



Ichthyosis Support Group Newsletter

Spring 2011

'People who care about ichthyosis'

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ISG member
Daniel Dicker
pictured with
Phillip in 2006

TV Presenter Phillip Schofield becomes Patron of the ISG

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Dear Member

With Spring in the air and the sun making regular welcome appearances lets try and forget about the gloomy economical outlook for a moment and focus on some good things that are happening within the ISG. Your Board of Trustees are working on a number of initiatives and I highlight just a few of them below.

We are delighted to receive the support of well known personality Phillip Schofield who is lending his name as Patron to the ISG. A very big thank you to Phillip for supporting us in this way.

Another thank you goes to one of our members Mike Davies who volunteered a while ago to develop a new website for us. Working with Mandy Aldwin and Liz Dale, Mike has produced a fantastic site for the ISG which will take us forward. Visit www.ichthyosis.org.uk

We are pleased to announce the introduction of the ISG's very own Youth Forum. Suggested by members, Jenni and Lauren Robertson, we hope the Youth Forum will provide a platform for our younger members to champion new ideas.

As we develop as an organisation we need to review the governance issues that face us and with that in mind we are moving the status of the ISG into an incorporated entity. Read more about this later in this newsletter.

Don't forget the diary date of the year! No, not the royal wedding but the ISG conference which takes place on the 18th/19th June in London. I look forward to seeing you there.

Last but by no means least I would like to extend recognition and a big round of thanks to Clive Bowen, a founder trustee, who after many years of loyal service to the ISG, has decided to step down as a trustee. We wish him well and look forward to catching up with him at member events.

In the meantime remember this is your charity, please support it with your fundraising efforts. Every little helps!

Kind regards,

Paul Whitehouse, Chairman

TV Presenter Phillip Schofield becomes a patron of the ISG

We are delighted to announce TV Presenter Phillip Schofield has become a patron of the ISG. Several ISG families have appeared on ITV's show This Morning, for which Phillip is one of the current presenters.



Image courtesy of ITV.com

Phillip Schofield says: "Over the years in the course of my work in television I have met several individuals and their families who have been affected by ichthyosis. It gives me great pleasure to be able to offer my name in support and recognition of the Ichthyosis Support Group, whose work in offering advice and guidance for this difficult and misunderstood congenital condition is vital in helping individuals and families deal with the impact that ichthyosis has on their lives."

You may also recognise him from the TV shows Dancing on Ice and The Cube.

ISG on Facebook

Become a fan of the Ichthyosis Support Group and keep up to date with the latest news and event details. It's a great way of viewing photos from our past events, including the last Funday at Thorpe Park. Members can upload photos from events they have held or attended too! It's also a fantastic means to communicate with other members and people living with ichthyosis from all over the world!



ISG's 'Youth Forum'

Is there a young member in your family who would like to help influence the future of the ISG, and give us a valuable insight into what they want from the organisation?

Would they like to be part of a youth forum?

An exciting new initiative of the ISG is to create a 'youth forum' for ichthyosis in the UK and Ireland. We'd like to get young people directly involved in the planning and influencing of forthcoming ISG events, including our family days and fundraising. If you are under 21, or your child(ren) are between the ages of 13 and 20, and would like to get involved with helping to mould the future direction of the ISG, email us at

isg@ichthyosis.org.uk. If you have any questions or comments please contact us.



Isle of Wight Beach Soccer returns for 3rd year

For the 3rd year running the Isle of Wight Beach Soccer event is hosting the Ichthyosis Charity Cup. The event will be held on Appley Beach, Ryde on Sunday 3rd July 2011. Join the fundraising event to support the players, meet other families, enjoy a BBQ, music and raffle all whilst raising awareness of ichthyosis.

ISG's New Website launched

We are delighted to announce that the ISG's new website is up and running. Please visit the new site for announcements, news, events and, most importantly information about ichthyosis and subjects that are of interest to you. Information will be updated and added to regularly so check back often to see what's new!

My Story

My name is Nusrit Shaheen and I am 27 years old. I have a skin condition called Harlequin ichthyosis and I live in

Coventry with my Brothers and Mum. I had four other siblings who were also born with the same

condition but who died as small children. I am possibly the oldest living sufferer of the condition in the UK.

The things I do to look after myself are that I have to have a bath and cream myself and make sure I have creamed well as my skin will get dry and sore. I cream about 5 to 6 times a day.

I try and not let it stop me from doing what I want like my sport and going out with my friends and going to college.

The best times in my life were going to a school called Sherbourne Fields, which I spent most of my life at from when I was 3 to when I was 19 years old. Some of my favourite moments are participating in sports like the 100 metres sprint and the 200 metres. I also do javelin, swimming, shooting, table tennis and Boccia.

My achievements include swimming 120 lengths for my 1500 metre badge and I have also done the Coventry fun run that was 4½ miles and did it all on foot. I didn't need my wheelchair, which I was very pleased with as I feel this is a major achievement for someone with my disability.

I have participated in the British Skin Foundation's Walk for Skin event, and was featured in local newspapers to promote the walk in Birmingham.



I try and not let it stop me from doing what I want like my sport and going out with my friends and going to college.

I stay positive about my disability but have been through a lot when I was a kid, as I was ill quite a lot and had a few operations but I have come through the other end.

