

Getting involved in promoting people to register as potential bone marrow donors

The majority of individuals diagnosed as having Fanconi Anaemia (FA) go on to have a haematopoietic stem cell transplant (a 'bone marrow transplant'). In most circumstances, the haematopoietic stem cells for the transplant are donated by an unrelated donor who has volunteered through one of the world bone marrow donor registries. The closer the match between donor and recipient the better the outcome of the transplant.

Coping with a diagnosis of FA is difficult for all those involved. Becoming involved in organising bone marrow donor registration clinics through the Anthony Nolan charity (see below and also <http://www.anthonynolan.org.uk>) is empowering, helps with morale, and ultimately increases in a small way the chances of any individual affected by FA to ultimately get the best bone marrow donor match possible.

Currently there are just over 12 million people worldwide on bone marrow donor registries. When a bone marrow transplant is planned on an individual in the UK or Ireland, all worldwide registries and not just those in the UK and Ireland are searched so as to ensure the best match possible for that individual. More information about bone marrow registries worldwide can be found at <http://www.bmdw.org>.

- **UK & Northern Ireland.** There are two bone marrow donor registries in the UK, one run by the National Blood Service and the second run by Anthony Nolan charity.
 - **National Blood Service Bone Marrow Donor Registry.** For anybody who is already or wishes to become a blood donor they should check on their next blood donor visit that they have also being signed up to the National Blood Service's Bone Marrow Donor Registry. A blood donor is not automatically signed up to the donor registry. The upper age limit for a blood donor who wishes to go on the National Blood Service's Bone Marrow Donor Registry is 50 years. The lower age limit is 18 years. More information can be found at http://www.blood.co.uk/pages/marrow_info.html.
 - **The Anthony Nolan Bone Marrow Donor Registry.** You do not have to be a blood donor to go on the Anthony Nolan Bone Marrow Donor Registry. What is involved? An application form has to be completed and a saliva sample has to be given. The Anthony Nolan charity enables individuals to go on the Anthony Nolan registry by post. ***They will also organise local bone marrow donor registration clinics in your local area or workplace. All you have to do is have a suitable venue in mind, the local school/community centre/church/spare offices at work, and they will do the rest.*** They will risk assess the venue, provide personnel and equipment, and dispose of any waste materials. They will also help

with publicising the event locally including through the media such as TV and radio. Helping to organise such an event is a very rewarding and indeed therapeutic process. Thomas Carroll, a doctor and FA parent, said “*when I helped organise an Anthony Nolan donor registration clinic, a significant proportion were patients I had previously treated...it was quite emotional to see the extent of support offered by others to my family’s situation*”. The upper age limit for a blood donor who wishes to go on the Anthony Nolan Bone Marrow Donor Registry is 40 years. The lower age limit is 18 years. For more information, call Anthony Nolan on 020 7284 1234 or visit their website at <http://www.anthonynolan.org.uk>.

- **Republic of Ireland.**

- The only organisation currently in the Republic of Ireland that runs a bone marrow donor registry is the **Irish Blood Transfusion Service**. You have to be a blood donor with the Irish Blood Transfusion Service to go on the registry. Unfortunately at this point in time, there is no opportunity to be involved in the organisation of bone marrow donor registration clinics as there is in the UK with Anthony Nolan. The upper age limit for a blood donor who wishes to go on the Irish Blood Transfusion Service’s Bone Marrow Donor Registry is 45 years. The lower age limit is 18 years. More information concerning the bone marrow donor registry run by the Irish Blood Transfusion Service can be found at <http://www.ibts.ie>.

Cord Blood Registries.

The use of unrelated umbilical cord blood is increasing as a source of haematopoietic stem cells for haematopoietic stem cell transplantation in young children. Reasons for this include an appreciation that the chance of graft versus host disease, a complication of a haematopoietic stem cell transplant, appears to be significantly less with umbilical cord blood than from an adult unrelated bone marrow donor. As a result, umbilical cord blood banks are being developed to take umbilical cord blood donations. Otherwise umbilical cord blood, the umbilical cord, and the placenta (the ‘afterbirth’) are simply disposed of. There are two cord blood banks in the UK, one being the NHS cord blood bank (see <http://cord.blood.co.uk/cordblood>), the other run by Anthony Nolan. Currently, only parents in a limited number of London hospitals have the opportunity to altruistically donate their new born child’s umbilical cord blood. There is no cord blood bank in the Republic of Ireland.

‘Saviour Sibling’

About 20% of FA affected families are in the very fortunate position of having a HLA-matched sibling, i.e., a brother or sister not affected by FA but who are an exact tissue match. A matched sibling provided the best outcome for a haematopoietic stem cell transplant for a FA affected individual. ‘Saviour Sibling’ or more technically ‘preimplantation genetic diagnosis (PGD)/HLA-selection/in vitro fertilisation (IVF)’ is now available in the UK for FA affected families. Note that in France, the term ‘Saviour Sibling’ is not used but ‘Enfant de deux espoir’ or baby of two hopes (the first hope is have a FA unaffected child, the second hope is to provide umbilical cord stem cells to their FA affected brother or sister). Saviour Sibling is only an option for a family if the mother is less than forty years and the FA affected child is not in severe bone marrow failure. See relevant information sheet on www.fanconianaemia.nhs.uk website for further details.

What are HLA antigens?

Matching up a donor to a recipient involves finding the donor with the closest set of 'HLA antigens' to the individual receiving the transplant. A good explanation of HLA antigens and the matching process can be found at

http://www.marlow.org/PATIENT/Donor_Select_Tx_Process/The_Search_Process/HLA_Matching_Finding_the_Best/index.html.