August 2012

ISG E BULLETIN

Issue 26 August

Last Month

BAD 92nd Annual Meeting & BDN 22nd Annual Meeting 3rd - 5th July

Mandy & Maggie Aldwin attended the annual British Association of Dermatologists and British Dermatological Nursing Group conference, which was held in Birmingham in July. Continuing on from previous years, the ISG exhibited at the event to raise awareness of ichthyosis and the ISG amongst Dermatology Consultants and Dermatology nurses. These events are also an excellent opportunity to establish and maintain working relationships with pharmaceutical companies, a number of whom already support the ISG with financial sponsorship.

Ichthyosis in the Media

ISG member Nelly Shaheen appeared on Channel 4’s TV show ‘Beauty & the Beast: The Ugly Face of Prejudice’ last month on the 24th July. Twenty-one-year-old glamour model Holly Kent meets 27-year-old Nelly Shaheen where they share their views and experiences of appearance and discrimination. To view the show please visit: www.channel4.com/programmes/beauty-the-beast-ugly-face-of-prejudice/4od#3384079

ISG on Facebook

We all know social media sites are the place to be if you want up to date and instant information. The Ichthyosis Support Group has a well established Facebook page where you can stay in touch with any new ‘happenings’ and events. We encourage you to post messages, make contact with other members and share your experiences with others affected by ichthyosis. To visit and join us on Facebook please go to www.facebook.com/pages/Ichthyosis-Support-Group/301038155873

We would like to hear your experiences of living with ichthyosis and share these on our ‘My Story’ page of the website: www.ichthyosis.org.uk/category/my-story/ Please send ‘Your Story’ to: isg@ichthyosis.org.uk. Have you ever thought about raising awareness, volunteering, becoming a trustee, fundraising, holding a regional event or any other ways of getting involved with your ISG? If so please let us know. For information about how to get involved with your ISG please contact us or visit our website pages Get Involved www.ichthyosis.org.uk/get-involved/

ISG Members

The ISG welcomed 10 new members during July

Covering regions of the UK:
London, Central, Anglia, Wales, West Midlands, NW

Welcome also to those from the rest of the world:
USA, Canada and India

Events In August & September

Ichthyosis Support Group Beach Soccer Charity Cup 12th August
Appley Beach, Ryde, Isle of Wight
www.hampshirefa.com/News/2012/06/IchthyosisSupportGroupBeachSoccer-CharityCup.htm

BDNG Paediatric dermatology nurses meeting, 13th September, Liverpool. ISG Trustee, Mandy Aldwin, will be presenting on behalf of the ISG. For more information visit: www.bdn.org.uk/events/educational_meetings/ess_paeds.html
Top Tips For Ichthyosis

Do you have any tips for living with ichthyosis you would like to share with others?

- Maybe you have discovered a product that has changed your life.
- Maybe you have some practical tips about the management of ichthyosis.
- Do you have a unique way of doing something to help make life easier when living with ichthyosis?

Please send us your experiences and tips and help others discover new ways of dealing with ichthyosis. isg@ichthyosis.org.uk

Fundraising

Thank you to those who have made donations or carried out fundraising events in the last month:

Mr J Butler who kindly donated money received for his birthday in lieu of presents from friends and family

With no government funding you are the main reason the ISG exists. Without your hard work the ISG would struggle to support those affected by ichthyosis and would not be able to support ongoing medical research.

Remember 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 donations.

Want to raise some money but don’t have the time?

Why not donate straight from your wages, as you shop or even whilst searching the Internet with no effort at all!

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

Research

Psychological affects of living with ichthyosis The Centre for Appearance Research, UWE and the Ichthyosis Support Group are looking for young people to test out, in their own homes, a new 7 week online support programme, called ‘YP Face It’, for young people who have worries because of a condition that affects appearance. It has 7 weekly sessions and uses interactive and learning activities, illustrations, videos, audio, photos and advice from other young people with a condition that affects appearance, to help young people feel and act more positively and confidently. If you’re interested in finding out more about this study, please contact the researcher, Catrin Griffiths, on 01173283947 or email catrin.griffiths@uwe.ac.uk