

Pictures from Owl Patrol 2007



XP Support Group Newsletter

April 2007



Owl Patrol 2007

Thursday morning the day before camp we woke to snow covered roads and lanes wondering if we could get to St Katharine's. Our first campers were due to arrive from the States that afternoon. We should have known nothing would stand in the way of Ollie's annual gathering. On Friday the volunteers arrived and with the help of our American friends St Katharine's was turned into a Disney Wonderland to welcome campers to Owl Patrol 2007. Disney villains and heroes were to be seen all around St Katharine's. Rumours that Cruella de Ville had captured a Dalmatian were abounding. But the rumour that turned out to be true was that someone famous would join us later. We were delighted to welcome TV presenter and former England Footballer, Ian Wright who delighted children and parents with a football coaching session. Ian is seen above with Alex, Ben and TJ having a warm up. (For more pictures from Owl Patrol see page 8)



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Fundraising

Donations



Thank you to all of you who sent donations over the Christmas period, we would like to say a particular thanks to the following:
Great Missenden Guides for **£61**.
Hazlemere WI for **£374**. We were adopted as their Charity for 2006. Staff from the
Bucks Free Press for **£517** who instead of sending Christmas Cards sent the money to us. The pupils of **Prestwood Infant School** who raised an incredible **£325** from a sponsored spell. **The London Law Trust** for

£2,500 for Owl Patrol. **Project Skem** for **£259**. **Sarah Ellis, Jo Coles, Carole Hazlehurst, Debbie Hayman and Sandra Walters** from Prestwood who raised **£232** from a coffee morning. **High Wycombe Lions** for **£150** for Owl Patrol. **The XP Family Support Group** for **\$5,000** (£2,555) for Owl Patrol and finally a very special Thank You to **1st Wendover Rainbows** (seen above) for £142 raised by selling cookies that they had decorated with smiley faces. Their donation will be used to buy a Fatboy bean bag for the night time camps

London Marathon 2008 - 12 April 2008

The XP Support Group has one silver bond entry to the 2008 Marathon. We are looking for someone to run this on our behalf. To take on this silver bond entry the runner will have to raise a minimum of £1500 in sponsorship. If you are interested please contact Sandra Webb at XP UK Headquarters.

Hydro-Active Run for ladies-16 September

The on-line entry is now open at www.womenschallenge.co.uk. The cost is £15. Please join our team. If you would like to take part and would like us to register you, please send your name, address, date of birth and cheque for £15 made payable to XP Support Group.

Auction of Promises – 15 September 2007

Venue : St Katherine's, Parmoor

This is our major fundraising event that raises money for Owl Patrol. This is a black tie event with 3 course meal. If you would like to attend or donate a promise or gift, please complete the booking form on page 3

Enfants de la Lune

The French XP organisation will be holding a night-time camp in Dax, near Biarritz from **22-29 July**. For further information, please e-mail Françoise & Bernard Seris at bernard.seris@wanadoo.fr

Camp Sundown

The XP Society is now accepting applications for their annual Camp Sundown night time camps. The camps will take place as follows:

10-13 July For new families

15-18 July Teens only weekend

21-24 July For returning families

To apply for Camp Sundown, please download the application form from the XP Society's website at www.xps.org

Other News

Do you Blog?

Blogging is having a huge effect on the way information is spread on the internet. If you blog why not tell everyone about living with XP or a light sensitive condition, tell them about your day to day life and add a link to our website www.xpsupportgroup.org.uk. If you are a volunteer or a parent or someone who comes in to daily or regular contact with someone with a light sensitivity, tell your story too. This can only help to raise awareness of these conditions.

UV Protective clothing & The European Space Agency

Many of you know that we have been working with the European Space Agency to provide UV protective clothing for XP and light sensitive children. We regret to advise that the ESA are no longer willing to continue. However several of the partners are keen to progress the project. As it has now been four years since we started, we would like you to contact us to let us know that you are still behind us in continuing this project. It is likely that the new project will concentrate on a face mask and undergarments for younger children. Please let Sandra have your views urgently by telephone 01494-890981, post or e-mail xpsg@btinternet.com

New supplier of sun protective clothing

www.suninsight.com

This company has a good range of adult clothing. At the moment they only have hats that are suitable for XP children. They do intend to introduce long sleeved shirts for children in the near future. They also supply RIT wash-in Sungard. Members of the Support Group can order on-line and claim a 10% discount by quoting ref. XXPSG0607. This applies to all goods except factor 60 sun creams.

