Paediatricians Dermatology Course at Birmingham Children’s Hospital May 27th. Mandy and Maggie Aldwin, Trustees, attended this course for Specialist Registrars in dermatology. Mandy gave a presentation based on patient experiences of dermatology appointments, giving an insight into patient perceptions, with the aim of improving services as well as highlighting the importance of support groups.

Walk for Skin During June more walk for skin events took place - 6th June-Southampton, 13th June-Fife, 27th June-London. This year we had 4 walkers for London but unfortunately none signed up for Southampton or Fife.

Flora Women’s Mini Marathon Monday 7th June Mary Kneafsey, Irish regional contact, and Edel Kenny, member, took part in Dublin and supported the ISG. [http://www.womensminimarathon.ie/](http://www.womensminimarathon.ie/)

Dermatology For Paediatricians Course Heartlands Hospital, Birmingham 8th-10th June. Mandy and Maggie Aldwin, Trustees, were invited by Dr Helen Goodyear to attend this course for Paediatricians on 9th June. Mandy gave a presentation based on patient experiences of dermatology appointments, giving an insight into a patient’s perception with the aim of improving services. The talk also highlighted the value of informing patients about the existence of support groups.

Dermatology meeting for London GP’s with Special Interests June 14th (GPwSIs). Liz Dale, ISG Administrator & Mandy Aldwin, Trustee, attended with the ISG stand and literature to raise awareness of both the ISG and ichthyosis.

Skin Care Campaign meeting 17th June Cancelled by SCC [http://www.skincarecampaign.org/](http://www.skincarecampaign.org/)

Buggy walk 19th June More than 100 people arrived at Stanwick Lakes, Northamptonshire in memory of baby Freddie who sadly passed away last year at just 12 weeks old suffering from a severe form of ichthyosis. Liz Dale, ISG administrator, and family took part in the walk whilst Maggie & Mandy Aldwin, Trustees helped to raise awareness by manning the ISG stand and selling merchandise. Freddie’s parents Becky Jeffery and Darren Pattenall were overwhelmed at the support shown. [www.justgiving.co.uk/baby-freddie](http://www.justgiving.co.uk/baby-freddie) They have so far collected £4000 in sponsorship.

London to Brighton bike ride 20th June Steve Stringer, a friend of Becky Jeffery, Cycled 54 miles for the ISG.

BSF Summer Fete London 27th June marked the end of the walk for skin, Fitzroy square, 1-6pm.

### Diary Dates

**BAD Conference, Manchester 6th—8th July**
Clive and Mandy will be attending this year’s British Association of Dermatologists (BAD) Conference and will report back.

**NCG Meeting July 16th**
Liz Dale, ISG Administrator, & Mandy Aldwin, ISG Trustee, attending with members of the Medical Advisory Board.

**ISG Trustee meeting 8th August**
BMW Sytner High Wycombe 12—4pm

### Training & Courses

**Charity Comms Seminar 15th July**
Focusing on communication within the organisation.

**NCVO Data Protection and Communications for the voluntary Sector September 6th**
10-4pm London looking at relevant areas of data protection including developments in recent legislation.

If anyone would like further details for any of the training or would like to attend, please contact Liz [liz@ichthyosis.org.uk](mailto:liz@ichthyosis.org.uk)

Not all training courses are free and will have to be agreed by the trustees prior to booking.

### Forthcoming Events

**Council of European Rare Disease Federations**
Geske Wehr, from Germany, currently managing the European Network for Ichthyosis [eni@ittiosi.it](mailto:eni@ittiosi.it) (eni), will be attending 3rd Workshop in Paris 1st & 2nd July representing eni.

**Changing Faces 17th July**
Early Years Day, 10:30-16:00, Birmingham. Focusing on parents/carers’ experience of bringing up a child (0-5 years old) with a condition that affects his/her appearance.

**Isle of Wight Beach Soccer 15th August**
An annual charity event supporting the ISG run by the husband of one of our members living in the Isle of Wight [http://www.iwbsa.com/events.php?EID=33](http://www.iwbsa.com/events.php?EID=33)

**Changing Faces 11th September**
Explore Space Day, Glasgow 11.00 am for children and adults who have a condition affecting their appearance. The day will focus on confidence building, other people’s reactions, meeting others and having fun. For more information visit [www.changingfaces.org.uk](http://www.changingfaces.org.uk) or e mail [michelleb@changingfaces.org.uk](mailto:michelleb@changingfaces.org.uk)
News

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 wrong address. However, there will be a 6 month crossover period where mail will be redirected.

ISG Website to get a makeover We are in the process of looking into updating our website www.ichthyosis.org.uk so please keep visit the site and soon you may see a new look.

Claire Winter taking a 6 month sabbatical. Claire will be stepping down from the ISG for a while due to reasons associated with her health. During Claire’s sabbatical she will be missed as Regional Contact Coordinator for all the hard work she puts into the group. If anyone would like to take over this role during Claire’s absence please contact Liz Dale liz@ichthyosis.org.uk or 0845 602 9202

New Regional Contacts We have a new Regional contact on board. Yvonne Peet will take on the role of Regional Contact for London & the Thames Estuary.

Specialist Clinical Service for Ichthyosis Mandy Aldwin and Liz Dale, along with members of the Medical Advisory Board (MAB), are meeting with Dr Martin Ashton-Key, medical advisor for the National Commissioning Group (NCG), on the 16th July to discuss submitting an application to hopefully obtain funding into a specialist clinical service for ichthyosis sufferers.