I didn't know that there was a support group until I watched Lucy and Hannah Betts on TV and on the end of the show.

For people out there with this condition don't let it get you down try and stay positive and look after yourself. I notice when I am out with friends or family on an outing they tend to notice that people are looking but I don't notice this.

I was invited to appear on ITV's daytime TV programme This Morning. I found the experience was very good. I was very nervous but I felt very welcomed by Phillip and Fern and they were really friendly and very polite. After my interview I asked if I could have a photo taken with them and have their autograph, so they gave me a signed photo but I still got to have some photos taken with them.

Nusrit Shaheen, West Midlands

Please share your story with us for the next newsletter (no more than 500 words) by emailing it to isg@ichthyosis.org.uk or writing to us at PO Box 1404, Bagshot, GU22 2LS. Send a photo of yourself to accompany your story if you want to!

My Story is written by individuals who want to share with others their experiences of living with ichthyosis. Wherever possible the wording of the story remains the same as the writer's original article. The content of the story is the contributor's views and opinions and not necessarily those of the Editor or the Ichthyosis Support Group.

ISG Funday 2010 - Thorpe Park

In September 2010 families gathered together at Thorpe Park for the ISG Funday.

Are you a parent with an infant with ichthyosis and have loads of why, how and what questions? Are you an adult with ichthyosis and still have loads of questions about the condition? How many other people do you actually know with ichthyosis? Have you even ever met anyone else with the condition?



Members getting to know one another over lunch

At Thorpe Park last September, the ISG Funday brought together 33 ichthyosis families to have a brilliant day out in one of England's best known theme parks. We hired the park's private marquee ensuring we had our own area to mix together and ask all these questions of each other. Do you wish you had come along?

The day was a fairly informal affair. Families were able to spend the day enjoying what the park had to offer, whether it was big scary rides or family friendly rides, the wet and wild rides or the more sedate rides for younger visitors.



Having fun on the rides

Members returned to the marquee for a delicious lunch followed by

the Annual General Meeting (AGM) of the ISG.

The AGM meetings are important because it is an opportunity for us to actually talk to you, our members, about important news or developments, and for you to ask us questions about the ISG. Children were entertained by a magician and learned circus tricks whilst the grown ups held their meeting.

During the AGM the Fundraiser of the Year award for 2009 was announced. The winner for 2009-2010 was the ISG's Calvey family, following the Robbie Fowler Golf Day. The Kenny family from Ireland were the proud recipients of the Irish Fundraiser of the Year award. Congratulations to both families and a huge thank you from the ISG for your generous support.

It was lovely to see old friends, and meet new families attending for the first time. Here are some snapshots of the event. Please remember that we do have at least one get-together each year, so next time we hope to see you too!



AGM



Presentation of the Irish Fundraiser of the Year award

ISG National Conference 2011

Join us on 18th & 19th June for our 7th bi-annual conference at the Holiday Inn Kensington Forum Hotel, London. Registration from 9.30am for a 10.30am start.

The conference will be a one and a half day event, with a social occasion on the Saturday night after the first day's conference, followed by further activities on Sunday.

Why come to an ISG conference?*

- Speak directly to medical professionals with an interest and specialist knowledge of ichthyosis, including professors, consultants and nurse specialists
- Exchange information with other families affected by ichthyosis
- Talk to pharmaceutical companies about their products
- Our conference incorporates lectures, group sessions and workshops, to discuss in depth the various aspects associated with having ichthyosis
- Get involved – in a youth forum, join the ISG committee, become a regional contact
- Refreshments and lunch will be provided
- Children can either go on the London Duck Tour trip** (visit www.londonducktours.co.uk), or stay onsite with educational and play specialists Digikidz. Following the trip, children will then join Digikidz, or the older children can participate in a Strum n' Drum music workshop.
- Stay for dinner and socialise with other ISG members
- Further sessions inc AGM Sunday morning
- Book an 'at conference' one to one appointment with a specialist
- Registration fee only £20.00 per family



This event is kindly supported by Jeans for Genes

*Content subject to change **Places limited so book early!

You may wish to organise your transport in advance to potentially take advantage of much cheaper air, rail or bus fares.

By Car - see conference venue address below

The hotel has an onsite car park, other car parks available nearby.

By Air

London Heathrow (LHR)

Distance: 14 MI / 22.53 KM East to Hotel

Time by train: 30 minutes, with a direct connection on the Piccadilly Line to Gloucester Road Tube Station

London Gatwick (LGW)

Distance: 37.4 MI / 60.19 KM North West to Hotel

Time by train: 35mins

By Train or Bus (Nearest)

Main bus station name: Victoria Station

Distance: 2.5 MI / 4.02 KM West to Hotel

Underground station name: Gloucester Road

Distance: 0.5 MI / 0.8 KM West to Hotel

Conference venue details & accommodation

Approx £160# per double room per night

Approx £200# per triple room per night (very limited no. of rooms avail)

Holiday Inn Kensington Forum, 97 Cromwell Road, London SW7 4DN

Check prices and book by either calling tel: +44 (0)871 942 9100

or online at www.hikensingtonforumhotel.co.uk

Suggested alternative accommodation nearby

Approx £100# per room per night (double and family rooms avail)

Premier Inn Kensington (Earl's Court) 5-7 minutes walk from conference venue

11 Knaresborough Place, London SW5 0TJ

Check prices and book by either calling tel: +44 (0)871 527 8666

or online at www.premierinn.com

Or call us to enquire - limited number of rooms reserved for ISG families.

