Last Month

ISG Trustee Meeting Sunday 7th November The committee met for an ISG strategy meeting to discuss the working structure within the ISG and to make plans for the next Family Conference. Sub committees have now been formed to enable more effective planning and an improved working structure. The 16th – 19th June 2011 have been agreed for the next Family Conference. The venue is still to be confirmed but it’s likely to be in London.

British Society for Paediatric Dermatology (BSPD) AGM 11th and 12th November, Cardiff
Mandy Aldwin, ISG Trustee, and Gill and Theresa Davis, ISG Regional Contacts for Wales and Gloucester, attended the British Society for Paediatric Dermatology meeting in Cardiff. The ladies took the ISG stand along to help awareness of ichthyosis and to raise the profile of the ISG. It was mainly consultant dermatologists at the meeting.

Delivering quality care for people with rare and complex conditions 16th November 2010 Liz Dale, ISG Administrator, and Mandy Aldwin, ISG Trustee, attended this conference in London, hosted by the Specialised HealthCare Alliance (SHCA). It highlighted core quality standards for specialised services, covering issues such as diagnosis, treatment, care, commissioning and outcomes. Presentations were given by Earl Howe, Minister for Quality, DoH, Teresa Moss, Director of National Specialised Commissioning Team, Jim Easton, National Director for Improvement and Efficiency, DoH and Professor Tim Briggs, Chair of the Federation of Specialist Hospitals.

eni Board of Directors Meeting 19th November, Cologne, attended by Maggie Aldwin, Trustee, and President of the eni. Maggie met with the other board members of eni to sign and finalise the registration of eni. Dr. Schmitz and Dr. Piehler were the notaries who witnessed our signatures. Geske Wehr, CEO of eni showed the group a little of Cologne before everyone had dinner together in a typical German Bierhaus. The following day the group met again for the first eni BOD meeting.

Dermatology Continuing Professional Development (DCPD) Society Meeting 20th November Mandy went back to Cardiff to attend this meeting for GPs and GPwSIs in Dermatology. All delegates have taken an academic course at Cardiff University as a GP to further their knowledge of dermatology. By attending this the ISG was able to raise awareness and the profile of ichthyosis and the ISG amongst primary care!

Diary Dates

5th December ISG Conference call 8pm
9th December RDUK and AMRC workshop on rare disease research, London information leaflet
23rd January Regional contacts meeting, Great Ormond Street Hospital 12-4pm.
27th January Psychodermatology UK Annual General Meeting, London

Forthcoming Events 2011

April Sophie Trotter (ISG member) will be taking part in a sky dive arranged in conjunction with the Eggborough Community Sixth Form College in Plymouth. This is to raise funds for the ISG in support of her mum who has ichthyosis.

May EURORDIS General Assembly and Annual Membership Meeting 13th-14th May Amsterdam.

May eni assembly May 15th, 2011 in Amsterdam.

May German SI (support group) annual meeting, May 27th - 29th in Rehe when they will be celebrating their 15th anniversary. They are inviting 2-4 teenagers from all eni member countries to attend.

June ISG Family Conference 18th-19th June.

September French Ichthyosis Association, Avène, is celebrating it’s 20th anniversary, September 16th-18th.

October eni board meeting October 21st -23rd, Rome
News

**Incorporation of the ISG** Rex Codling, ISG Treasurer, and Maggie Aldwin, ISG Trustee, have been meeting with Solicitors and seeking legal assistance working towards the incorporation of the ISG to become a company limited by guarantee. This is now moving forward and should be completed some time next year.

**New Regional Contact Co-ordinator** Yvonne Peet, member of the ISG and grandmother of a child with ichthyosis, has formally agreed to take over the role of Regional Contact Co-ordinator, enabling Claire Winter, previous Regional Contact Co-ordinator, to focus on other projects within the ISG Structure. We welcome Claire back to the ISG following her Sabbatical.

**Funding Applications** Ros Taylor, Fundraising Consultant, has been working with members of the ISG committee helping to identify the funding needs of the charity. During this process, Ros has spent time identifying where these needs fit into funding opportunities through various Trusts, Foundations and other funding organisations. So far, with Ros’ help, we have made more than 10 applications for funding during the last 2 months for various projects. These include a full time salary for a new job role of project co-ordinator, a youth camp and an information / literature pack project for health professionals and those affected by the condition. Thanks to Ros’ input, the process of applying for funding will be an ongoing task that will be undertaken as part of the role of the project co-ordinator.

