have a lucky number don't delay or you may be too late. Pay in advance and pay as you go options available.

Ally Fraser,
30 Penrith Road, New Malden, Surrey, KT3 3QS
📱 079 6701 9430 ☎ 020 8942 1075 💻
ally_f@msn.com

In Memoriam

It is with great sadness we announce the passing of Dilsha, aged 9, on December 22nd 2002.

I was privileged to meet her in Germany in 1999. Our condolences to Mehmet and his family.

Future Events

Skin Information Days

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

29 March 2003 Lincoln
May 2003 Gloucester
June 2003 Bournemouth
September 2003 Newcastle upon Tyne
October 2003 Manchester

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

Charity Auction

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 Owl Patrol.

The price of ticket is to be confirmed but will be about £25-30. Bed and Breakfast accommodation at £25per person per night is available at St Katharine's. We shall be running a crèche, so no need to book the babysitter.

We already have a promise of a weekend in New York and a Chinese dinner party for 6 cooked in your own home. If you would like to donate a promise or a gift , or book a table (there are to 8 tables of 10), please contact Sandra Webb at XP UK Headquarters. More details will follow in the next issue of the Newsletter

Other News

Camp Sundown 2003

There will be two session of Camp Sundown in the new retreat facility. They are:
Wednesday 9 July to **Sunday 13 July** and
Wednesday 16 July to **Sunday 20 July**

We are now accepting applications for those of you who would like to attend, as you know we try to sponsor at least one family a year to attend Camp Sundown and we are in a position to do so as we have some free tickets from American Airlines. If you would like to attend please send a letter to the Trustees saying why you would like to attend. Those of you who were unsuccessful last year, please let us know if you would like to be considered this year as well. Applications will be considered on a "greatest need" basis.

Applications must be received by **17th February 2003**.

Disneyland Paris

We are currently in negotiations with Disneyland Paris for special arrangements for patients and their families to go to Disneyland Paris at very special rates.

More details will follow in the next Newsletter.

Rare Disorders Alliance

The Rare Disorders Alliance, RDA.UK was launched in 1997 by Contact-a-Family. It brought together groups, families and individuals affected by a rare disorder such as XP. Contact-a- Family has until 2002 provided the secretarial and management support of group. The XP Support Group has been member of this Alliance and is now part of the Advisory Board.

Now that Contact-a-Family no longer manages the Alliance, members are seeking to establish the Alliance independently. Sandra Webb is a member of the Task Force working on this.

A rare disorder as defined by the European Union, is a condition which affects 5 or less people in every 10,000. Individually, rare disorders affect relatively few. Collectively they affect the lives of between 5-8 per the European population of 25-30 million. It is estimated that up to 4 million children and adults are affected by rare disorders in the UK.

The Alliance believes that rare disorders should be a public health priority. The large numbers of people affected, as well as the severity of some of the disorders, means that those with rare disorders have to compete for equal access to health resources and social services. In the UK there is little recognition of rare disorders at a national level. The Government has yet to take on board the recommendations of the European Union to consider rare disorders within the context of public health programmes (Article 6(2) of Decision 12951991EC).

As rare conditions have little recognition at national level the Alliance is working to ensure that they are included the current government National Service Frameworks (NSF) for children and long term medical conditions.

In that effort we seek your help with the NSF for Children. For those of you where the member of your family affected is a child, we have included a questionnaire that we would like you to complete and return to Dr. Julia Grimshaw at the Department of Health. A stamped addressed envelope is enclosed.

The Alliance is also part of the European Alliance – Eurordis. Sandra Webb recently represented the UK at the 5th European workshop in Paris. The workshop discussed projects to provide an information network for rare disorders in Europe. The projects are being funded by the European Union

For further information about rare disorders in the UK, please see Contact-a-family's website at **www.cafamily.org.uk/ rda-uk.html**
For information about rare disorders in Europe, please see the Eurordis website at **www.eurordis.org**

All Party Parliamentary Group on Skin

As reported on page 1, please find following the letter requesting written evidence. We do hope that many of you will take the opportunity to be involved in the decision making at governmental level.