The Ichthyosis Support Group will reimburse you with a total of £50 towards the cost of your accommodation (either Friday or Saturday night) against a copy of your hotel receipt.

#correct at time of printing

Please register by 1st May 2011 to attend this event.

Incorporation of the ISG

Those who attended the Annual General Meeting in September will recall we announced our plans for the next development of the ISG by becoming an incorporated charity. This would result in registration not only with the Charity Commissioners but also on the Companies Register. We have been advised by our solicitors that the Charity is now at a stage where this step is strongly recommended, particularly as the Charity has become an employer and given the complications and difficulties posed by the numerous statutes and regulations relative to employment law.

At present, as an unincorporated Charity, the ISG has no separate legal identity which gives rise to an important consideration in that the Charity cannot enter into contracts in its own name. Instead, individual trustees have to do this and thus become personally responsible for complying with the terms of the contract and they have to assume personal liability for losses if the Charity has no funds to reimburse the trustees. This can be a major disincentive for trustees to enter into contracts otherwise advantageous to the charity and discourage the recruitment of new trustees with particular skills of value to the Charity. Once incorporated, however, the Charity becomes a legal entity in its own right and can enter into contracts on its own behalf, thus relieving trustees of personal liability. Nevertheless, trustees remain personally liable for wrongful acts of themselves or their colleagues or for operating outside the objects of the Charity.



Although costs are involved in making the transition, these are offset

by incorporation representing a step-up in the standing of the ISG, which could be advantageous when applying for grants or other forms of funding and put the Charity on the same legal footing as the larger national charities.

At present, our solicitors are drafting out articles of association which will become our governing document and, once they have been approved by the trustees, they will apply for registration with the Companies Register followed by the Charity Commissioners. We anticipate putting a resolution to members at the general meeting to be held on June 19th 2011, as part of the National Conference weekend, to authorise the implementation of the transfer, which we plan to come into effect on July 1st 2011.

Becoming a member of an incorporated body is a much more formal process than we have been used to in the past and involves completion of an application form and giving a guarantee, although this will be for a nominal amount. It therefore seems sensible, to restrict "corporate membership" to the trustees and a roughly equal number of others in order to achieve a balance. Most present members would become "Associate Members" and in practice see little or no change to what happens now except the Annual General Meetings, held in conjunction with our national day, would be replaced by Annual Conference Meetings, which would have much the same format apart from voting on resolutions.

It is proposed that at the Annual Conference Meeting associate members would have the chance, should they wish, to vote for two of their number to become "corporate members". This would provide direct representation at annual general or other general meetings of the company.

Should you have any comments or queries about these proposals, please feel free to contact us by letter or email.

Rex Codling, Treasurer

Research

Growing lamellar ichthyosis mimic skin in the laboratory and using it to find novel therapies

The skin barrier is like a brick wall that protects the skin from infection and the harsh external environment. In

lamellar ichthyosis, this brick wall is defective. Individuals with the disease get thick scales over their skin due to overgrowth of the outermost layer of the skin, the epidermis. Understanding why this occurs is the focus of our current research, which has been funded by the Ichthyosis Support Group. We are very aware that although there is no cure for the genetic disease, any treatment with the potential to reduce scaling will reduce the burden of the disease on families. Although retinoids are highly effective at reducing scaling, there is a need for different treatments that would reduce long term reliance on retinoids, and reduce the potential side effects from long term retinoid use.



Fig 1 – Cultured disease mimic skin treated with interleukin-blocker looks like normal cultured skin.

A significant step towards this is our ability to accurately model lamellar ichthyosis by reducing the levels of transglutaminase-1, one of the genes mutated in lamellar ichthyosis, in skin cells in the laboratory, which allows us to produce disease mimic skin that looks almost identical to patient skin (see above). We can use this to help determine why individuals with ichthyosis get scaling, and how it could be possible to stop scaling occurring. We have determined that an increased amount of a cellular signal called interleukin-1 alpha is the master switch responsible for the overgrowth of the epidermis and the resulting scaling. Increasing the amount of interleukin-1 alpha causes skin thickening and scaling, and blocking interleukin-1

alpha from being able to signal to cells is enough to prevent scaling in our disease mimic skin (see opposite). We have recently published this work, and have presented the data to the ichthyosis scientific community.

Importantly, we see high levels of the interleukin-1 alpha in all 20 individuals with lamellar ichthyosis we have recruited for our studies, both with and without defects in transglutaminase-1. This suggests that what we saw in our model is a common feature in the real disease. Eventually we would like to use this information to make new creams, or oral treatments, to reduce scaling in people with lamellar ichthyosis.

Our work on why ichthyosis causes skin scaling is ongoing, as the more important protein signals we can find, the more potential therapies can be devised. Gehad Youssef, a PhD student in my lab, is expanding the work initially funded by the Ichthyosis Support Group and is trying to understand why increased amounts of interleukin-1 alpha leads to scaling. He is also striving to understand how scales form in individuals with lamellar ichthyosis with different gene mutations. In this way we hope to be able to take scale from children with lamellar ichthyosis and determine what gene defect the child has simply by looking at what the scales are made of.

