

About Fanconi Hope

In 2008, three parents of affected children, Thomas Carroll, Richard Kawalek and Bob Dalglish, together with three clinicians with an interest in FA, started the Fanconi Hope Charity, to fund research into this disease, to help engender consistent best practice treatment across the UK by initiating and running an NHS FA Clinical Network and to provide much-needed support to affected families through the provision of information and improved family contact. To this end, more than £250,000 has been raised since the Charity's inception.

The Charity is very fortunate to work under the patronage of The Duchess of Devonshire, who takes an active part in Annual Trustee meetings.

Due to the rarity of the disease Fanconi Hope has had to reach out internationally, with the US-based Fanconi Anaemia Research Fund (FARF) being our principal partner. FARF provide considerable support and guidance and we have been able to use their Scientific Advisory Board for Fanconi Hope-sponsored research projects in the UK.

Although the charity is small and staffed by volunteers in their spare time, Fanconi Hope has been able to make significant progress in a number of areas:

Through its connections with the medical community in the UK, the Charity was able to instigate a Fanconi Anaemia Clinical Network with around 30 clinicians across the UK and Ireland. Through this group, a UK Standards of Care document was published for the first time.

One of the key objectives from the outset was to establish a UK FA Registry, and this is finally being realised through the Fanconi Hope-funded *Long Term Effects of FA Study* run by Dr Stefan Meyer at Manchester University.

We are currently refreshing our Board of Trustees due to two of our number retiring/leaving: Dr Mary Morgan and our Chairman, Mr Thomas Carroll. In doing so we have taken the opportunity to broaden the medical skill base of the Board of Trustees and widen our geographic spread of operations, to include London, Liverpool and potentially Cambridge.