Last Month

**Sponsored Zumbathon 21st August, London** Laura Levy, ISG Regional Contact for London and the Thames Estuary, held a Charity Sponsored 'Zumbathon' to help raise awareness and funds for ichthyosis. To view pictures of the event and for information on other events Laura has planned, please visit SkinDeep’s facebook page: [www.facebook.com/event.php?eid=132745343478500](http://www.facebook.com/event.php?eid=132745343478500)

**WellChild Awards 31st August, London** WellChild, the national charity for sick children, held their annual awards ceremony and their Patron, Prince Harry, met all the 15 winners. The night was about recognising children who show spirit and bravery, and for the carers and professionals who make a profound difference to these young lives. The ISG was proud to nominate Professor Celia Moss, Birmingham Children’s Hospital, for the ‘Doctor’ category and delighted to learn that she won. Along with Celia’s family, Maggie and Mandy Aldwin, ISG Trustees, attended the ceremony and applauded Celia as she accepted this much deserved award. For more information and to view the pictures visit: [www.wellchild.org.uk/Events-Awards.asp](http://www.wellchild.org.uk/Events-Awards.asp)

**New members to the ISG** During the month of August the ISG welcomed 18 new members to the group. We are amazed that more and more people affected by ichthyosis are finding us as a direct result of the new website, which is much more interactive and easier to navigate. One of the aims of the ISG is to reach more people and offer support and information to all those affected by ichthyosis.

**Volunteers for ISG Projects** The ISG has been contacted by three new members offering help to in areas of their expertise. Sarah Narraway, a Graphic Design graduate, has offered to help redesign our literature and give the ISG a consistent design theme and corporate identity throughout. Jenna Hedges, an international relations undergraduate, will be working with us in relation to our links with other related organisations and the resources and information they offer. Jenna will also be helping the ISG to update its policies as a working organisation in view of the recent change having become a charitable company. And finally Louise Richmond has offered support to the younger members and may be involved in the evolving youth forum.

### ISG Members Events

**Adidas Women’s 5K Challenge, 11th September, Hyde Park** Laura Levy, Regional Contact for London, has teamed up with some friends and family to take on this challenge for the ISG. [www.justgiving.com/teamskindeep](http://www.justgiving.com/teamskindeep)

For more information please visit: [www.womenschallenge.co.uk](http://www.womenschallenge.co.uk)

**Run for it, 11th September, Thruxton** [www.hiow-airambulance.org.uk/page.cfm/run-for-it](http://www.hiow-airambulance.org.uk/page.cfm/run-for-it)

Amanda Sullivan, ISG member, is taking part to help raise awareness for ichthyosis and collecting sponsors for the ISG. To support Amanda visit: [www.hiow-airambulance.org.uk/page.cfm/run-for-it](http://www.hiow-airambulance.org.uk/page.cfm/run-for-it)

**Clubnight, 24th September, London** Laura Levy is kick starting ‘Ichthyosis Awareness Week’ with a clubnight, speed dating and a human auction. Please visit: [www.facebook.com/theskindeepfundraisingproject](http://www.facebook.com/theskindeepfundraisingproject) for more information.

### Forthcoming Events

**Rare Disease UK AGM, 12th September, London** ISG representatives hope to attend this meeting and feed back to ISG members any new developments.

**Ichthyosis Awareness Week, September 24th - 30th, 2011**

Over the next few weeks we will be sending out more details so please watch out for information and check out the ISG website regularly [www.ichthyosis.org.uk](http://www.ichthyosis.org.uk) and don’t forget to start collecting your empty cream tubs!