Ryan O'Shaughnessy
Senior Research Associate in Skin Biology
Immunobiology
UCL Institute of Child Health

The Ichthyosis Support Group is currently in the process of awarding its annual research grant of £5,000. This year we have teamed up with the British Skin Foundation to award a joint grant of £10,000 towards research into ichthyosis.

Your ISG

Join the Youth Forum

Hello all ichthyosis sufferers, my name is Lauren.



I was born in 1996 as a collodion baby. It was later that I was diagnosed with non-bullous ichthyosis. I understand the impact that ichthyosis has on the lives of both yourself and your family.

If you are a young person aged between 13 and 20 years old with ichthyosis then this little section is for you, to inform you that there is a place for you to get involved!

I have loads of ideas and plans but I need your help. You may have some ideas of things to do or ways to help and we just need to kick start them into action. Our aim is to take our ideas, try to bring them to life and get to know people exactly like you. We can share tips, stories, go places and meet up! What are you interested in – because I know there is someone you can chat, laugh, and even create with?

We are a big part of what the ISG is all about and it's our turn to take a bit of the power and use our enthusiasm and talents to influence the group.

But most importantly we need you ... If you want to do a big bit, or a really tiny bit, it doesn't matter. All we want are your ideas and help, so if you would like to get involved please contact me via isg@ichthyosis.org.uk and we can chat about how to get you involved in the ISG's Youth Forum!

Lauren

Events

British Skin Foundation Walk for Skin 2011

The BSF is pleased to announce details of the 2011 Walk for Skin. As well as the guided city and parkland walks that you've become accustomed to, this year there are also a series of walks aimed at the more adventurous among you.

This year's event kicks off in London on 22nd May with a guided walk taking in the historic sites along the city's famous river Thames.

Leeds will once again be hosting a walk, which will take place on 26th June in Roundhay Park, just a couple of miles from the city centre.

The BSF is currently looking at staging further city and parkland walks for later in the summer/autumn. Visit www.britishskinfoundation.org.uk to keep updated.

For those who feel up for a challenge:

On 30th July there will be a day long walk from Cheddar to Glastonbury, where you can experience the spectacular Somerset countryside, as well as the historic and picturesque towns of Wells and Glastonbury.

17th September sees the Walk for Skin heading to the North Pennines for a truly spectacular 10mile/16km walk, starting at the village of Dufton in the Eden Valley and taking in some of the most stunning scenery in the UK.

On 24th September the village of Amberley in West Sussex takes centre stage as the start of a spectacular and challenging 9 mile walk along the South Downs. Along with the amazing scenery, this fully guided walk offers a taste of the area's varied history.

For more information see enclosed information. Please nominate the ISG to benefit from your sponsorship!



Practical info

Looking after the scalp

You would not be alone if you have difficulty looking after your or your child's scalp and hair. The following information has been approved by a Dermatology Nurse Specialist.

Use your normal moisturiser or try 50/50 or Emulsifying ointment. As an alternative, and if you have longer hair, you may prefer to use a product like coconut oil or olive oil.

Starting at the back, so it minimises the amount of moisturiser getting onto the face or near the eyes, divide the scalp into four sections and moisturise working your way towards the front.

Gently massage the oil or cream into the scalp to help lift the scales of skin.

Comb gently through hair, it doesn't matter if it's short or long, lifting scales before washing the product out.

If there is thick scaling, apply moisturiser as described but do not wash the product out, instead leave it on overnight, and wash the product out the following day. Repeat this process until the scaling has improved. Maintain the scalp condition by doing the process once or twice a week.

You may want to cover the scalp overnight to keep the moisturiser on the scalp. Some people use the gusset of an old pair of tights, cut most of the legs off and tie the remaining fabric together.

This is an introduction and overview about treating your scalp. For more detailed guidance please refer to our website or request an information sheet.

Dermatology Nurse Specialist



Ear Care and ichthyosis

Many patients and parents contact the ISG about problems with ears. The following has been written by Jo Williams, Advanced Nurse Practitioner ENT at Birmingham Children's Hospital

In all other parts of the body, the superficial skin (the squamous epithelium) is constantly shed, usually as a result of friction from clothing or washing. This is not possible in the ear, so the ear cleans itself! Skin cells in the ear are formed at the ear drum and then they gradually move out along the ear canal. In the outer third of the ear canal there are sebaceous glands (sweat glands), which secrete cerumen. The cerumen mixes with the skin cells and this in turn forms ear wax. Most of the ear wax eventually falls out of the ears as the skin cells move out along the ear canal. Some wax in the ear canal is good, as it keeps the delicate skin of the ear canal moist and also can trap dirt and insects from entering the ear canal.

When you have ichthyosis, you have continual and widespread scaling of the skin. This can apply to the ears too. The skin scales in the ear can build up, block the ear canals and in some cases the hearing can be affected. Sometimes the skin in the ear can be managed by applying regular softening drops, such as olive oil, in the hope that the skin scales eventually fall out of the ear canal. If this doesn't occur, it may be necessary for the skin scales to be removed. This needs to be done either at the GPs or in an Ear, Nose and Throat (ENT) department.

It is difficult to say how often that the ears will need to be cleaned out, as everyone is different. I would suggest that you try a monthly appointment and then alter accordingly.