News from abroad



First Meeting of the XP Freunde Mondscheinkinder (Friends of the Moon Children) took place at the Jagdhof Glashütte Hotel in Bad Laasphe (Wittgensteinerland, Germany) on 5th/6th November 2006

For the first time ever, 10 XP patients and their families came together near Cologne in Germany to exchange experiences and information. This included one family from England and a couple from the Netherlands. The Jagdhof Glashütte very kindly treated us to a free weekend at their hotel where we were able to leave our everyday XP worries behind and bring a bit of light into our “darkness”.

A delicious barbeque, moonlight carriage rides, beauty treatments or massages, a splash in a rock pool, followed by a trip to the sauna or a challenging game of skittles rounded off with a cosy evening with good conversation around the fireplace provided relaxation and fun for young and old alike.

Dr. Mark Berneburg, an XP specialist from the Tübingen Referenz-Zentrum, held an interesting lecture on XP and provided informative and helpful answers to questions from listeners.

One of the event’s highlights was the arrival of Ms. Helga Kühn-Mengel, a member of the German Bundestag who is in charge of patient matters in Germany. With health insurances increasingly reluctant to pay for UV protection, everybody is hoping for a change in the law. Ms. Kühn-Mengel gave assurances that she would include this matter in her agenda - a big step in the right direction.

Report by Moni Prenting on behalf of the German XP Support Group “XP-Freunde”

Walk by the Light of the Moon—27 October 2007

Venue: London, Los Angeles, San Francisco, Tennessee

We are planning to join our colleagues in the USA, France and Germany and walk to raise awareness of XP and light sensitivities. We plan to walk along the South Bank from HMS Belfast ending up with a night flight on the London Eye. If you would like to take part and would like a sponsor form, please contact Sandra Webb at XP Headquarters. This event is open to children and adults. There will be a cost of approximately £13 for adults and £6.50 children for the London Eye

Other dates for your diary

Owl Patrol for Teenagers – 20-22 July 2007

Venue : St Katharine’s, Parmoor

BBQ and Fireworks – 3 November 2007

Alex’s night time garden, Prestwood

Volunteer Training—November 2007

Venue to be advised

Owl Patrol - 15 –18 February 2008

Venue : St Katharine’s Parmoor

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Auction of Promises— 15 September 2007

Name _____

Address _____

_____ Tel no _____

We require:

_____ Dinner tickets @ £30 _____ Adult B+B @ £20

_____ Children’s B+B @ £10 _____ Kids programme @ £10

Total enclosed _____

We wish to donate a promise/gift. Please give details below :

Owl Patrol for Teenagers

20th - 22nd July 2007

Are you between 12 and 18 years old?
Do you love spending time at Owl Patrol?
Would you like to have more teenage activities available?

Would you like a weekend away from your parents?!

Come to Teen Camp this year for a whole weekend of brand new activities including sports, music, parties and even a trip to London to see a major west end musical!

It will just be you and the volunteers (no parents allowed!) and a weekend packed with activities designed especially for teenagers and we are all looking forward to a weekend of fun. Make sure your parents let Sandra know that you want to come along as it will be very popular and we don't want you to miss out.

So if you think you will be bored in the summer holidays this year and fancy joining us for our first ever Teen Camp with our top secret new activities then make sure you sign up now!

See you there!

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Application for Teen Camp (minimum age 12 by 31st August 2007). Open to XP and light sensitive children and their siblings. Please copy if more than one child is attending.

NAME _____

ADDRESS _____

_____ POST CODE _____

DATE OF BIRTH _____ TEL NO _____

I hereby give permission for my son/daughter* _____ to attend Owl Patrol for Teenagers

Signed _____ Parent/Guardian*

**Please delete as applicable*

Volunteer Vacancies

Trust Fundraiser

Responsible to : The Board of Trustees
Commitment: 20 hours per month

Main responsibilities:

- To make applications to relevant grant giving trusts and foundations for the purposes of funding group activities
- To be involved in agreeing the timing of funding applications and where necessary, the specific amounts required
- To liaise with Secretary re: current funding priorities and other committee members as required e.g. treasurer for accounts
- To research new funding Trusts
- To ensure that all supplementary information accompanies all applications
- To provide monthly reports on applications made, activity applied for and date decision expected

Peer Counsellors funded by Jeans for Genes (2 vacancies)

Responsible to : Secretary Trustee
Commitment : 2 days training, thereafter 2 hours per week

Main responsibilities:

To be available for 2 hours a week (fixed time) to answer telephone calls from members

Volunteers will be given full training and all expenses paid.

Would suit a good listener.

To apply or for further information please contact Sandra Webb at XP UK Headquarters