Last Month

Egg bucklands Sixthform College Sky Dive for Charity, 1st June 2011 Student Sophie Trotter inspired this event amongst her fellow students and lecturers in Plymouth, as her mum has ichthyosis. What lengths some people will go to to help raise awareness and money for ichthyosis! Well done to all and thanks to Sasha Inglott for organising the event.

Flora Women’s Mini Marathon, 6th June, Dublin Mary Kneafsey, ISG Regional contact for Ireland and Edel Kenny, ISG member, once again took part in the ‘Flora Women’s Mini Marathon’ this year supporting the ISG. Congratulations to you both and well done.

Primary Care Dermatology Society Conference 10th/11th June, Brighton Mandy Aldwin, ISG Trustee, attended this conference (on her birthday!) with the ISG stand and presented to medical professionals working in Primary Care. Raising awareness to the health professionals and educating them about ichthyosis is so important for the future of all those affected by ichthyosis.

Football Charity Match, Blue Town Pub, 11th June, Isle of Sheppy ISG member Nathan Hill’s young daughter was the inspiration behind this event, which raised over £1800. With the support of friends and family a fun day was had by all, a few more people are now aware that ichthyosis exists and the difficulties faced by those living with the condition.

Nuneaton Carnival, 12th June, Nuneaton Danny and Julie Oldacres, ISG Members, walked in the procession helping to raise awareness of ichthyosis and Netherton’s Syndrome of which their son Jack is affected. For more information please visit: www.nethertonsyndrome.com/previous-events.php

ISG National Conference 18th/19th June 2011 This year’s ISG National Conference, sponsored by ‘Jeans for Genes’ was another huge success. More than 50 families attended at the Holiday Inn Kensington Forum, London, many of which were new to the ISG. People travelled from all across the UK including, Scotland, Wales and Ireland along with families from outside of the UK who travelled from Eire and Denmark! Everyone appeared to have enjoyed the weekend including the social event on the Saturday evening giving people the chance to engage in a less formal environment.

Thank you to all those who were involved in making this year’s conference happen, so much was gained from a well organised, informative and fun event.

Walk For Skin (WFS) 2011 Leeds 26th June Many people walked around Roundhay Park raising awareness as well as money for various skin conditions. A number of those were walking for ichthyosis.

Forthcoming Events

British Association for Dermatologists & the British Dermatology Nursing Group Annual conference 5th, 6th & 7th July Mandy Aldwin, ISG Trustee, Maggie Aldwin, ISG Trustee & Liz Dale, ISG Administrator, will be attending this event to raise awareness amongst the health professionals most likely to be caring for people with ichthyosis

This event is for Medical professionals only and not open to the public.

Walk For Skin (WFS) 2011 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

Ichthyosis in the News ISG member Laura Levy appeared on ITV’s Anglia evening news with her son Mekhi who has lamellar ichthyosis helping to raise awareness for the condition. To watch the interview please follow the link: www.ichthyosis.org.uk/2628/lauras-fundraising-for-ichthyosis. The Ichthyosis Support Group is often contacted by various media sources looking to tell a story, this may be in the form of a TV programme, National Newspaper or magazine article. Conducted in the correct manner this has proved very effective in raising awareness into ichthyosis. If you are interested in being contacted by the ISG to consider telling your story and raising awareness through the media please let us know.

Syndromes Without A Name (SWAN UK) is a project recently set up by Genetic Alliance UK to offer support and information to families of children with undiagnosed conditions. One of their initiatives is to share information and experiences between families affected by rare diseases through a blog set up by SWAN so families can access information about what it is like living with rare conditions and how they present in everyday life. For examples of some stories already posted please visit www.swanuk.wordpress.com or if you would like to write a piece please email it to SWAN@geneticalliance.org.uk

Skin Care Campaign (SCC) Following the SCC members forum last month Dr Christine Clark, SCC Chairman, announced the following statement “It is with a great sense of disappointment that the Skin Care Campaign’s board of directors has decided that it needs to close down the SCC. This is largely due to increased financial pressures and the unsustainability of the organisation”. Despite the ‘closure’ of the SCC it was suggested that with consultation with all relevant stakeholders, there should be the development of a needs-based assessment of what sort of organisation is required to succeed the SCC, and if needed, a steering group may be formed for the development of a new organisation.

New Regional Contacts Laura Levy, mother to a young child with ichthyosis, has agreed to take on the role of Regional Contact for London and the Thames Estuary. Sally Lark, mother to a child with ichthyosis, has volunteered to take on the role of Regional Contact for Scotland and Dawn Rowe, a mother whose son is also affected by the condition, will be the Regional Contact for the West Midlands. Thank you to all the Regional contacts for offering their time to support other families affected by ichthyosis. If you do not know who your regional contact is for your area please get in touch via the ISG where we can put you in touch. Tel: 0845 602 9202 or email: isg@ichthyosis.org.uk

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

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 siblings. If you would like to participate or require further information, please contact the team on Tel: 0292 074 2672 or email: RXLlstudy@cardiff.ac.uk
Members and Fundraising

Justgiving ISG www.justgiving.com/isg. Currently we have 20 live Justgiving pages:

- Laura Levy - Adidas Women’s 5k Challenge www.justgiving.com/teamskindeep
- 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-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/skindeep-isg
- Eggubuckland 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
- Richard Peet - 30 mile Cycle Ride www.justgiving.com/Yvonne0
- Matt Jefferies - Nethertons Research Group www.justgiving.com/nethertonsyndromeresearch
- 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:

- Laura Levy for her ongoing support through various fundraising events.
- Paul Handscome who took part in the London ‘Walk for Skin’ raising more than £600!
- Tammy & Wyatt Rothwell for organising the ‘Rainbow Funday’.
- St James’ School year seven students who raised money during ‘lent’ this year.
- Mr W E Ellis for his kind donation to the ISG.

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

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.

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.