If you feel that the hearing is affected, it would be advisable to have a hearing test.

Advanced Nurse Practitioner ENT



Specialist Multidisciplinary Clinical Service for Patients with Ichthyosis

The ISG and our Medical Advisory Board are currently in the process of applying for funding to provide a Specialist Multidisciplinary Clinical Service for Patients with ichthyosis across England.

NHS Specialised Services is the national organisation responsible for the commissioning of specialised services that help improve the lives of children and adults who have very rare conditions.

Commissioning in the NHS is the process of ensuring that health services meet the needs of the population. It is complex and includes assessing the needs of the population, selecting health care service providers and ensuring that these services are safe, effective, patient-centred and of high quality.



Although most services in the NHS are currently commissioned by about 150 local Primary Care Trusts (PCTs), there are different arrangements for commissioning specialised services. A specialised service is defined in legislation as a service covering a planning population (catchment area) of more than a million people. Each PCT contributes some of its budget to funding specialised services.

Commissioning at a national level

About 60 highly specialised services are commissioned nationally by NHS Specialised Services. Generally speaking, these are services that affect fewer than 500 people across England or involve services where fewer than 500 highly specialised procedures are undertaken each year.

The Clinical Service

To fit the above criteria the clinical service for patients with

ichthyosis, including collodion babies, could aim to provide the following:

- A Managed Clinical Network: A National Managed Clinical Network consisting of a nurse-led outreach service to families at home and dermatologists throughout England.
- Dedicated Ichthyosis Clinics with a holistic and multidisciplinary approach: The co-coordinator of the Managed Clinical Network will assign patients to these clinics.
- A laboratory-based genetics diagnostic service: Providing genetic diagnosis for the ichthyoses, with state of the art next-generation sequencing technology, enabling accurate diagnosis and prenatal testing.

Unfortunately, as with a lot of services, funding is being cut. However we hope to be successful in our application to improve services for people in the UK living with ichthyosis. We will keep you posted on any news - if you are happy for us to contact you via email, please provide us with your email address.

If you have previously advised us of your email address you should have received an email requesting your participation in a survey "Are you interested in a specialist service for ichthyosis?". It is a short online anonymous survey where we would like to find out a little more about you and how you manage and care for your ichthyosis. The questions were written using input from the ISG Medical Advisory Board, parents and sufferers. The survey is still live so please visit www.surveymonkey.com/s/nationalISG or use the link from our website.

The information you provide will help to inform us of the current services you use, and identify how the system does or doesn't effectively help people living with ichthyosis.

Thank you to everyone who has already completed the survey. So far we have received a good number of participants, however, the more the better!

Skin Care Campaign updates ...

The Skin Care Campaign (SCC) works hard to improve dermatology services. Below are a number of updates on various subjects from Andrew Langford.

Dermatology Council for England (DCE)

I have worked a lot over the last few years to try to get a formal forum together where all the key stakeholders can talk about the major issues affecting dermatology and develop ways of both tackling problems and establishing proactive ways of improving all dermatology services. It has not always been that easy getting collective approval for this, but I'm really pleased that the DCE is now up and running. I'm delighted that some of the patient groups, including the Ichthyosis Support Group, have been able to make the meetings.

Now that it has found its feet I really hope the DCE can constitute itself even more effectively and become a 'force to be reckoned with' through standing united on significant issues that affect us all.

Public and Patient Involvement (PPI)

In order to be as proactive as possible, ensure patients get a say in the services they require, and to ensure there is 'no decision about me, without me', I am working with the DoH, NHS Executive and individual PCTs to promote the right of patients to be part of the decision making processes:

- At a commissioning level through Stakeholder Commissioning Groups that include representation from patients, professionals, commissioners etc. and work collectively on making the best decisions possible and together monitor and improve services
- At a service level through developing Patient Panels / User Groups in each service that works with the providers of services on the quality and experience that patients receive and influencing the full 360° governance/management of the service

- At a national level through working with the NHS Executive on developing national and local Patient Champion Networks – which will then be part of the full process of NHS services, ensuring PPI in all that the NHS does.

NHS White Papers and The Health and Social Care Bill
Along with others involved in dermatology including the BAD, APPGS, PCDS, BDNG etc, the SCC has responded to some of the white papers and put forward the patient perspective. In my opinion tweaks may well be made to the changes suggested, but in reality, it is far better to keep ahead of the changes that are being implemented and influence those as best as possible in the best interests of people with skin conditions (these are best achieved by the PPI developments outlined above).

GPs and GPs with a special interest in dermatology (GPwSIs)

The SCC has worked with others on improving the standards for GPwSIs that safeguard patients and provide guidance on the minimum requirements for a GP to work as a GPwSI. We now need to work with the DoH on securing proper monitoring and policing of this.

More importantly the evidence base is increasing to show that the majority of GPs do not have enough dermatology training at either pre or post graduate level – it is a major objective for this year to get something done about improving this. I am hopeful that changes in key personnel at the Royal College of GPs might make this easier than in the past.

Contact: Andrew Langford
Chief Executive
Skin Care Campaign
e: alangford@skincarecampaign.org

Buggy Walk in Memory Of My Brave Son Freddie James Patenall

On June 19th 2010, I Rebecca Jeffery and my partner Darren Patenall, organised a walk in memory of our son Freddie. Freddie would have been a year old on June 21st 2010. We felt it important to organise this event to raise money and awareness for the condition ichthyosis.

