ISG New Website Launch During the last few months the ISG has been working with ISG Member Mike Davies to redesign its website. Mike has a daughter with ichthyosis and also runs a web design company www.propage.co.uk. Mike very kindly offered to work with the ISG on a voluntary basis to help improve resources and create a more extensive and user-friendly website. The ISG is very pleased with the result and would like to encourage everyone to visit the site regularly, as the ISG will be updating it regularly with announcements, news, events and information about ichthyosis. Please visit www.ichthyosis.org.uk.

London Marathon April 17th Clive Pollard, aged 46, and a member of the Ichthyosis Support Group (ISG), tackled this year’s Virgin London Marathon to raise awareness and money for the ISG. This was the first time Clive has run a marathon and he completed the course in five hours fifteen minutes. Congratulations to Clive in his brave efforts and a big thank you for helping those affected by ichthyosis. Visit Clive’s Justgiving page www.justgiving.com/Clive-Pollard.

ISG In The Media Last month two ISG families appeared in the media to help raise awareness of ichthyosis. Irene Levy, grandmother to a child with ichthyosis, organised a local sponsored walk which was featured in ‘The Comet 24’ www.thecomet.net/news/hitchin_grandmother_s_push_for_rare_skin_condition_1_857791 as well as being interviewed on the local radio station ‘Jack FM’ helping to further raise awareness of ichthyosis www.thecomet.net/news/hitchin_grandmother_s_push_for_rare_skin_condition_1_857791. Clive Pollard, following his successful completion of the London Marathon, was interviewed and featured in the ‘Leyton Buzzard Observer’.

ISG Members 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.

Blue Town Pub, 11th June, Isle of Sheppy
Family Fun Day supported by ISG member Nathan Hill whose little girl has ichthyosis. For more information please contact Liz at the ISG; 0845 602 9202 or email: liz@ichthyosis.org.uk

Isle of Wight Beech Soccer 3rd July
Appley Beach, Ryde I.O.W
Join Sophie Newman, ISG Regional Contact for the South, for the 3rd year of this popular fundraising event. Come along and cheer on the teams, enjoy a BBQ, music and a raffle and meet other families affected by ichthyosis. For more information please visit: www.iwbsa.com/events.php?EID=33

Forthcoming Events

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

ISG National Conference 18th/19th June 2011
The conference this year is to be held in London. Please remember to return your registration forms ASAP. If you require further information please contact Liz: 0845 602 9202 or email: liz@ichthyosis.org.uk. Please note the children’s trip www.londonducktours.co.uk/

If you have returned your registration form and have not yet heard from us please call 0845 602 9202 to confirm your place as soon as possible.

Walk For Skin (WFS) 2011
London on the 22nd May with a guided walk.
Leeds on the 26th June, a walk around Roundhay Park.
Cheddar to Glastonbury on the 30th July.
South Downs on the 24th September in West Sussex.
For more information on WFS 2011 please visit the BSF website www.britishskinfoundation.org.uk/Events/WalkforSkin2011.aspx.
News

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.

Survey of ISG Members During March 2011, 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. If you have not yet completed the survey, and would like to, please visit www.surveymonkey.com/s/nationalISG

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.

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-wAlz03DJ5

Don’t forget to visit the New ISG Website www.ichthyosis.org.uk

Please note our new address is PO Box 1404, Bagshot GU22 2LS.

The ISG Needs Your Help

ISG Volunteers Needed Do you have some spare time, a skill, or a particular interest that you feel you may be able to assist the ISG with? Do you feel there are areas within the ISG that could be improved upon and are able to contribute? If you have any ideas or would simply like to get involved please contact the ISG by Telephone: 0845 602 9202, Email: isg@ichthyosis.org.uk or Post: PO Box 1404, Bagshot, GU22 2LS.

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 fall into this category, and would like to take part, please contact Dr Jan Idkowski j.idkowski@bham.ac.uk

X Linked Study Wales - request for participants A research team at Cardiff University, are carrying out a study looking at adults (aged 18 - 60 years) in the Cardiff area affected by X-linked ichthyosis - compared to their non affected male siblings. If you would like to participate or require further information, please contact the team on Tel: 0292 074 2672 or E mail: RXL1study@cardiff.ac.uk
Members and Fundraising

Justgiving ISG  [www.justgiving.com/isg](http://www.justgiving.com/isg)  Currently we have 18 live justgiving pages:

- Tobias Stewart - Walk For Skin, London  [www.justgiving.com/Tobias-Stewart](http://www.justgiving.com/Tobias-Stewart)
- Tammy Rothwell - Various events  [www.justgiving.com/tammy-rothwell](http://www.justgiving.com/tammy-rothwell)
- Professor 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)
- 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)
- Laura Levy - Fundraising for her son Mekhi Barbour  [www.justgiving.com/Laura-Levy](http://www.justgiving.com/Laura-Levy)
- Eggbuckland Community College  [www.justgiving.com/Eggbuckland-IGS](http://www.justgiving.com/Eggbuckland-IGS)
- Rebecca Jeffery - Buggy Walk  [www.justgiving.com/baby-Freddie](http://www.justgiving.com/baby-Freddie)
- David Roberts 2,000 Mile Cycle Ride  [www.justgiving.com/Wheresthepoint](http://www.justgiving.com/Wheresthepoint)
- 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)
- Serena Gibson - General Fundraising  [www.justgiving.com/serena-gibson](http://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:

- Mrs J Stansfield who kindly made a donation.
- Mr & Mrs Lunt who celebrated their 50th Birthdays and asked guests to make a donation in lieu of gifts.
- Wilcomatic whose staff hold regular dress down days and choose a charity to make a donation to.
- Julie Smith & Jayne Woodward who held a fundraising day with raffles, cake sales, jewellery sales and more.
- Enterprisemouchel whose staff all bought raffle tickets last Christmas
- Alton Levy who did a sponsored walk.
- Professor Celia Moss who celebrated her 60th Birthday and asked guests to make a donation in lieu of gifts
- Irene Levy who organised a sponsored walk around Hitchin.
- Clive Pollard who ran in the London Marathon.