ENI based in Germany Geske Wehr will be managing (continue to manage) eni from Germany. Her role has yet to be determined but she will remain the main contact for eni eni@ittiosi.it. Geske, representing the eni, attended a European Translational research on Ichthyosis (ENTRI) meeting in Maastricht at the beginning of June. Details of this will be published in the August edition of the ISG E Bulletin.

Philip Schofield as ISG Patron Philip has agreed to be patron for the ISG. This agreement is currently in name only but what great news to have such a respected TV personality supporting the Ichthyosis Support Group.

ISG has joined Genetic Alliance UK (formerly Genetic Interest Group), a national charity of over 130 patient organisations, supporting all those affected by genetic conditions. Genetic Alliance seeks to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them. For more information about Genetic Alliance please visit http://www.geneticaaliance.org.uk

Mölnlycke Medical Devices Company Supporting the ISG Following a meeting with Mandy Aldwin, ISG Trustee and Paul Whitehouse, ISG Chairman, Mölnlycke (which produces Epaderm and Tubifast) has agreed to provide PR support via its agency, Indigo.

Glaxo Smith Kline (GSK) to review treatments for ichthyosis Emilio Arbe, independent pharmaceutical professional working with Steifel pharmaceutical company, advised us that the orphan indications team at GSK are going to have a fresh look at liarazole and other potential treatment for ichthyosis.

National Honours Professor Andrew Finlay was awarded a CBE in the Queen’s Birthday Honours list for services to medicine with reference to his work in dermatology and the development and validation of the Dermatology Life Quality Index (DLQI) http://www.cardiff.ac.uk/news/articles/queens-birthday-honours.html

Pride of Northamptonshire Award Becky Jeffery, member, has been nominated for this award for fundraising by a local reporter who has followed her story and efforts for organising the ‘buggy walk’ over the last few months.

£105,541 awarded for research into ichthyosis Action Medical Research awarded £105,541 to David Kelsall for a 2 year project identifying mutations in HI parents’ genes and studying HI skin cells to find out how they differ in the proteins and fats from healthy skin. www.action.org.uk

YP Face it A project, being carried out by Centre for Appearance Research at the University of the West of England, which involves developing an online CBT programme for young people with visible differences. The ISG is supporting this research by posting a link to the survey on our website, and on facebook with the hope some of our members will participate in this new area of research Romantic Relationship Survey

Taiwanese Ichthyosis Patient Centre opens A Kaohsiung association for ichthyosis patients centre has been given permission to open in Kaohsiung Metro rent free for 1year. http://www.etaiwannews.com/etn/news_content.php?id=1274192&lang=eng_news&cate_img=logo_taiwan&cate_rss=TAIWAN_eng
The ISG Needs Your Help

TV Documentary, request for people to participate
For more information please contact hannah.runham@mentorn.com or visit http://www.mentorn.tv

X Linked Study Birmingham - participants wanted! The University of Birmingham and Birmingham Children’s Hospital have jointly set up a research study in boys and men with X-linked recessive ichthyosis (XLI) aged from 6 to 30 years. If you know of any members who may like to take part, and fall into this category, 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 please ask them to contact William 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 by researchers from the National Nursing Research Unit, King’s College London, and the Point of Care Programme at The King’s Fund, over a nine-month period. 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

Rare Disease UK’s Survey of Patients’ and Families’ Experiences of Rare Disease Paper copies of the survey will be sent to all ISG members. Alternatively you can access it via the following link http://www.surveymonkey.com/s/QZJM8PP

Members and Fundraising

Justgiving Currently we have 10 live justgiving pages:

- Rebecca Jeffery—Buggy Walk 19th June 2010—Raised so far £2054.82
- Ellamay Dale—Buggy walk 19th June 2010—Raised so far £165.00
- David Roberts—2000 mile cycle ride during May 2010—Raised so far £1200.00
- Rebecca Towers—Sky Dive 17th September 2010—Raised so far £140.00
- John Dale—30 mile cycle ride during Ichthyosis Awareness Week—Raised so far £85
- Melanie Bradley—Walk for Skin 23rd May—Raised so far £40
- Richard Peet—30 mile cycle ride during Ichthyosis Awareness Week—Raised so far £35
- Matt Jeffries—Nethertons 10K walk—Raised so far £5.00
- Matt Jeffries—Nethertons Research Group—Raised so far £76.00
- Emma Picken—Ichthyosis Camp—Raised so far £0.00

Donations & Fundraising

- A member, Jo Wilkinson, Mummy to 3 year old Maya sent in a cheque for £2210.11, which was kindly donated by DHL Logistics from auction of packages damaged in transit for B&Q and not eligible for resale.
- On the 16th May, Mary Judge completed 10k Manchester in 69 minutes for ISG and raised a fantastic £500
- Buggy Walk so far has raised about £4,000 and Becky is still collecting sponsorship. This includes Steve Stringer's bike ride and Debbie Richards’ parachute jump.

New Members Last month 2 new member families contacted the ISG. However, we probably lost as many if not more through returned mail. This could be minimized by keeping regular contact with families through our regional contacts.

Useful Links

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

Facebook Remember to help raise awareness, publicise events and meet new members by registering with and using the ISG facebook http://en-gb.facebook.com/pages/Ichthyosis-Support-Group/301038155873?v=info

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