In 2005, me and my partner watched a documentary on Channel 4 about a condition called Harlequin, we watched in deep shock at this condition and admired the bravery of the families featured.

We never thought at the time that a similar condition would affect our family.

In 2007, we had our first child our beautiful daughter Bella, we took to parenting like a duck to water and enjoyed every minute, we decided when Bella was one to try for a second child; I fell pregnant within a month.

This pregnancy was very different to my first. I was constantly sick and always had abdominal pain, I always had a feeling this child would be born early as I felt like the baby had little room to move.

At 36 weeks I went into labour and gave birth to my beautiful son Freddie. I thought he looked a bit different, but put this down to being premature. 5 minutes later our world turned upside down when a rush of doctors came and said Freddie had very dry skin and needed to go to SCBU, they suspected he had something called Ichthyosis. In my naivety I felt they were making a fuss of nothing, how could dry skin warrant a stay in SCBU?

We were told he had collodion skin and that this would turn in to CIE, but two days later he was sent home with one pot of 50/50 cream and that was it!



Freddie

Every day we saw Freddie decline, we took Freddie to the doctors 13 times in 10 weeks, saw a paediatric doctor and dermatologist twice, but they never helped Freddie, even though me and my partner were begging for help, because at 10 weeks old Freddie only weighed 4lb 6oz and never opened his eyes, but my doctor told me not to cry wolf!

At 10 weeks we were at our wits end and decided to take Freddie to hospital and not leave until they helped him. 10 days later Freddie passed away in our arms in hospital, the help came too late. Freddie had lost his sight, had a severe infection and it had gone unnoticed he had only one kidney.

My son suffered very badly and to this day I feel if he had been seen by a professional when he was born he may still be here now.

Due to the circumstances in which my son died it is of up most importance that this condition is made aware of to the public and the medical profession.

Our buggy walk raised over £8,000 and at least 150 people attended, I hope we did our son proud that day. My son achieved more in the 12 weeks of his life than some people do in a life time and I am so very proud that Freddie was my son.

Rebecca Jeffery



150 people joined the buggy walk for Freddie

Rebecca had further support from Steve Stringer who completed the London to Brighton bike ride, and Debbie Richards participated in a parachute jump. These activities raised £353.00 of the above total.

Fund-raising

10K run for ISG

My name is Tim O'Sullivan, I am 31 and my older brother Rob and I both have X-Linked ichthyosis. My brother's condition is slightly worse than mine but we both still have to put Calmurid® cream all over ourselves after every bath or shower. As the younger brother by six years, by the time I came along, Rob had been put through several different treatments. This was a really difficult time for my Mum, who had to battle to get an accurate diagnosis and to find something that would work to help control the unbearable itchiness that Rob had to endure. Once he rubbed his wrists on the carpet so much that they were left bleeding. Eventually, the Calmurid® cream was prescribed and really made a difference. This is the cream I have used since birth. The only time I have escaped this daily regime was when I lived in Hong Kong as a small child. The humidity helped my skin hugely, to the point of being able to use Mately bubble bath - something which, as a child, I begged my Mum for as all my friends could use it.



Tim following the run up with the condition and in retrospect would have liked somewhere

I decided to run a 10K race to try to raise some money for the ISG. I hadn't run this far in about 15 or so years I had to train quite hard. I decided to race for two reasons – my wife and I were expecting our second child and given that the child could be a girl (it turned out she was) then there was potential for the condition to continue along the family tree. Secondly, a number of my female cousins are settling down and about to have families and there is a chance that they may have children with ichthyosis as well. I considered my life growing

to turn for support and information. I am sure my parents would have as well.

Happily I made it through the race in one piece (just) and with the matched funding from my employer (Deloitte) I raised over £1300 having completed the course in just over 50 minutes. Through all the training miles and the race itself I kept myself going by considering the time, effort and energy put in by my Mum, school staff and relatives to look after me and my skin whilst I was growing up - the running paled in comparison. Often it is these people who support treatment regimes, donate time, money and effort (and often love, support and guidance) who go without thanks – so thanks to everyone (especially my Mum) who has supported me thus far and I hope the money I have raised can go some way to supporting the ISG to continue the excellent work they do.



ISG Trustee Ray Rowley accepting cheque from Tim

Tim O'Sullivan

Medical Advisory Board member also completes a 10K run

ISG Medical Advisory Board member, Dr Mary Judge, from Manchester completed a 10K run for the ISG raising a fantastic £500.

Thank you Tim and Mary!



Dr Mary Judge



Fundraising for the ISG over the past months (up to Jan 2011)

A friend of ISG's family the Pollards', has generously donated over £1105 from the sale of excess stock from Colart Fine Art & Graphics. The Pollard family would like to thank Kerry Robinson for her generous support. The Pollard family also sent us 2 cheques donated by work colleagues. £100 was donated out of the winnings of Mr Langeroodi, who won the work's Lottery. Another £170 was donated by B/E Aerospace Sports and Social Club, which held a fundraising event.

ISG member Rebecca Bullent did a parachute jump raising £340.

Member, Jo Wilkinson, Mum to 3 year old Maya, sent a cheque for £2210.11, which was kindly donated by DHL Logistics from the auction of packages damaged in transit for B&Q and not eligible for resale.

