

What is Fanconi Anaemia?

Fanconi Anaemia (FA) is a rare, inherited life-limiting genetic disorder causing bone marrow failure in children and a predisposition to gynaecological and head & neck cancers, together with other complications both in childhood and in later life. Whilst the bone marrow failure element can be corrected through bone marrow transplantation from a well-matched donor, there is still no cure for the cancer-predisposing condition.

Who are we?

Fanconi Hope is a national charitable trust set up in 2008 and run by volunteers who are parents of FA-affected children and clinicians with an interest in FA. Because of the rarity of the condition we work closely with international support organisations such as the US-based

Our Patron: The Duchess of Devonshire



"In accepting the role of Patron of the Fanconi Hope Charitable Trust I believe that this small charity can have a big impact on many lives. I have been impressed with the passion and drive of the Trustees and I, too, share this passion. Of course it is not enough to simply believe we will make a difference, and the charity cannot change anything without receiving the full support of those impacted by Fanconi Anaemia. I would encourage all who want to change the lives of those affected by Fanconi Anaemia to unite together behind this charitable cause. There are so many stories about this terrible condition that one cannot help but be moved - often saddened, and it is incumbent on all of us to work together to give hope to those suffering because of Fanconi Anaemia."

The Duchess of Devonshire DL

February 2009

What do we do?

We promote awareness and understanding of Fanconi Anaemia among affected families, the medical profession, and the general public.

We encourage and fund research that should directly benefit Fanconi Anaemia affected individuals and their families.

We encourage and fund research in the area of Fanconi Anaemia that might have benefit for the general public, e.g. in the treatment of cancers in general.

Why should I be interested?

Although FA only affects a small number of people in the UK, the genes concerned, i.e. the 'Fanconi pathway', are of great potential importance for all, as they keep our DNA healthy and preventing cancers. The Fanconi pathway is often responsible for a cancer's resistance to chemotherapy drugs.

Knowing how to manipulate the Fanconi pathway is likely to lead to better and more successful treatments for *all* cancers.



Are you affected by FA?

As FA only directly affects around three in a million people in the UK, those affected and their families can feel isolated and have difficulty in obtaining information about the condition.

You can find information on our website www.fanconihope.org, but you can now also contact **Beth Lee**, who has a UK FA Liaison role funded by Fanconi Hope under our Study into the long term effects of FA. Beth has many years' experience working within the FA Clinic at Manchester Children's Hospital.

She is keen to make contact with as many patients and their families as possible to provide more information about the condition and to understand more about each person's situation and treatment.

Ask Beth



Please email Beth at beth.lee@fanconihope.org and she will be happy to correspond by email or arrange to call you at a mutually convenient time.

Keep in Touch



Our website: www.fanconihope.org



(Open Group): fanconihope

@ fanconihope

How you can help

By donating directly or by organising fundraising events you will be helping us to support the FA community in the UK and Ireland and to fund research to improve the prospects for those affected by Fanconi Anaemia.

Fanconi Hope is run by volunteers, so your donations will directly support the aims of the

For sponsored events we are registered with both JustGiving and Virgin money giving.

 JustGiving

 Virgin money giving

Raise money for free!
Donate while you shop with Easyfundraising.

 Easyfundraising



Please help us find a cure

Please support our charity

Donate Online at www.fanconihope.org

or

Boost your donation by 25p of Gift Aid for every pound you donate.

Gift Aid is reclaimed by the Charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer.

In order to Gift Aid your donation you must tick the box below.

I want to Gift Aid my donation of £ _____ and any donations I make in the future or have made in the past 4 years to Fanconi Hope.

I am a UK taxpayer and I understand that if I pay less income tax and or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

My Details

Title _____ First name or initial(s) _____

Surname _____

Full Home address _____

Postcode _____ Date _____

Please notify the charity if you

- want to cancel this declaration
- change your name or home address
- no longer pay sufficient tax on your income and/or capital gains tax.

If you pay income tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

Please tear off and send to our Treasurer: Mrs L Parry, 79 Sandown Crescent, Cuddington, Northwich, Cheshire, CW8 2QN

www.fanconihope.org


fanconi
hope

Helping to find a cure
for Fanconi Anaemia



Fanconi Hope Charitable Trust

PO Box 905, Southsea, Hants, PO1 9JG

Phone: 0300 330 1410

Email: info@fanconihope.org

Registered Charity No. 1126894