GP’s with Special Interest (GPwSI) RCGP Dermatology Training Day, Leeds 11th-12th February
Mandy Aldwin, ISG Trustee, attended on the Friday to give a fantastic presentation and overview of ichthyosis. Mandy received positive feedback from attendees following her presentation. On the Saturday, Mandy talked individually to delegates, displaying the ISG stand and literature, sharing information and raising awareness of ichthyosis and the ISG.

Mölnlycke Medical Devices Company continues to support the ISG. Paul Whitehouse, ISG Chairman, and Mandy Aldwin, ISG Trustee, met with a colleague at Mölnlycke (which produces Epaderm and Tubifast) on 24th February to continue discussions about how the ISG can continue working together with Mölnlycke during 2011. Currently they provide the ISG with PR support through its agency Indigo.

Rare Disease Day 28th February 2011 - Mandy Aldwin, ISG Trustee and Liz Dale, ISG Administrator, attended the Royal Holloway, University of London (RHUL) a leading Institution in the development of therapies for rare diseases, in support of their event for Rare Disease Day www.rhul.ac.uk/rarediseaseday. We had the opportunity to meet the students and staff of the university, as well as members of the general public and talk about ichthyosis as a rare disease. We managed to move a small step further in raising awareness of ichthyosis, as out of all the people who attended the event, and visited our stand, not one had heard of ichthyosis. The support and interest was great and everyone left the ISG stand having learnt something different that day.

Courses & Conferences
www.cafonline.org/charitytraining
www.theclarerefoundation.org/training.php
www.ncvo-vol.org.uk/training-events
www.charitycomms.org.uk/events/conferences/

Royal College of Nursing (RCN)
Dermatology Nursing Forum annual conference
March 31st
www.rcn.org.uk/newsevents/events/
forthcoming_events
Places must be booked and there is a fee!

London Marathon April 17th
Clive Pollard, ISG member, is running to help raise awareness and money for the ISG www.justgiving.com/Clive-Pollard

Bring your Bear to School May 2011
Please visit the link below to see how you can take part. www.action.org.uk/get_involved/bring_your_bear

Walk for Skin 2011
London, Leeds, South Downs, Pennines & Cheddar. Please support Paul Handscombe, ISG member, who has registered for the London walk, 22nd May 2011 www.justgiving.com/Paul-Handscombe0
**News**

**ISG National Conference 2011** Please put 18th/19th June 2011 in your diary for the ISG 7th bi-annual conference. The conference will be a one and a half day event, with a social occasion on the Saturday night following the first day’s conference. There will then be a morning of further activities on the Sunday. The venue will be the Holiday Inn Kensington Forum [www.hikensingtonforumhotel.co.uk](http://www.hikensingtonforumhotel.co.uk). Being a conference venue within a hotel, onsite accommodation is available. Please remember you must register prior to the event. For more information contact Liz on 0845 602 9202 or Email the ISG [isg@ichthyosis.org.uk](mailto:isg@ichthyosis.org.uk).

**Professor Celia Moss will be celebrating her 60th Birthday in April.** Kindly, Celia has suggested to her friends and family rather than buying gifts they could make a donation to the ISG through her Justgiving page [www.justgiving.com/Robin-Ferner](http://www.justgiving.com/Robin-Ferner). Wishing Celia a very happy birthday and thank you to her for all of her encouragement and support for the ISG.

**Ichthyosis in the Media** On the 25th February 2011 Jack Oldacres, aged 2yrs, appeared on the ‘Jeremy Kyle Show’, with his parents Danny and Julie, featuring children who look different. Jack suffers from Netherton Syndrome, a type of ichthyosis. He along with his parents, is doing all he can to raise awareness of ichthyosis and has inspired numerous fundraising events over the last year to help fund research into Netherton Syndrome. If you would like to watch the interview please click the following [www.itv.com/itvplayer/video/?filter=216835](http://www.itv.com/itvplayer/video/?filter=216835) and move the slider to 32 minutes (after the 3rd set of adverts) where Jack’s interview is the last in the show.

**Media volunteers needed** The ISG is approached frequently by journalists and TV producers who are interested in ichthyosis, as a feature in a newspaper or magazine, or in making a documentary. The ISG would like to create a register of people who may be willing to consider talking to various journalists or TV producers about the possibility of taking part. If you, or someone you know, may be interested in raising awareness of ichthyosis through the media please contact Liz on 0845 602 9202 or by e mail [liz@ichthyosis.org.uk](mailto:liz@ichthyosis.org.uk).

**New ISG Website Soon to be Launched** Finally, the time has nearly arrived to launch the ISG new website. We are aiming to go live with the new website in the next few weeks so please keep visiting, as there will be lots of new links and information to view [www.ichthyosis.org.uk](http://www.ichthyosis.org.uk).

**Redirection of post to the new PO Box address has expired** Please note our new address is **PO Box 1404, Bagshot GU22 2LS**. The six month crossover period has now ended and we are unable to further extend the redirection service. Any mail posted to the old address will no longer be forwarded to the new ISG address and will be lost.

