Bank Holiday Party, Taking You Way Back! 1st May
Laura Levy, ISG member and mother to a baby with ichthyosis, has been organising various charity events to help raise money for the ISG. On Sunday 1st May she hosted a club night at Hitchin nightclub, Bliss. The music was great and everyone that attended had a great time. Victor Ebuwa from Ultimate Big Brother attended the night which raised £330.

eni General Assembly 15th May 2011
Maggie Aldwin, ISG Trustee and eni president, travelled to Amsterdam to attend the meeting of countries who are part of the European Network of Ichthyosis (eni). The UK joined Germany, Italy and Denmark as representatives at the meeting to discuss ichthyosis across Europe.

Dermatology Council for England (DCE) Reception 19th May
In January, a multi-stakeholder workshop was held to explore how to best ensure that people with skin disease are appropriately represented in the forthcoming NHS reforms, and improvements made in accessing treatment. Evidence based outcome measures were defined in a document. A reception took place during May to launch this document Sir Paul Berresford MP, Chair of the All Party Parliamentary Group on Skin welcomed the collaborative working of all those involved. Stephen Jones, BAD President, gave a presentation illustrating the work of a dermatology department and the common and rarer diseases and statistics about patient numbers. The guests included representatives of the patient support groups, the BDNG, PCDS and the dermatology special interest groups.

Birmingham Children’s Hospital 12th Annual Paediatric Dermatology Course
Mandy Aldwin was asked to attend the course on 26th May to give a presentation about the Ichthyosis Support Group and talk about her childhood dermatology appointment experiences. Information was available on the ISG’s stand for the Specialist Registrar delegates.

Skin Deep Fundraising Project Launch Party 29th May!
Laura Levy, as mentioned above, held a party to launch her fundraising activities formally at Ember, a bar in Farringdon, London. The afternoon included a raffle and human auction! The activities are part of her Skin Deep Fundraising Project, which aims to raise awareness of ichthyosis and the ISG, and help fund research into the conditions. Mandy and Maggie Aldwin and Professor Kelsell from Queen Mary, University of London, joined Laura, her friends and family. Laura was recently interviewed on ITV Anglia news and has also been featured in a Women's magazine.

Primary Care Dermatology Society 10th/11th June
For medical professionals only
The ISG has been invited to attend with a stand and to present during the conference in Brighton to medical professionals working in Primary Care.

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/
**News**

**BAD Grant application for Literature packs for patients and Health professionals.** The ISG applied for a BAD Patient Support Group grant to help us overhaul, redesign and rewrite our information packs. We are pleased to have been awarded a proportion of the money we applied for which will cover the costs of paying for the technical writer.

**Jeans for Genes grant.** The ISG 2011 conference is largely being supported by the charity Jeans for Genes. Unfortunately the funding has been delayed and we anticipate receiving the grant around September. The conference is costing £18,000 this year and this grant is not covering all of the costs.

**Childwick Trust Grant to part fund a project worker.** The ISG applied for funding to part fund a project worker. Although we were not awarded anything like the figure we applied for, we are pleased to have been awarded some funds.

**Genetic Alliance UK Research Project for New Medicines** Genetic Alliance UK are looking for people who are affected by a severe, rare or genetic condition, to take part in a Citizens’ Jury later this year. They are looking for up to 16 individuals, to form a diverse jury that will deliberate a very important issue - the risks and benefits of new medicines. Not only will jurors get their voice heard in an innovative and high profile way, but they will be paid for their time too! For more information please visit: [www.geneticalliance.org.uk/projects/risksandbenefits2.htm](http://www.geneticalliance.org.uk/projects/risksandbenefits2.htm)

**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. A lot of conditions, such as ichthyosis, which affect children have no information regarding quality of life. It has been shown through a lot of research, that given the same set of circumstances, a child will give different interpretations of their quality of life than that of their parent/carer. A Department of Health report identified a need for a quality of life measure, self scored (i.e. by the child). The team at UCL have developed a novel way of doing this using an interactive computer ‘game’ which children love filing in and call this e-SILCWORM. For more information or to take part in the survey please visit: [www.wazdaka.com/silcworm](http://www.wazdaka.com/silcworm)

**Don’t forget to visit the New ISG Website** [www.ichthyosis.org.uk](http://www.ichthyosis.org.uk)

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

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**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.

**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, 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 email: RXL1study@cardiff.ac.uk
Members and Fundraising

Justgiving ISG [www.justgiving.com/isg](http://www.justgiving.com/isg). Currently we have 19 live Justgiving pages:

- Mary Judge - Bupa Great Manchester Run [www.justgiving.com/Mary-Judge](http://www.justgiving.com/Mary-Judge)
- 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)
- Eggubuckland Community College [www.justgiving.com/Eggubuckland-ISG](http://www.justgiving.com/Eggubuckland-ISG)
- 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:

- Laura Levy for her ongoing support through various fundraising events
- Mrs B Upton for her donation
- Mr Colin Taylor for his donation
- The Oldacres family for their continued fundraising efforts raising money and awareness in various ways such as quiz nights and charity football matches

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 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.

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](http://www.easyfundraising.org.uk/). Also go to easy search [www.easysearch.org.uk](http://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](http://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](http://www.ebay.co.uk/ebayforcharity)/.


**Payroll Giving** - Another easy way to donate to charity direct from your pay [www.payrollgiving.co.uk](http://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](http://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](http://www.shop2fundraise.co.uk/directory.php?Ichthyosis+Support+Group).