Gill and Theresa Davis, Welsh Regional Contacts, sent in a cheque for £500 raised by creating their own fundraising walk in Wales. This was in lieu of the Walk For Skin 2010 because there was not an event last year in Wales.

ISG member Becky Curtis (formerly Antrobus) held a sponsored head shaving event in Manchester. One brave individual, Paul Anderson, raised £217 by having his head shaved!

Sophie Newman, Southern Regional Contact, sent £105 raised during the Ichthyosis Awareness Week coffee morning held in Ryde, Isle of Wight. There was an additional £543.88 raised at the 2010 Beach Soccer Event.

Lydia Whitehouse and Darci Holcroft, both aged 8 yrs, decided they wanted to try and raise money for the ISG. Their school, Moor Hall Primary School in Four Oaks Sutton Coldfield, supported their efforts. They collected a big jar of sweets and the school children were invited to buy a guess of how many sweets were in the jar at 50p a go. They raised the grand sum of £37.24 (one little boy had spent most of his pocket money so the girls felt sorry for him and gave him a discount!). They were very pleased with their efforts and so was Amy Willetts who won the sweets!

Sue Hall, a family friend, of ISG members the Bowen family raised £200 by doing a 10k BUPA run.

Annette Hobbs, friend of ISG family the Sullivans' sent a cheque for £70 raised at work by selling and enjoying cakes made by another member of staff.

£420 was received from Peter Casasola, brother-in-law to ISG Chairman Paul Whitehouse, who completed the Great Midlands Fun Run.

ISG Medical Advisory Board Member, Jean Robinson, asked guests invited to her birthday party to make a donation instead of buying a gift. £145 was donated to the ISG from the generosity of the guests.

Jeanette King, friend of ISG member and Regional Contact for East Anglia, Sam Bowen, kindly sent £205.94 raised following a Pampered Chef fundraising evening.

Ellamay Dale collected the rest of her 'Buggy Walk' sponsorship money and sent £80 to add to the £165 she raised on Justgiving.

Irish member Edel Kenny presented a massive cheque for £8205 at the Thorpe Park Funday, which was the result of all her fundraising in the last 12 months.

Our members and supporters raised nearly £3000 during the Walk For Skin 2010. Money raised is split 50/50 between the ISG and the British Skin Foundation.

In memory

Shelly Batt, ISG founder Trustee and former Secretary of the ISG, donated £107, which was raised in memoriam of her grandmother. She also emptied her grandmother's collection box totalling £27.32.

Gill Davis, Welsh Regional Contact, kindly donated £263.50 raised in lieu of flowers, following the passing away of her husband David.

Jo Wilkinson also donated £210 raised in memory of her late uncle who passed away last June.

There are so many personal donations, fundraising events and generous individuals that unfortunately we cannot name them all - thank you to everyone who has donated, held events and raised money!

Advice & Support

Romantic Relationships Survey Results

Last year the Centre for Appearance Research (CAR), based at the University of the West of England in Bristol, conducted a study exploring the experiences of developing romantic relationships from the perspective of young people with visible differences (Griffiths, Williamson & Rumsey, in preparation).

A visible difference is the visible effect of a skin condition, scar, burn, cleft or disfigurement.

40 young people, 22 males and 18 females (aged between 13 and 20) with a visible difference, completed an online survey that explored their experiences of developing romantic relationships.

The results revealed a number of common issues that they were concerned about. Young people felt social pressure to 'look perfect' and felt 'in the real world appearances are important'. They were concerned that their visible difference made them less attractive to others. In some cases these concerns discouraged them from even contemplating the possibility of instigating relationships. When possible, many concealed or camouflaged their visible difference and some avoided certain social activities (e.g.: swimming) or intimacy, so that their boy/girl friend would not see it. They also worried about how and when to reveal their difference to their boy/girl friend.

However, others were not troubled by their visible difference and spoke of positive past or current relationships. Some felt many of their romantic concerns were not different to those of the average teenager and this helped to moderate their worries. Others described useful coping strategies to overcome appearance-related concerns. They felt that social support was important. Being able to talk openly to friends, family and boy/girl friends about their visible difference



had helped them cope with their difference and most had received positive reassurance about their visible difference. These adolescents accepted that their difference was part of their identity and not something to be ashamed of. They boosted their self-esteem by focussing on other positive aspects of themselves such as their personality, intelligence, humour or kind nature and other interests such as sport or music. They felt that potential partners should like them for who they are, 'it's what's in the inside that counts', and felt 'if boy/girl friends are too shallow to accept you for what you are and how you look, then they don't deserve you'.

Young people told us that, if they needed it, they would rather receive online support for developing romantic relationships, from a young person with a visible difference or a psychologist/counsellor. They preferred online support because they could look up

information and post questions anonymously, in their own time.

Adolescents felt that young people with a visible difference would understand their experiences better than those without. They thought that

older young people would be able to offer more relevant advice because they would have already 'been through it'.

The findings from this study will inform the development of YP Face IT, an online support programme for young people who are finding it difficult to cope with their visible difference.

