November 2011

ISG E BULLETIN

Last Month

Nottingham Ultramarathon, 9th October 2011 Thank you to Michael Shelton, who completed his run for the ISG, inspired by Annabelle Whitehouse, aged 7yrs, who has ichthyosis. For more information visit: www.justgiving.com/Michael-Shelton

Together Against Genodermatoses (TAG) Conference 13th - 15th October Maggie and Mandy Aldwin, ISG Trustees, attended the TAG conference in Paris last month. Ichthyosis was largely included in the programme and topics such as diagnosis, everyday life tips, ears and eyes and genetic counselling were discussed. Presentations by pharmaceuticals and cosmetic companies, together with a discussion about future partnerships, concluded the conference. For more information about TAG, please visit: http://asso.orpha.net/TAG/cgi-bin/

Medical Research For Ichthyosis On the 18th October the ISG presented a cheque for £10k to the Institute of Child Health, for research into Netherton Syndrome. This money was raised by the Oldacres family who have been holding fundraising events over the last year in aid of their son Jack, who has the condition. The Oldacres family requested that the money they had raised goes to research specifically into Netherton syndrome, a type of ichthyosis.

European Network for Ichthyosis (eni) The board of the eni met on the 22nd October in Rome. ISG Trustee and eni president, Maggie Aldwin, attended the meeting representing both the ISG and the UK. www.ichthyose.eu/

Forthcoming Events

British Society of Paediatric Dermatology (BSPD) AGM 11th & 12th November, Nottingham www.bspd.org/


Please note: An ISG representative aims to attend these meetings, as they are not intended for the general public. If you have an interest in any of the above please contact the ISG at: isg@ichthyosis.org.uk

ISG Members Events

If you have an event planned, or would like support with an event, please get in touch. For ideas on planning events please visit: www.ichthyosis.org.uk/916/fundraising-guide/
News

ISG Welcomes New Trustee Andy Corbett  Andy has been working with the ISG for some years but has recently committed to becoming a trustee and will take on various roles, including Chair of the Youth Forum Sub Committee, a member of the fundraising team and being largely responsible for the ISG I.T.

ISG Merchandise We are in the process of updating our merchandise along with our online shop. We have seasonal items for sale such as Christmas cards, diaries and calendars for 2012. Please keep visiting the ISG website for updates.

Grants and Funding for the ISG  The ISG has submitted an application for funding to the British Association of Dermatologists (BAD) and is about to submit two applications to the Big Lottery Fund for projects such as new information packs, for health professionals and patients, and an ISG event.

Ichthyosis in the Media  Last month ISG members, the Oldacres family, appeared in the ‘Mail Online’ talking about how they were accused of allowing their son Jack to be severely sun burned. To read the story please click on the following link:  www.dailymail.co.uk/health/article-2056545/Strangers-accused-scalding-son-Parents-son-suffering-800-000-1-skin-condition-launch-fund-educate-public.html

New members to the ISG  Last month the ISG welcomed 17 new members to the group.

The ISG Needs Your Help

Do you have any items over the value or £250 that you would be willing to donate for auction?  May be a celebrity signed item or something unusual. If so please get in touch!

Volunteers Needed

- Do you have some time to spare?
- Maybe you have a particular interest or skill?
- Do you think there are areas within the ISG that could be improved?

If you have any ideas, or would like to volunteer, please contact the ISG by: telephone: 0845 602 9202, email: isg@ichthyosis.org.uk or post: PO Box 1404, Bagshot, GU22 2LS.

Get Involved

There are many ways in which you could get involved with your ISG:

- Surveys / research studies  ▪  Fundraising  ▪  The ‘Youth Forum’  ▪  Starring in our educational DVD

For more information about how to get involved please visit the ISG website ‘Get Involved’ Pages:  www.ichthyosis.org.uk/get-involved/
Top Tips For Ichthyosis

Staring at me won’t help me or cure my condition!

Education and raising awareness helps to reduce people’s ignorance. If people make unkind remarks, or stare, explain about the condition or simply hand them an ISG contact card and suggest they have a look at the website.

To request some cards email: liz@ichthyosis.org.uk

Don’t let other people affect how you feel about yourself, stay positive and remain confident.

Fundraising

Justgiving ISG Currently we have 21 live Justgiving pages. www.justgiving.com/isg

Donations & Fundraising Thank you to the following who have all made donations or carried out fundraising events during the last month:

• Kerry Robinson, on behalf of the Pollard Family and Colart Fine Art & Graphics Ltd
• Laura Levy and team, who completed the Adidas women’s 5k challenge at Hyde park
• Simply Health People Ltd
• Mrs Priscilla Pittock for her donation

Want to raise some money but don’t have the time? Why not donate straight from your wages, while you shop or even searching the internet - with no effort at all!

• www.easyfundraising.org.uk/
• www.shop2fundraise.co.uk/directory.php?Ichthyosis+Support+Group
• www.ebay.co.uk/ebayforcharity/
• www.easysearch.org.uk/
• www.payrollgiving.co.uk/

For ‘Text Giving’ please visit: www.ichthyosis.org.uk/3075/support-us-with-a-text/

Without your hard work the ISG would struggle to support those affected by ichthyosis and would not be able to support ongoing medical research. Every penny counts, no matter how small.

If you have an ISG collection box, please do not forget to empty it and send in your cheques.

Links

Relevant medical publications www.ichthyosis.org.uk/1250/publications-2/

ISG Facebook en-gb.facebook.com/pages/Ichthyosis-Support-Group/301038155873?v=info

Please visit the ISG website for more useful links www.ichthyosis.org.uk/links/