‘**Fill your pot to the brim for ichthyosis skin**’

**Walk For Skin (WFS) 2011 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](http://www.britishskinfoundation.org.uk/Events/WalkforSkin2011.aspx)
**News**

**Ichthyosis Awareness Week 24th - 30th September**

This year's ichthyosis awareness week will take the form of a 'Pot of Gold' event where we are encouraging our members to fill an old tub of emollient cream with money. How you do this is up to you and you can make this event as big or as small to suit you. You can decorate your tub and leave it on your desk at work for donations, you could have a dress down day, you could have a sponsored event and collect sponsors in your tub. If you would like more information, or support for your event please contact us on 0845 602 9202 or email: **isg@ichthyosis.org.uk**

**Ichthyosis in the Media** ISG member Nusrit Shaheen who has Harlequin ichthyosis appeared on ITV's This Morning with David Paige on Thursday 25th August. You can view the interview at [www.itv.com/this-morning/life/living-with-harlequin-ichthyosis/](http://www.itv.com/this-morning/life/living-with-harlequin-ichthyosis/)

**Funding for the ISG** The ISG works closely with various pharmaceutical companies that produce products suitable for use for the management and treatment of ichthyosis. Recently GlaxoSmithKline plc generously awarded the ISG a grant towards its ongoing support to those affected by ichthyosis.

**ISG Gives Grant to The Centre for Appearance Research (CAR)** The ISG teamed up with the British Skin Foundation (BSF) [www.britishskinfoundation.org.uk/](http://www.britishskinfoundation.org.uk/) which has resulted in them matching our grant allocation for research. A number of projects applied and a decision was agreed by both BSF and ISG to award the grant to CAR [http://hls.uwe.ac.uk/research/car.aspx](http://hls.uwe.ac.uk/research/car.aspx) for its research into psychosocial support for young people with visible differences. The money will be used to pilot a study to explore the feasibility of computerised psychosocial support (YP Face It) for young people with appearance-related concerns as a result of ichthyosis.

**ISG Conference Survey** Thank you once again to all those of you that completed an ISG survey at this year's conference. A brief report will soon be available to all members with a summary of the findings. The information gathered from the surveys has been quite interesting and useful. In fact it has already been used in support of the need for a specialised service for ichthyosis with data being used in a proposal to the National Specialised Commissioning Team (NSCT). This is in addition to the evidence highlighting the need for greater support to both health professionals and families affected by ichthyosis for which the ISG is seeking funding.

**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 Tel: 0845 602 9202, email: **isg@ichthyosis.org.uk** or post: PO Box 1404, Bagshot, GU22 2LS.

**Satisfaction in Life for Children With Own Report Measures (SILCWORM)** Some paediatric doctors at University College London have developed a quality of life measure for children aged 4 to 10 years old with chronic illnesses such as Ichthyosis. For more information or to take part in the survey please visit: [www.wazdaka.com/silcworm](http://www.wazdaka.com/silcworm)

**Survey of ISG Members** The ISG would like to find out a little more about its members and how they manage their ichthyosis. The aim is to try to work towards improving services for those affected by the condition. If you have not yet completed the survey, and would like to, please visit: [www.surveymonkey.com/s/nationalISG](http://www.surveymonkey.com/s/nationalISG)

**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 Idkowiak j.idkowiak@bham.ac.uk

**X Linked Study Wales - request for participants** A research team at Cardiff University is 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 email: **RXLstudy@cardiff.ac.uk**
Top Tips For Ichthyosis

Most of us know the problems caused by emollients, clothes and washing machines. Many of us get through many rubber seals, our machines break down and the creams and ointments clog up the pipes! Only when the much needed machine breaks down do we learn the insurance we took out doesn’t cover it so here are some useful tips to help lighten the load!

- Once a month do an empty wash at 90° using a biological washing powder as this will help to digest grease build up.
- Take out washing machine insurance but check first they include seals and cover damage caused by emollients.
- Avoid overloading the machine to rid the clothes of grease thoroughly.
- Most washing machines are cold fill, if you can get a hot fill machine it will be worth it, the grease dissolves better.
- If you have space try having two washing machines at home, one just for the greasy clothes, this will help preserve the life of other clothes and the machine. Also if one breaks down you will always have backup as those with ichthyosis appreciate the importance of a good washing machine more than others!

Members and Fundraising

Justgiving ISG  Currently we have 19 live Justgiving pages. To view ours supporters pages please visit: www.justgiving.com/isg and see the various ways people are fundraising for the ISG.

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

- The White Hart Pub, Bagshot - collection box emptied.
- Nuneaton North Scouts

With thanks to all those who have either donated or participated in fundraising events. 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.

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/.


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.