March 2012

ISG E BULLETIN

Issue 21 March

Last Month

Dermatology Council for England (DCE) Meeting 9th February Mandy Aldwin, ISG Trustee, attended the DCE meeting in London, representing the ISG. For more information please visit: www.dermatologyengland.org.uk

Skin Care Campaign (SCC) Meeting 23rd February Members of the board of directors for the SCC joined Patient Support Groups to discuss the existence of the umbrella organisation the SCC. Due to lack of funding, being the main issue encountered by the organisation, it is likely the SCC will cease to exist in the future.

All Party Parliamentary Group on Skin Session 28th February Changing Faces www.changingfaces.org.uk invited Mandy Aldwin, ISG Trustee, to join them in a session highlighting the psychological impact of having a skin condition to MPs.

Royal Holloway College Rare Disease Day Event 29th February Liz Dale, ISG Administrator, and Yvonne Peet, ISG Regional Contact Coordinator, went along to the Royal Holloway, University of London, who hosted the largest Rare Disease Day event in the UK on 29 February 2012 - a rare day itself as it is a leap year. The event was well attended by school children, charities and those affected by rare diseases giving the ISG an opportunity to raise awareness of ichthyosis. Please visit: www.rhul.ac.uk/aboutus/newsandevents/news/newsarticles/royalhollowayhostsukslargestreddiseasedayevent.aspx for more information about this event.

The Royal College of Nursing Dermatology Conference 29th February Maggie & Mandy Aldwin, ISG Trustees, represented the ISG at this event which was well attended by dermatology nurses enabling the ISG to raise greater awareness amongst these health professionals.

ISG Members

‘Pick Me Up’ Magazine 29th March ISG Member and NE Regional Contact, Tammy Smith, will be appearing with her two sons in an article for Pick Me Up magazine.

3 Peaks 24 hr Challenge ISG member John Dale, will be joining a team of 14 lads from Surrey to undertake the 3 Peaks Challenge in 24 hrs to help raise money for the ISG. For more information please visit: www.virginmoneygiving.com/team/3PeaksChallenge-SurreyLads

Forthcoming Events

Andover College Change of Tune Festival, Friday 16th March.
The ISG will be attending this event to help raise awareness of ichthyosis.
For more information please visit: www.andover.ac.uk/?page=Events

ISG Family Day, Saturday 19th May
Please put this date in your diaries and visit our website where information regarding this event will be displayed and updated regularly www.ichthyosis.org.uk

Ichthyosis Support Group is a charitable company limited by guarantee and incorporated in England and Wales. Company No. 7609904, Charity No. 1142457. Registered Address: 562 Wokingham Road, Earley, Reading, Berkshire, RG6 7JB
The ISG Needs Your Help

🥰 Get Involved with your ISG 😍

Do you have some time to spare? Are there any areas within the ISG you think could be improved? Maybe you have a particular interest or skill? Do you simply want to help?

Contact a Family Survey 📝 Deadline 11th March

Contact a Family is calling on parents, and other family members, caring for a disabled child to take part in their important research about the financial situation for families with disabled children.

For more information please visit: [www.ichthyosis.org.uk/3746/contact-a-family-survey/](http://www.ichthyosis.org.uk/3746/contact-a-family-survey/)

My Story and Top Tips 🔖 please keep sending us your ‘Top Tips’ for ichthyosis and sharing your experiences for the ISG’s website ‘My Story’ section by sending them to [isg@ichthyosis.org.uk](mailto:isg@ichthyosis.org.uk)

For more information about how to get involved, please visit the ISG website ‘Get Involved’ pages: [www.ichthyosis.org.uk/get-involved/](http://www.ichthyosis.org.uk/get-involved/)
Top Tips For Ichthyosis

For parents and carers of children with ichthyosis

- Keep them involved and make sure you talk to them about their condition, treatment and care. Ask their opinion on what they want - encouraging them to take control of their condition.
- Make contact with other families, sharing experiences helps and the children do not feel alone.
- As a parent or carer always listen and encourage your child to talk about their condition.
- Involve the school, talk to teachers and students, educate the parents - raise awareness!


Fundraising

On line Fundraising Currently we have 16 live Justgiving pages. www.justgiving.com/isg and 1 Virgin money giving page: www.virginmoneygiving.com/team/3PeaksChallenge-SurreyLads

Donations & Fundraising Thank you to the following who have all made donations, or carried out fundraising events, during the last month:

- Walton Girls High School
- Mrs K McGuiness
- Mrs E M Wilkinson
- Colwyn Bay School

Want to raise some money but don’t have the time? Why not donate straight from your wages: www.payrollgiving.co.uk/ or www.cafonline.org/my-personal-giving/plan-your-giving/caf-give-as-you-earn.aspx?, while you shop www.easyfundraising.org.uk/ or www.ebay.co.uk/ebayforcharity/ or www.shop2fundraise.co.uk/directory.php?Ichthyosis+Support+Group or even when searching the Internet www.easysearch.org.uk/ - with no effort at all!

For details of ‘Text Giving’ please visit: www.ichthyosis.org.uk/3075/support-us-with-a-text/

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.

If you have an ISG collection box, please do not forget to empty it and send in your cheques.

Useful Links

European Network for Ichthyosis: www.ichthyose.eu/, support groups across Europe

Contact a Family: www.cafamily.org.uk/ can help with benefit advice

Changing Faces: www.changingfaces.org.uk for psychological support

Please visit the ISG website for more useful links www.ichthyosis.org.uk/links/