If you would like to find out more about this project or any of the other projects that the Centre for Appearance Research (CAR) is developing, please contact CAR@uwe.ac.uk



The Centre for Appearance Research (CAR), School of Life Sciences, University of the West of England, Bristol, Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY



Kid's Page

Easter time wordsearch



Basket

Egg

Bonnet

Flowers

Bunny

Hunt

Chicks

Parade

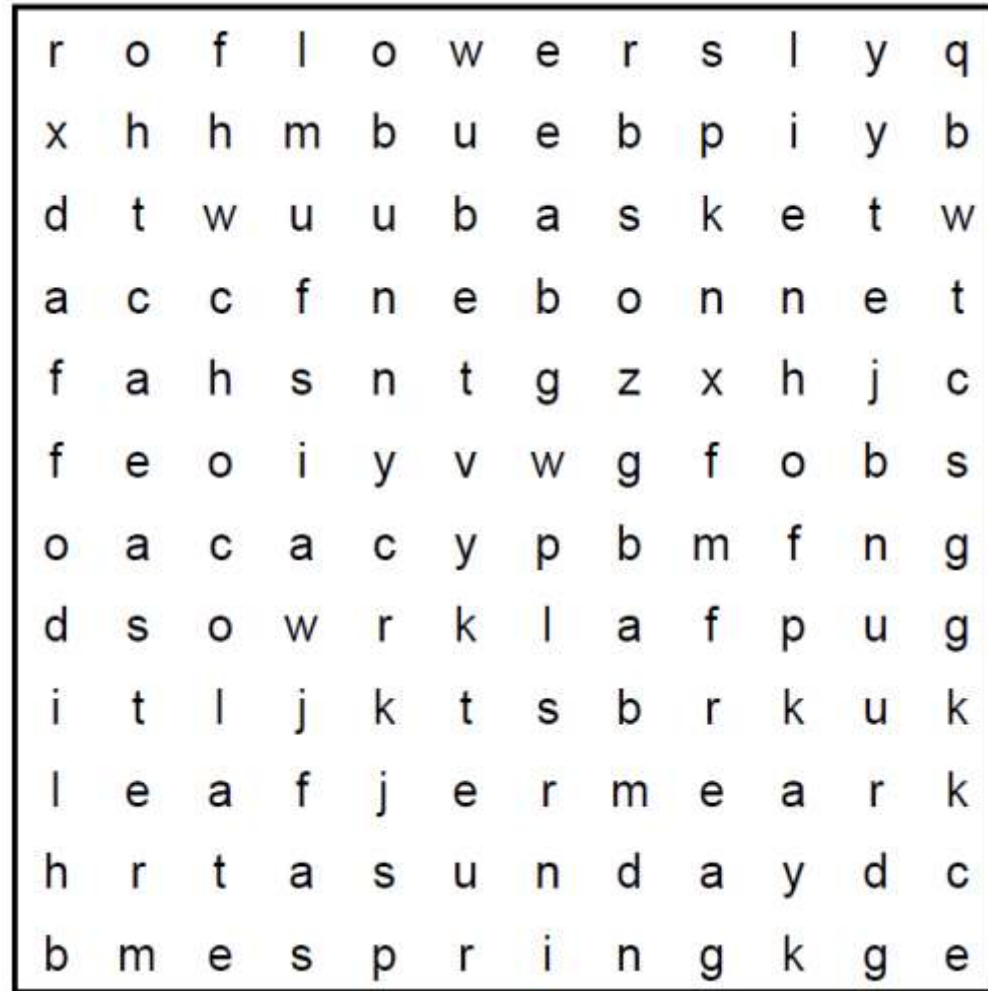
Chocolate

Spring

Daffodil

Sunday

Easter



For more Easter activity ideas visit www.ActivityVillage.co.uk

Find all the words and send your completed wordsearch, along with your name, age and address, to us and you could win a prize. Under 10 year olds only please. Photocopy this if you need to and send it to us!
 Send to Ichthyosis Support Group, PO Box 1404, Bagshot GU22 2LS

Closing date 31st May 2011





Ichthyosis Support Group Conference 18th & 19th June 2011

Registration Form

To register for the conference complete and return the following registration form by 1st May 2011.

Please complete all details for every person you are registering to attend the conference, including any special dietary requirements.

ADULTS

Title	First Name	Surname	ISS Member? (Please tick)	Any Special Dietary Requirements

CHILDREN WISHING TO GO ON THE FULLY SUPERVISED TRIP (18th June only) Note: limited no. of places avail

Title	First Name	Surname	Birth Date	Any Special Dietary Requirements

CHILDREN STAYING IN THE CRECHE/ONSITE (18th June only)

Title	First Name	Surname	Birth Date	Any Special Dietary Requirements

We will be providing dinner on the evening of Saturday 18th June for families staying overnight to attend the Sunday morning sessions. Will you be joining us to socialise with other ISG families? Yes No (Please tick)

Full Address, Telephone Number and Email address

No. Street Name Town County Postcode

Tel. No. Email address (please print clearly)

I have enclosed a donation of £20 for my ISG family (2 adults and our children) plus £10 for each additional person (maximum 2).

If you have any queries regarding the above please contact us on 0845 602 9202. (amount)

(signature)

Please complete and return your registration form by 1st May 2011

Please return to:

Ichthyosis Support Group, Bagshot, Surrey GU22 2LS UK

Cheques should be made payable to the 'Ichthyosis Support Group'