**Last Month**

**Survey of ISG Members**  Last month the ISG contributed to setting up a survey to find out a little more about our members and how they manage their ichthyosis, with the aim of trying to work towards improving services for those affected by the condition. The response was phenomenal. The link to the survey was circulated to all ISG members, for whom we hold email addresses (approximately 300). We received more than 100 responses to the survey, most of which were in the first few hours. The information gathered from this survey will be used as evidence that there is a need to improve services for this rare condition.

**National Service for Severe Ichthyosis**  On the 17th of March approximately 18 dermatology health professionals, with a special interest in ichthyosis - including professors, consultants and nurses - all gathered at the British Association of Dermatologists (BAD) house to discuss the possible progression of a national service for ichthyosis. Mandy Aldwin, ISG Trustee, and Liz Dale, ISG Administrator, attended on behalf of the ISG and its members in support of such a proposal. Among others, Mandy Aldwin gave a presentation to the group, outlining what the ISG feels its members would like from such a service and how they feel they would benefit. The feedback was very positive. The submission of an application for national commissioning, for such a service, is likely to be submitted in December this year, with Professor Edel O’Toole taking the lead.

**Royal College of Nursing (RCN) Dermatology Nursing Forum Annual Conference March 31st**  Mandy Aldwin, ISG Trustee, and Liz Dale, ISG Administrator, attended this event in London at the end of March, to raise awareness among nurses who specialise in dermatology. The opportunity to meet and talk to about 100 nurses proved a success, as it was surprising how many of these nurses had little knowledge of ichthyosis. Thank you to Galderma Pharmaceuticals Ltd for sponsoring the ISG’s attendance at this event.

**Dermatology Council For England (DCE) meeting March 31st**  Formed in December 2009, the DCE meets 3-4 times a year with the aim of providing a wide representation to Government, other decision-making or policy-related bodies, and potentially the media, from interested parties in the skincare field - on matters of broad interest to all. The ISG is a member of the DCE and tries to attend meetings where possible. Last month the DCE formally agreed to adopt and launch the document ‘Outcomes for skin diseases’, compiled following the Multi Stakeholder Workshop in January this year. For more details about the launch please email Liz liz@ichthyosis.org.uk  The launch is due to take place on the 19th May, starting with a drinks reception at 6pm.

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**Courses & Conferences**

- [www.cafonline.org/charitytraining](http://www.cafonline.org/charitytraining)
- [www.theclarefoundation.org/training.php](http://www.theclarefoundation.org/training.php)
- [www.ncvo-vol.org.uk/training-events](http://www.ncvo-vol.org.uk/training-events)
- [www.charitycomms.org.uk/events/conferences/](http://www.charitycomms.org.uk/events/conferences/)

**Forthcoming Events**

**Bank Holiday Party, Taking you way Back! 1st May**  
Laura Levy, ISG member and mother to a baby with ichthyosis, is organising a charity event to help raise money for the ISG. For more information, please visit the Events section on the ISG website and click on members [www.ichthyosis.org.uk](http://www.ichthyosis.org.uk)

**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](http://www.action.org.uk/get_involved/bring_your_bear)
London Marathon April 17th Clive Pollard, aged 46 and a member of the Ichthyosis Support Group (ISG), is tackling this year’s Virgin London Marathon to raise awareness and money for the ISG. This is the first time Clive has run a marathon and he is hoping to complete the course in around five hours. Please help support Clive in his brave efforts to help those affected by ichthyosis by visiting Clive’s Justgiving page www.justgiving.com/Clive-Pollard or by simply cheering him on, on the day.

Walk For Skin (WFS) 2011 The British Skin Foundation (BSF) is pleased to announce details of the 2011 walks. This year’s event starts off in London on the 22nd May with a guided walk through London. The event then moves to Leeds on the 26th June, where you may experience a leisurely walk around Roundhay Park, just a couple of miles from the city centre. For those of you more energetic, there are longer and more challenging walks taking place from Cheddar to Glastonbury on the 30th July and then heading to the North Pennines for a 10 mile walk on the 17th September. The event finishes on the 24th September with a challenging and fully guided walk along the South Downs in West Sussex. For more information on WFS 2011 please visit the BSF website www.britishskinfoundation.org.uk/Events/WalkforSkin2011.aspx

ISG National Conference 2011 Remember to put 18th/19th June 2011 in your diary for the ISG 7th bi-annual conference and hurry to register your place. The conference will span over one and a half days, 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 children will enjoy the exciting experience of an amphibious adventure through London’s streets and the river Thames on the ‘London Duck Tours’ www.londonducktours.co.uk/ and then back onsite for a ‘Strum and Drum’ jamming session. 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.

Evidence Based focus on Natural Oatmeal Emollients for Dry Skin Conditions An article was published in February this year looking at how Oatmeal can help relieve some of the symptoms associated with dry skin conditions. To view this article please follow the link: www.deepdyve.com/lp/royal-college-of-nursing-rcn/cpd-dry-skin-conditions-an-evidence-based-focus-on-natural-oatmeal-wAlz03DJs5

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. Please note: Any mail posted to the old address will no longer be forwarded to the new ISG address and will be lost.

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/. Also go to easy search 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.

Ebay For Charity — Donate a % to the ISG from your online sales www.ebay.co.uk/ebayforcharity/

Give As You Earn — Why not donate to the ISG straight from your wages www.cafonline.org/Default.aspx?page=7026

Payroll Giving — another easy way to donate to charity direct from your pay 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 and to start shopping click the following link www.shop2fundraise.co.uk/directory.php?Ichthyosis+Support+Group
Members and Fundraising

Justgiving ISG [www.justgiving.com/isg] Currently we have 17 live justgiving pages:

- Tobias Stewart - Walk For Skin, London [www.justgiving.com/Tobias-Stewart]
- Tammy Rothwell - Various events [www.justgiving.com/tammy-rothwell]
- Celia Moss - Supporting the ISG [www.justgiving.com/Robin-Ferner]
- Sharon Beattie - Fundraising for her son Harry [www.justgiving.com/Sharon-Beattie/]
- Amy Moxham - Poker [www.justgiving.com/Mekhi-Barbour-Poker]
- Amy Moxham - Speed Dating [www.justgiving.com/Mekhi-Barbour-SpeedDating]
- Laura Levy - Fundraising for her son Mekhi Barbour [www.justgiving.com/Laura-Levy-]
- Egguckland Community College [www.justgiving.com/Egguckland-ISG]
- Rebecca Jeffery - Buggy Walk [www.justgiving.com/baby-Freddie]
- David Roberts 2,000 Mile Cycle Ride [www.justgiving.com/Wheresthepoint]
- Richard Peet - 30 mile Cycle Ride [www.justgiving.com/Yvonne0]
- Emma Picken - Ichthyosis Camp [www.justgiving.com/Emma-Picken]
- Serena Gibson - General Fundraising [www.justgiving.com/serena-gibson]

Donations & Fundraising

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

- Professor Cunliffe who kindly asked everyone to give up their bottle of wine at an event and donate the money to the ISG.
- Galderma Pharmaceuticals Ltd, Genus Pharmaceuticals Ltd and Alliance Pharmaceuticals Ltd all of whom have made donations in support of the ISG National Conference this June.
- The Dicker family who emptied their collection box at their family bakery.
- Member, Terry Lee, who kindly made a donation.

With thanks to all those who have either donated or participated in fundraising events. Without your support the ISG would struggle to support those affected by ichthyosis and would not be able to so easily support ongoing medical research. Every penny counts, no matter how small.

The ISG Needs Your Help

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