Written Evidence Request – The Psychological and Social Consequences of Skin Disease

The All Party Parliamentary Group on Skin is conducting an Enquiry into the Psychological and Social Consequences of Skin Disease. The principal aim of the enquiry is to evaluate the ways in which skin diseases affect people's lives.

The Group is keen to obtain a wide range of evidence from people with skin diseases, clinicians, parents, carers and others who wish to contribute.

Interested parties are invited to provide written submissions in response to the questions below. Please note that this letter is directed at a large and varied group of stakeholders. Please respond only to the areas that you feel able to address. The questions are quite broad and are intended to act as a guide, but the Group will be pleased to receive any information you think relevant to the Enquiry, as well as references to studies or statistical data.

Questions

How does having a skin disease affect a person's day to day life – i.e. work, leisure, schooling, relationships, life plans, etc.? What factors are important in maintaining a good quality of life?

How do skin diseases affect parents and/or carers? What are the time implications, social implications and cost implications of supporting a person with a skin disease?

What are the social & psychological effects of having a skin disease, particularly in relation to how society views skin diseases?

Do consultant dermatologists and/or general practitioners and nurses understand the psychological and social effects of having a skin disease? What kind of support should be expected from clinicians?

Are there adequate support services available for people with skin diseases? Are carers/ parents supported in any way?

If not, what services do you think should be available, or how could current support services be improved? Are there any fast-tracking systems in place for patients to access specialist services?

What are the main blocks to developing services in this area - resources, other priorities, lack of awareness?

Are you aware of any reports of peer-reviewed research into the social, psychological or 'quality of life' issues associated with skin diseases? If so, please will you provide copies (ideally electronically) or references?

Are there sufficient resources to conduct research into the psychological and social effects of skin disease?

What are your key concerns about the priority that is given to the quality of life implications of having a skin disease by clinicians and by those who develop Government health policy?

What more could the Government and other agencies do to support people with skin disease?

Submissions of no more than three sides of A4 should be sent by 1st March 2003. The Group would prefer electronic submissions e-mailed to the Administrative Secretary:
natalie.delima@portcullisresearch.com
Hard copies can be sent to the Administrative Secretary at the following address:
The All Party Parliamentary Group on Skin
26 Cadogan Square
London SW1X 0JP

Owl Patrol Camp Programme 14-17 February 2003

Friday 14th
Arrival during the afternoon
7.00pm Welcome dinner and Wizards and Witches Party until late
Saturday 15th
08.00-11.30 Breakfast and free-time, there will be limited Arts and Crafts available for early rising children
12.00-17.00 Arts & Crafts and Games

12.00 XP Research & Diagnostics
Professor Alan Lehmann, MRC Cell Mutation Unit, University of Sussex
13.00 Some progress towards gene therapy
Professor Alain Sarasin, Centre National de la Recherche Scientifique, Paris
14.00 Lunch
15.00 UV Protective clothing
Discussion with Angeli Khatri of Sunsibility. Sunsibility offers a range of sun protective clothing, Angeli is looking for ideas to extend her range and members of the European Space Agency Task Force looking at providing equipment for XP patients. The Group is Led by Elie Znaty of Bertin Technolgies
16.30 Outdoor activities at St Katharine's (meet the pets)
18.00 Coach leaves for Marlow Sports Centre
18.30 Pool Party at Marlow Sports Centre
20.00 Coach leaves for High Wycombe
20.30 Dinner at Café Fresco, High Wycombe
22.00 Coach leaves for St Katharine's
22.30 Outdoor activities at St Katharine's

Sunday 16th
08.00-11.30Breakfast and free-time and limited activities for early risers
11.00 Short service in the chapel led by Pauline Jones
12.00-17.00 Arts & Crafts and Games
12.30 Questions and answers session
Sandra Webb XP Support Group, UK , Professor Alan Lehmann, Professor Alain Sarasin ,a Consultant Dermatologist and representative from the European Space Agency Task Force
14.00 Lunch
15.30 The Earthworm Jamboree – presentation by Tammy Freeman and Alison Fraser
18.00 Farewell Dinner followed by Puppet show
21.00 More outdoor activities

Campers leave after breakfast on Monday 17th

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