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**Useful Links**

**Easy Fundraising & Easy Search** To help raise money for the ISG register to shop online with over 2,000 well known retailers at [www.easyfundraising.org.uk](http://www.easyfundraising.org.uk). Also go to easy search [www.easysearch.org.uk](http://www.easysearch.org.uk) and select the Ichthyosis Support Group. Both are free to use.

**ISG Facebook**—Remember to help raise awareness, publicise events and meet new members by registering with, and using, the ISG Facebook [en-gb.facebook.com/pages/Ichthyosis-Support-Group/301038155873?v=info](https://en-gb.facebook.com/pages/Ichthyosis-Support-Group/301038155873?v=info).

**Ebay For Charity**—Donate a % to the ISG from your online sales [www.ebay.co.uk/ebayforcharity](http://www.ebay.co.uk/ebayforcharity).


**Payroll Giving**—another easy way to donate to charity direct from your pay [www.payrollgiving.co.uk](http://www.payrollgiving.co.uk).

**Shop2fundraise** - online shopping where a percentage goes to the ISG. For more information visit: [www.shop2fundraise.co.uk/schools/Ichthyosis+Support+Group-387742](http://www.shop2fundraise.co.uk/schools/Ichthyosis+Support+Group-387742) and to start shopping click the following link [www.shop2fundraise.co.uk/directory.php?Ichthyosis+Support+Group](http://www.shop2fundraise.co.uk/directory.php?Ichthyosis+Support+Group).
Members and Fundraising

Justgiving ISG  [www.justgiving.com/ISG](http://www.justgiving.com/ISG)  Currently we have 15 live justgiving pages:

- Celia Moss - Supporting the ISG  [www.justgiving.com/Robin-Ferner](http://www.justgiving.com/Robin-Ferner)
- Sharon Beattie - Fundraising for her son Harry  [www.justgiving.com/Sharon-Beattie/](http://www.justgiving.com/Sharon-Beattie/)
- Paul Handsome—Walk For Skin London 2011  [http://www.justgiving.com/Paul-Handsome0](http://www.justgiving.com/Paul-Handsome0)
- Amy Moxham - Poker  [www.justgiving.com/Mekhi-Barbour-Poker](http://www.justgiving.com/Mekhi-Barbour-Poker)
- Amy Moxham - Speed Dating  [www.justgiving.com/Mekhi-Barbour-SpeedDating](http://www.justgiving.com/Mekhi-Barbour-SpeedDating)
- Egguckland Community College  [www.justgiving.com/Egguckland-ISG](http://www.justgiving.com/Egguckland-ISG)
- Rebecca Jeffery - Buggy Walk  [www.justgiving.com/baby-Freddie](http://www.justgiving.com/baby-Freddie)
- Richard Peet - 30 mile Cycle Ride-  [www.justgiving.com/Yvonne0](http://www.justgiving.com/Yvonne0)
- Emma Picken - Ichthyosis Camp  [www.justgiving.com/Emma-Picken](http://www.justgiving.com/Emma-Picken)

Donations & Fundraising

Thank you to the following donors and fundraisers who have all made donations or carried out fundraising events in the last month:

- 3 Aces Scooter club who held a 'Northern Soul' charity night.
- The Rotary Club, Arbury, which generously made a donation.
- Mrs White, member, who kindly made a donation.
- The White Hart Pub, Bagshot, for emptying their collection box.
- All or Nothing Scooter club for making a donation.
- Ralph Oldacres for his continued support by playing music for various organisations that make a donation.
- The Inner Wheel Club of Camberley for making a generous donation.
- Mr Baker, ISG Member, who kindly made a donation.

The ISG Needs Your Help

**British Skin Foundation (BSF) Online Survey** has been set up to try to highlight how skin disease affects people not only physically and medically but also to identify the psychological and social impact of skin disease that so often goes unrecognised. Skin disease has a huge impact on a person’s life. It may affect relationships, encourage bullying and a lack of social interaction may be apparent. If you are a sufferer of skin disease, or know of anyone who would be interested in taking part in this brief survey, please go to the link  [www.surveymonkey.com/s/surveyautumn2010](http://www.surveymonkey.com/s/surveyautumn2010)

**X Linked Study Birmingham - participants wanted!** The University of Birmingham and Birmingham Children’s Hospital have jointly set up a research study with boys and men aged from 6 to 30 years, with X-linked recessive ichthyosis (XLI). If you know of any members who fall into this category, and may like to take part, please ask them to contact Dr Jan Idkowiak  j.idkowiak@bham.ac.uk

**X Linked Study Wales - request for participants** Dr William Davies, at Cardiff University, is carrying out a study looking at people in the Cardiff area affected by X-linked ichthyosis - compared to their non affected male siblings. If you know of any members who may be willing to participate, please ask them to contact William Davies  daviesw4@cardiff.ac.uk