Last Month

3 Peaks 24 Hour Challenge 17th June Following a disastrous attempt at the ‘3 Peaks 24 hour Challenge’ on the 20th April 2012, where bad weather took hold leaving the lads all stranded on Scafell Pike for 12 hours, they bravely made a second attempt at the challenge. On Sunday 17th June, 8 members of the original team took on the challenge again, setting off at 7:07am from the foot of Ben Nevis and finishing at the bottom of Snowdon at 6:20am, Monday morning, completing the challenge in a total time of 23 hours and 13 minutes. With a 25% success rate for this challenge and using a 62mph restricted minibus, the time was quite impressive. The lads have raised £6,552.27 www.virginmoneygiving.com/team/3PeaksChallenge-SurreyLads

Paediatric Dermatology Course, Heartlands Hospital, Birmingham, 20th June Raising the profile of ichthyosis amongst the medical profession is such an important challenge. We would assume, as parents, the doctors our children are referred to are experienced and knowledgeable of ichthyosis. However, being such a rare condition many dermatologists see very few cases and often lack the experience and expertise to manage and treat children effectively. The ISG regularly rises to this challenge, attending training days for doctors and nurses. Last month Mandy Aldwin, ISG Trustee, presented and talked to Paediatric Dermatologists in Birmingham, giving a patients’ perspective into living with ichthyosis.

Rare and Complex Dermatology Services Engagement Event, London, 27th June The ISG has been working closely over the last few years with dermatologists and the National Specialised Commissioning Team (NSCT) to improve services for people with ichthyosis. Last month another meeting was held in London to develop the design of a model of care for a Rare (and Complex) Dermatology Service. Maggie and Mandy Aldwin, ISG Trustees, attended this event to represent the voice of patients with ichthyosis. This is a positive step forward for dermatology and it is ahead of most other health/condition groups in working out their structure within the new commissioning framework. Dermatology is one of 2-3 pilots and will be a focus for other groups to learn how a service for specialised dermatology is structured and put into practice.

ISG Members

The ISG welcomed 15 new members in June!

Covering regions of the UK:
Scotland, NE, E&W Mids, Wales, Anglia and the South.

Welcome also to those from the rest of the world:
Australia, NZ, Singapore, Canada, USA and Holland

Forthcoming Events

Specialised Healthcare Alliance (SHCA) Meeting
11th July, London
Mandy Aldwin will be representing the ISG www.shca.info/

‘Annual Ladies Night At The Bridewell’
27th July, Liverpool
ISG Member, Faye Calvey, is helping to organise this awareness and fundraising event in support of the ISG.

Ichthysis Support Group Beach Soccer Charity Cup
12th August Appley Beach, Ryde, Isle of Wight
www.hampshirefa.com/News/2012/06/IchthysisSupportGroupBeachSoccerCharityCup.htm
Research Grants The Ichthyosis Support Group is keen to see medical advances in the treatment of ichthyosis and is committed to giving an annual small grant for UK based research. Last month saw the deadline for applications which will now be considered by the ISG Medical Advisory Board (MAB). The successful applicant will be notified by the end of August following which we will be pleased to announce details of the small grant awarded and the research it will support.

Psycho-social Services for Patients Changing Faces (CF) [www.changingfaces.org.uk](http://www.changingfaces.org.uk) is currently running a campaign called ‘Look at Me’ directed at NHS commissioners and health and social care professionals of dermatological services in England. Its focus is to advocate for improved psycho-social services for patients and their families. CF would like adults to tell their stories - by filling in a survey, taking part in a focus group or giving a one to one interview. For more information contact Henrietta [henrietta.spalding@changingfaces.org.uk](mailto:henrietta.spalding@changingfaces.org.uk). Or if you would like to complete the survey please visit: [www.surveymonkey.com/s/CGJQBQW](http://www.surveymonkey.com/s/CGJQBQW).

Contact a Family Launches Counting the Costs 2012 Contact a Family has launched its latest research ‘Counting the Costs 2012’ following a survey they conducted earlier this year. Findings show that families are going without essentials and getting into debt before the full impact of benefit cuts is felt. As a result of this, Contact a Family is calling on the government to exempt families with disabled children from cuts to financial support and to target additional support to families through Universal Credit when they publish details of the new single monthly payment. They have launched a campaign to raise awareness of the financial hardship for families with disabled children. and urge you to take action now! For more information please visit: [www.cafamily.org.uk/](http://www.cafamily.org.uk/)

ISG Regional Contacts are there to support you locally and help people in their area to make contact with each other. The UK is split into 12 regions, each region has at least 1 regional contact but the Southwest does not have a Regional Contact at all. If you live in the SW of England (or any part of the UK) and think this is a role you would like to take on please let us know by emailing: [isg@ichthyosis.org.uk](mailto:isg@ichthyosis.org.uk) or calling 0845 602 9202. Would you like to organise a local event but not sure how to go about it? If you would like to get in touch with your Regional Contact but are not sure how to please let us know.

Your Ichthyosis Support Group

Members Views
[www.ichthyosis.org.uk/members-views/](http://www.ichthyosis.org.uk/members-views/)

Please keep sending us your ‘Top Tips’ for ichthyosis by sending them to: [isg@ichthyosis.org.uk](mailto:isg@ichthyosis.org.uk)

Get Involved
For more information about how to get involved in your ISG please visit the website [www.ichthyosis.org.uk/get-involved/](http://www.ichthyosis.org.uk/get-involved/)

You can also email us your ideas: [isg@ichthyosis.org.uk](mailto:isg@ichthyosis.org.uk) or talk to us 0845 602 9202
Top Tips For Ichthyosis

**Body garments and clothing** - For most people with ichthyosis the continuous efforts in trying to keep the skin moisturised and prevent it from drying can create a huge burden and impact on daily living. Sometimes there are more troublesome areas than others, particularly around areas in constant use such as hands and feet, babies and young children may find it difficult to get comfortable.

Our members tell us that special body garments and clothing really do work and help to keep the cream on the skin, ease discomfort and help reduce the build up of scaling. For some this requires full body suits all the time, while others may wear them at night only. Some prefer to use garments for specific areas that may be more troublesome such as legs, hands and feet. Most of these garments come in various shapes and sizes and may be available on prescription. For more information please visit our website here: [www.ichthyosis.org.uk/pharmaceutical-companies/](http://www.ichthyosis.org.uk/pharmaceutical-companies/) where you will find links to relevant companies.

Fundraising

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

Lucy Hill & Alicia Williams who baked cakes in support of Lucy’s cousin, Annabelle Whitehouse

The Swannick Family

The Dicker 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/](http://www.ichthyosis.org.uk/3075/support-us-with-a-text/)

Tell Us Your Experiences

**My Story** Please visit our website to read how people cope with living with ichthyosis. You may be surprised how positive and determined people are when faced with an added struggle in life. These stories are very positive and encouraging, particularly for parents and children unsure what the future holds. You can read the experiences of Bill, Ted, Emma, Nusrit and Yael here: [www.ichthyosis.org.uk/category/my-story/](http://www.ichthyosis.org.uk/category/my-story/) and if their stories inspire you to put pen to paper please send us yours to: [isg@ichthyosis.org.uk](mailto:isg@ichthyosis.org.uk)