

Donation/Standing Order Form

I have pleasure in enclosing herewith £

As: * a donation to the Ichthyosis Support Group

Or: * a completed Bankers Order (£2 minimum)

Please make cheques or postal orders payable to the 'Ichthyosis Support Group'

GIFT AID DECLARATION - a national scheme whereby the Charity can reclaim tax on your donation, currently at 28p per pound donated. This requires the following declaration to be completed:

I want the Ichthyosis Support Group to treat the following as Gift Aid donations

- * the enclosed donation of £
- * the donation(s) of £..... which I made on/...../.....
- * **ALL** donations I make from the date of this declaration until I notify you otherwise,
- * **ALL** donations I have made since the 6th April 2000, and ALL donations I make from the date of this declaration until I notify you otherwise or
- * the enclosed donation is outside the scope of Gift Aid.

Title Initial(s)..... Surname

Address.....

..... Postcode

Signature..... Date/...../.....

BANKERS ORDER (For use for Monthly/Annual Donations - Please also complete Gift Aid section above)

To : Bank plc,

Address

On receipt of this order, and monthly thereafter for a period of a further years, please pay from my account with you to: CAF Bank Ltd, Sort Code 40-52-40, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent ME19 4JQ

The sum of pounds, for the account of the Ichthyosis Support Group. A/C No: 00013256.

Name :

Account Number :

Address :

Signature : Date/...../.....

Please make cheques or postal orders payable to the 'Ichthyosis Support Group'

Please send your donation or enquiry to the following address;

**Ichthyosis Support Group
PO Box 1404
Bagshot
GU22 2LS**

**Tel; 0845 602 9202
E-mail; isg@ichthyosis.org.uk
www.ichthyosis.org.uk**

If you are a medical professional and are interested in receiving further information, please complete this section and send to; Ichthyosis Support Group, PO Box 1404, Bagshot GU22 2LS

Title Name Surname

Address

Postcode

Profession

Hospital

The Ichthyosis Support Group is an independent organisation with no vested interest in any pharmaceutical company nor does it endorse any products for the treatment of ichthyosis type skin conditions.



Ichthyosis Support Group

**A National Support Group
for individuals and
families who live with an
ichthyosis condition.**

Registered Charity Number 1084783

www.ichthyosis.org.uk



Ichthyosis Support Group

Ichthyosis is a term used to describe persistent scaling of the skin due to an abnormality in the outermost part of the skin, the epidermis. It occurs as a result of a number of genetic disorders. Some of these conditions primarily affect the skin, such as; ichthyosis vulgaris; Lamellar ichthyosis; X-Linked ichthyosis; Non-Bullous ichthyosiform erythroderma and Harlequin ichthyosis - others are multi system disorders and these include Netherton's syndrome; Sjorgen Larsson syndrome; Refsum syndrome; Trichothiodystrophies; Neutral Lipid Storage disease; KID syndrome and Conradi Hunermann syndrome, as well as a number of other rarer disorders.

The ichthyoses are a large mixed group of conditions all characterised by scaling of the skin, which can vary in severity from mild scaling affecting some parts, to severe plate like scales affecting the whole of the body. In some conditions the skin is very inflamed, red and itchy, in others it may blister, and in some cases the conditions can be life threatening.

How was the Ichthyosis Support Group started?

The Ichthyosis Support Group (ISG) was formed in 1997 by a group of individuals affected by ichthyosis to create a network of parents, sufferers and medics.

The story so far ...

We have grown from a handful of people to several hundred sufferers and their families, some of which come from as far afield as Spain and New Zealand! A wide age group is covered from babies to adults, and also a large variety of the different types and severity of ichthyosis. The committee of volunteers, all of whom live with or are themselves ichthyosis sufferers, continue to have regular meetings. A newsletter is published quarterly, which covers a wide range of topics from personal stories, a Q&A section and a kids' page. Also available to buy is a selection of ISG branded merchandise. We have a Medical Advisory Board consisting of eminent dermatologists throughout the U.K. to advise and assist with our literature and to answer any medical queries that the group receives.



Image courtesy of DermQuest.com and Galderma

The ISG is run entirely by volunteers and receives no Government funding but relies totally on the generosity of individuals, companies and grants for its income. If you would like to make a donation to the Charity you can do so by using the standing order/donation form on the back of this leaflet, or you may prefer to donate through our



Baby with Lamellar Ichthyosis

website. Your donation will contribute to the support offered by the ISG and help to fund research into these extremely rare conditions.

The ISG mission statement is:

To provide support to all affected by ichthyosis and to raise awareness of the condition and the ISG amongst healthcare professionals.



Bullous Ichthyosiform Erythroderma

The ISG provides:

- A quarterly newsletter.
- An information pack.
- National events.
- National and regional contacts.
- A Medical Advisory Board.



From left to right; Dana Bowen, Hannah Betts, Lara Bowen & Lucy Betts, the Harlequin sisters as featured in the Real Families series shown on ITV1 on 4th October and ITV2 on 6th October 2005.