About Fanconi Hope

In 2008, three parents of affected children, Thomas Carroll, Richard Kawalek and Bob Dalgleish, 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 £350,000 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 in 2008.
- One of the key objectives from the outset was to establish a UK FA Registry, and this has finally been realised through the Fanconi Hope-funded *Long Term Effects of FA Study* led by Dr Stefan Meyer at the Manchester University NHS Foundation Trust.

Our current Board of Trustees includes a broad medical and scientific skill base of and a wide geographic spread of operations, including London, Manchester, Liverpool and Cambridge.

Our current organisational structure is as follows:-