Last Month

**Isle of Wight Beach Soccer 3rd July** Appley Beach, Ryde I.O.W. Sophie Newman, ISG Regional Contact for the South, hosted this popular fundraising event for the 3rd year. The event included a BBQ, music and a raffle, as the teams played for the charity cup. The *Isle of Wight* versus *Jersey* was one of many games during the ISG Beach Soccer Charity Cup, with the Jersey team winning the battle of the sands 4v3. For more information please visit: [www.iwbsa.com/events.php?EID=33](http://www.iwbsa.com/events.php?EID=33)

**British Association of Dermatologists & the British Dermatology Nursing Group Annual Conference** 5th, 6th & 7th July Mandy Aldwin, ISG Trustee, Maggie Aldwin, ISG Trustee & Liz Dale, ISG Administrator, attended this 3 day event to raise awareness amongst the health professionals most likely to be caring for people with ichthyosis. With the opportunity to meet many dermatologists and dermatology nurses from all over the country we were able to raise awareness for ichthyosis and help to educate the professionals.

**Charity Evening 30th July**, Tammy Smith, Regional Contact for North East, organised a fundraising event in her region raising over £1200 which was supported by golfer Lee Westwood who kindly donated raffle prizes.

**Walk For Skin (WFS) 2011 Cheddar to Glastonbury** on the 30th July again we had a number of people walking for the ISG helping to raise awareness for ichthyosis.

**ISG Website Diary** Last month we introduced an events diary to our website for members to keep up to date with events near to them that they may want to take part in whilst having the opportunity to meet other members. To view the diary please visit: [www.ichthyosis.org.uk/isg-diary/](http://www.ichthyosis.org.uk/isg-diary/). If you are organising an event, or know of something happening near you that people with an interest in ichthyosis may want to attend, please email the details to us at isg@ichthyosis.org.uk and we can add them to the diary.

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

This year’s ichthyosis awareness week will take the form of a ‘Pot of Gold’ event where we will be 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. 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).

**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)

---

**Sponsored Zumbathon 21st August, London**

Laura Levy, ISG Regional Contact for London and the Thames Estuary, has organised a Charity Sponsored ‘Zumbathon’. If you would like to take part, or would like more information, please contact the ISG on 0845 602 9202 or [isg@ichthyosis.org.uk](mailto:isg@ichthyosis.org.uk)
or visit the SkinDeep Facebook page: [www.facebook.com/event.php?eid=132745343478500](http://www.facebook.com/event.php?eid=132745343478500)

**Adidas Women’s 5K Challenge, 11th September, Hyde Park**

ISG member Laura Levy 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)

If you would like to take part please contact [liz@ichthyosis.org.uk](mailto:liz@ichthyosis.org.uk)
Ichthyosis in the News:

• South Woodford: Mum speaks out over son's rare skin condition. www.thisislocallondon.co.uk/whereilive/northeast/redbridge/9155647.STH_WOODFORD_Mum_speaks_out_over_son_s_rare_skin_condition/

Quality Standards for Dermatology A document has been published www.ichthyosis.org.uk/wp-content/uploads/2011/07/Dermatology-standards-final.pdf and has been worked on by a team of representatives from all the stakeholders in dermatology. These standards form the foundations of a good dermatology service for everyone with a skin condition. These standards will only be successful if we ensure they are used to best effect. For patients, clinicians and commissioners alike they will provide a clear outline of what should be expected – providing patients and clinicians with clear guidelines for best possible treatment and care and commissioners with the guidance to ensure best possible NHS services are designed, provided and monitored effectively.

Changing Faces Survey – Psychological & Social Support Changing Faces has designed three surveys in which they aim to find out about the current services that are available to provide psychological and social support for people who are living with a condition, injury or marking that affects their appearance. To do this they need your help! If you would like to take part please visit www.ichthyosis.org.uk/2985/changing-faces-survey-psychological-social-support/ and follow the appropriate links.

Top Tips – living with ichthyosis Living with ichthyosis can be difficult for not only the person with the condition, but also family members or those closest to you. Some of our members, and their families, have come up with some great tips to make life easier and help with the day to day living with ichthyosis. Please visit www.ichthyosis.org.uk/2751/top-tips-living-with-ichthyosis/ to view the top tips and if you have any words of wisdom or can offer any advice to anyone affected by ichthyosis please share them by emailing your 'Top Tips' to us at isg@ichthyosis.org.uk.

ISG Conference Survey Thank you to all those who completed the Survey at this years conference. We are pleased to announce that the winner of the £25 John Lewis Voucher is ISG Member Gemma Pittock.

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 illness such as Ichthyosis. For more information or to take part in the survey please visit: 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

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 sibings. 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
Members and Fundraising

Justgiving ISG www.justgiving.com/isg. Currently we have 19 live Justgiving pages:

- Desta Gumbs - Sponsored Zumbathon www.justgiving.com/sponsored-zumbathon
- Laura Levy - Adidas Women’s 5k Challenge www.justgiving.com/teamskindeeph
- Mary Judge - Bupa Great Manchester Run www.justgiving.com/Mary-Judge
- John Ham - Coast to coast cycle ride www.justgiving.com/John-Hamm2
- Tobias Stewart - Walk For Skin, London www.justgiving.com/Tobias-Stewart
- Tammy Rothwell - Various events www.justgiving.com/tammy-rothwell
- Professor Celia Moss - Supporting the ISG www.justgiving.com/Robin-Fern
- 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/skindeeph-isg
- Eggbuckland Community College www.justgiving.com/Eggbuckland-ISG
- Rebecca Jeffery - Buggy Walk www.justgiving.com/baby-Freddie
- David Roberts - 2,000 Mile Cycle Ride www.justgiving.com/Wheresthepoint
- Emma Picken - Ichthyosis Camp www.justgiving.com/Emma-Picken

Donations & Fundraising

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

- Richard & Yvonne Peet for their very generous donation.
- Emma Phipps who organised a fundraising cake sale.
- Inspirations Boutique for supporting research into Netherton syndrome by holding a fashion show.
- Park Street Lodge Charity Association for their generous donation.
- Sharon Beattie who held a fundraising event at her daughter’s school.
- Mark Rowlands for his donation.
- Nuneaton Carnival for their donation following the carnival last month.
- Mike Hunt who helped raise money at the Classic Corvette UK event last month.
- Janet Denby for her donation.

If you have an ISG collection box, please do not forget to empty it and send us the money collected.

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.