Last Month

Visit to Krakow On the 15th—16th May, Maggie & Paul attended the ENI meeting in Krakow. European Network for Ichthyosis (ENI), formed by the coming together of likeminded people from European countries who live with or have contact with someone with ichthyosis.

Dave cycles for ichthyosis Dave has been cycling around Britain to raise awareness for ichthyosis. Starting in Southport, he headed south to the Lizard, east to Lowestoft, north to Dunnet’s Head (Scotland) and west to Ardnamurchan Point again in Scotland, then back to Southport. He completed his 1770 mile ride on the 29th of May 2010 raising £500 www.justgiving.com/wheresthepoint http://davemaytour.blogspot.com/2010_05_01_archive.html

PDCDS Presentation Mandy & Maggie attended the Paediatric Dermatology Course for Dermatology SPR’s at BCH in Birmingham on the 27th May and did a presentation about ichthyosis & a patients’ perspective on clinics.

Walk for Skin During May the walk for skin events started off in Cheddar on the 9th where we had 2 walkers, followed by Leeds on the 16th at which we had 4 walkers and Manchester and the Midlands walks on the 23rd attended by 14 ISG walkers.

Ichthyosis Skin Relay During April many members got involved and relayed around the country visiting dermatology departments displaying posters and distributing leaflets. This was a success, thanks to those who promoted this event. Our Regional Contacts did a fantastic job such as Sophie Newman- I.O.W, Mary Kneafsey- Eire, Saeeda-Asian contact, Gill & Theresa Davis -Wales & Gloucester, Sam Bowen- Anglia who either participated or organized an event. We estimate this event enabled us to get over 100 more hospitals to display our poster and so raise awareness further.

Medical Devices Company Mölnlycke Health Care Ltd supported our relay. During ichthyosis awareness week Mölnlycke reps distributed our posters to GP surgeries across the country and paid half (£350) towards the cost of printing.

Manchester 10K Run Mary Judge took part in this raising money and awareness for the ISG. On Sunday 16th May Mary ran the 10k wearing her ISG T-Shirt in just under 70 minutes. Well done Mary.

Forthcoming Events

Buggy walk 19th June Becky Jeffery has organised a sponsored walk around Stanwick Lakes, Northamptonshire, at 2pm to help raise awareness and money for ichthyosis. This event is in memory of her son Freddy who sadly died last year at just a few months old and will mark what would have been his first birthday.
www.justgiving.co.uk/baby-freddie

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

Walk For Skin
6th June-Southampton
13th June-Fife
27th June-London - 2 walkers signed up

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

Flora Women’s Mini Marathon Monday 7th June Mary Kneafsey, Irish regional contact, is taking part in Dublin and is running for the ISG.
http://www.womensminimarathon.ie/

Diary Dates

Trustees Meeting, 13th June. There will be lots to discuss at this meeting as it will have been some time since we all met. Please remember to let Sue know your suggested items for the agenda in plenty of time.

BAD Conference, Manchester 6th—8th July
Clive and Mandy will be attending this years BAD conference and will report back.

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. Contact kathryn@changingfaces.org.uk By June 29th

Training & Courses

June 9th Cascade ‘Writing for the Web’ 10-4pm London

10th June Clare Foundation ‘Funding from Trusts and Foundations’ Buckinghamshire

24th June Developing a Communications Strategy in a Changing World, Charity Comms, St Albans

If anyone would like further details for any of the training or would like to attend, please contact Liz liz@ichthyosis.org.uk Not all training courses are free and will have to be agreed by the trustees prior to booking.
ENI Moving forward Maggie becomes President.

At the founding meeting of the eni Maggie was voted to become its president. Delegates attending Maggie Aldwin (UK), Paul Whitehouse (UK), Annette Brunner (Switzerland), Geske Wehr (Germany), Kirstin Kiekbusch (Germany), Kristina Baer (Germany), Dorota Balk (Sweden), Sandra Lystad (Norway), Trude Kvaloy (Norway), Flavio Minelli (Italy), Mateusz Drygas (Poland). Statutes and Board of Directors agreed. Maggie Aldwin President, Falvio Minelli Vice President, Kirstin Kiekbusch Treasurer.

ISG awarded more than £13,650 grant for the 2011 conference. Following Ray’s presentation in London in December 09 the ISG were awarded this huge sum by ‘Jeans for Genes’

Justgiving Currently we have 6 live justgiving pages:
- Rebecca Jeffery—Buggy Walk 19th June 2010—Raised so far £532.82
- David Roberts—2000 mile cycle ride during May 2010—Raised so far £500
- Rebecca Towers—Sky Dive 17th September 2010—Raised so far £140
- John Dale—30 mile cycle ride during Ichthyosis Awareness Week—Raised so far £85
- Anthony Curtis—Head shave for charity 20th March 2010—Raised so far £45
- 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

Donations & Fundraising
- Salsbury £25
- Saeeda Rangzeb £50
- Mr/s S Baker £30
- Bill Ellis £20
- Mr/s McNiven £100
- and via Joe Wilkinson and an auction by DHL for B&Q stores damaged packages £2210.11

New Members Last month 5 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.

PO Box address to change Maggie is handing over the ISG mail to Liz as of the 11th June and so the PO Box address will be changing (details to follow) so 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.

Liz has returned from Maternity leave After having a baby on April 1st 2010, Liz returned to work with the ISG on the 17th May. Maisy June Dale was born without ichthyosis and is so far behaving herself.

The ISG Needs Your Help

Media volunteers needed for Jeans 4 Genes As part of the conditions for getting the J4G grant the ISG are required to provide at least 4 case studies for J4G to use in there media publicity campaign. They also require people to be speakers at schools to promote the J4G charity as a one off to talk about ichthyosis. If anyone is interested or can recommend a family please let Liz or Maggie know.

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

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

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

face book 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 www.cafonline.org/pdf/GAYE_0971B_DIF_180609.pdf.