**ISG in the Media** The Whitehouse family were due to appear on the ‘This Morning’ TV programme with Patron Phillip Schofield on the 16th November, however, this has now been postponed until the New Year. Date yet to be confirmed


**ISG Youth Forum** At the last trustee meeting on 7th November Jenni Robertson, ISG Member, and her teenage daughter, Lauren, joined the committee to discuss the setting up of an ISG ‘Youth Voice’. Jenni works for ASDAN, a development organisation and internationally recognised awarding body, that offers awards and qualifications [http://www.asdan.org.uk/Award_Programmes/Volunteering_SC](http://www.asdan.org.uk/Award_Programmes/Volunteering_SC). ASDAN has an award for volunteering and our youth members could work towards achieving this. Both Jenni and Lauren have agreed to help move this project forward and try to reach out to the youngsters affected by ichthyosis, who are the potential future of the ISG, by creating a youth sub committee within the ISG. Empowering our teenage members to help move the work of the ISG forward will enable them to have a voice and let them know they are not on their own.

**New ISG Website Soon to be Launched** Mike Davies, member of the ISG and father of an affected adult, has been assisting the ISG to set up and re design the website. Although this is taking time, progress is being made and soon our new look website [www.ichthyosis.org.uk](http://www.ichthyosis.org.uk) will go live. Please keep visiting the site and soon you may see some changes.

**PO Box address has changed** Please note our new address is PO Box 1404, Bagshot GU22 2LS. Please be aware the literature you have may have the old address on it. The six month crossover period, where mail will be redirected, has been extended for a further six months and will expire at the end of June 2011.

**Useful Links**

**Easy Fundraising & Easy Search** To help raise money for the ISG register at [http://www.easyfundraising.org.uk](http://www.easyfundraising.org.uk) to shop online with over 2000 well known retailers. Also go to [http://www.easysearch.org.uk](http://www.easysearch.org.uk) search engine and select the Ichthyosis Support Group, both are free to use.


**Ebay for charity**—donate a % to the ISG from your online sales.

**Give as you earn**—Why not complete the following form and donate straight from your wages [http://www.cafonline.org/pdf/GAYE_0971B_DIF_180609.pdf](http://www.cafonline.org/pdf/GAYE_0971B_DIF_180609.pdf).
Members and Fundraising

Justgiving Currently we have 14 live justgiving pages:

- http://www.justgiving.com/Mekhi-Barbour-Poker  Amy Moxham
- http://www.justgiving.com/Mekhi-Barbour-SpeedDating  Amy Moxham
- http://www.justgiving.com/Laura-Levy  Laura Levy — Fundraising for her son Mekhi
- http://www.justgiving.com/Yvonne0  Richard Peet — 30 mile cycle ride during Ichthyosis Awareness Week
- http://www.justgiving.com/Emma-Picken  Emma Picken — Ichthyosis Camp
- http://www.justgiving.com/Maggie-Aldwin  Maggie Aldwin — Leila's 6km walk 17th August 2010

Donations & Fundraising

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

Jean Robinson, Nurse Specialist for ichthyosis and part of the ISG Medical Advisory Board (MAB), who raised money for the ISG by asking party guests to donate money to charity instead of buying presents. Thank you to Jean and all those who kindly made donations.

Thank you to:
Great Midlands Fun Run Organisation
Neil, Richard and Kerry Orton
All those who took part in the Walk For Skin this year which raised nearly £1500 for the ISG.

Who have all made donations or carried out fundraising events last month

The ISG Needs Your Help

Media volunteers needed! Launch of RDUK publication: "Experiences of Rare Diseases: An insight from patients and families" To accompany the launch on the 6th December 2010, RDUK is hoping to get media coverage to raise awareness of rare diseases and some of the issues faced by patients and families. These include: Accessing a correct and timely diagnosis, the availability of information about the condition, accessing the range of support needed, accessing treatment coordination of care, the availability of information and the ability to participate in research.

If you, or anyone you know, is interested in raising awareness of the need to create a strategy for rare diseases please download and complete the form Download the form (Word doc.) and return it to stephen@raredisease.org.uk at RDUK. Please note – anyone submitting this form must be happy to be interviewed by the media and the possible publication of their story appearing in the press.

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 know of any members who fall into this category and may like to take part, please ask them to contact Dr Jan Idkowiak j.idkowiak@bham.ac.uk

X Linked Study Wales - request for participants Dr William Davies, at Cardiff University, is carrying out a study looking at people in the Cardiff area affected by X-linked ichthyosis - compared to their non affected male siblings. If you know of any members, who may be willing to participate, please ask them to contact William Davies daviesw4@cardiff.ac.uk

What Matters to Patients Project
A study, commissioned by the Department of Health and the NHS Institute for Innovation & Improvement, aims to strengthen the evidence base for understanding and improving patient experience. The study is being conducted, over a nine-month period, by researchers from the National Nursing Research Unit, King’s College, London and the Point of Care Programme at The King’s Fund. For more information, or to take part in this survey, please contact Dr Glenn Robert glenn.robert@kcl.ac.uk or Jocelyn Cornwell j.cornwell@kingsfund.org.uk This Project finishes January 2011