

All Party Parliamentary Group on Stem Cell Transplantation
Progress of the Stem Cell Strategy: Improving equity of access for Black, Asian and
minority ethnic patients, Wednesday 9 March, 2016

Note of meeting

The meeting provided an opportunity for the aligned registries to report on the progress in recruiting stem cell donors from Black, Asian and minority ethnic (BAME) community. While the chances of BAME patients receiving a stem cell transplant has substantially improved, a vast disparity remained with only 20 per cent of people from BAME backgrounds finding the best possible match, compared with 60 per cent for white northern Europeans.

Mark Tami MP, Co-Chair of the APPG on Stem Cell Transplantation, opened the discussion by saying that unfortunately David Burrowes MP, Co-Chair of the APPG on Stem Cell Transplantation would be unable to join the discussion due to business in the Chamber. The Minister for Public Health, Jane Ellison MP, would be joining the discussion later, following a series of presentations from invited speakers.

Ann O’Leary, Head of Register Development, Anthony Nolan said that there were a number of issues around the provision of stem cells for patients from BAME backgrounds, including the complexity of matching, an under-representation of BAME donors on international registers, and a lack of registers in certain countries and regions. Anthony Nolan took a three-pronged approach to addressing these issues: increasing the number of BAME donors on the register by working with partner organisations; increasing the number of cord blood units available, which provide an alternative to adult donors; and helping the rest of the world to develop registers of their own.

Previous research had shown that people from BAME backgrounds were more likely to sign up through face to face recruitment events, than by signing up online. The recent patient appeal #MatchforLara had caused an unprecedented influx of online sign-ups, with over half coming from people from BAME backgrounds. We would now need to monitor carefully how many of those who sign up during these patient appeals actually joined the register, and in particular the follow through once the appeal ended.

Andrew Hadley, General Manager of Specialist Services, NHS Blood and Transplant said that cord blood was at the heart of the strategy to meet the needs of BAME patients, and that outcomes were now comparable with adult donor stem cells. Since 2010, NHSBT and Anthony Nolan had been working to build up the cord blood inventory. There had been a rapid increase in the last year in the use of UK cord blood for UK patients, and cost effectiveness for cord blood had been better than expected in 2014 estimates. Guidelines and advisory groups were helping clinicians to choose cord blood.

Myfanwy Morgan, Professor Medical Sociology, Kings College, presented her findings on the barriers to deceased organ donation among Black and South Asian ethnic minority groups. There was a significant level of unmet demand among people from BAME backgrounds needing kidney transplants, which resulted from a high rate of need and a low donor rate. Average waiting times for BAME patients were therefore significantly longer. A study into attitudinal barriers to organ donation showed that issues such as lack of knowledge, faith beliefs and a lack of trust in health professionals were more prevalent in BAME communities. In policy and practice terms, we needed greater education and community interventions, and to provide training for ICU nurses and hospital chaplains to help support family consent.

Nilush Aponso, a stem cell donor patient spoke about his experiences. Nilush was diagnosed with Acute Myeloid Leukaemia in 2012 and underwent 3 cycles of gruelling chemotherapy, before being told he’d need a stem cell transplant. After finding his brother

was not a match, Anthony Nolan began a search for an unrelated donor. Due to Nilush's Sri Lankan background, finding a match proved difficult but eventually two cord blood matches were found. Cultural barriers and a lack of a donor register in Sri Lanka meant that people like Nilush were dying without a match, including Nilush's cousin, who sadly died shortly after being diagnosed with Leukaemia in Sri Lanka. One of the benefits of cord blood was that, for pregnant women, donating formed a small part of giving birth and so was not a significant additional burden on the woman or hospital.

Dr Jill Shepard, Regulation Manager, Human Tissue Authority made a short announcement about the recent publication of guidance on cord blood banking. The aim of the guidance was to empower parents to understand and make decisions about cord blood donation.

Jane Ellison MP, Minister for Public Health thanked the APPG for continuing to raise awareness and welcomed the opportunity to highlight the scale of the challenge for the provision of stem cell donors for BAME patients. There had been progress over a generation, but there was more to do. Recent patient appeals such as #MatchforLara and Vithiya's Appeal showed how a personal tragedy could be the basis of a huge campaign that could change lives, through harnessing the positive power of social media. We should also pay tribute to the work of organisations such as the African-Caribbean Leukaemia Trust (ACLT) and Team Margo in improving the provision of donors. Our National Health Service had benefited greatly from people who had been brave enough to take on difficult issues. Organisations and charities were able to reach out and speak to people in a way that government could not. There was more we could do to learn and improve. The Department of Health would shortly be confirming future funding arrangements for Stem Cell Transplants.

Mark Tami MP thanked Jane and the other speakers, and opened the floor up for discussion. He asked for views on how we recruit more BAME donors, and importantly how we ensure that they go on to donate when they are found to be a match.

Discussion

The following points were made in discussion:

- Only 40 per cent of cord blood samples collected were clinically viable and therefore made it onto the database.
- We needed to work hard to educate women on the benefits of cord blood donation. However, we also had to consider that lots of women wanted to donate their cord blood but were unable to due to lack of provision of services. Collecting cord blood was complex (it took six months on average to train a cord blood collector) and expensive.
- The 60 per cent figure for matches for BAME patients referred to an acceptable match, and the figure for a perfect '10/10' match was much lower. Education in BAME communities on the importance of donor registration should be a bespoke message carefully delivered by the right people.
- There could be issues around sibling donors and visa issues, when a sibling was resident in another country.
- When signing people up through mass patient appeals, we should carefully monitor the attrition rate of donors. We should communicate the implications of signing up carefully (i.e. that you are signing up to help anybody, not just one particular person) to reduce drop-outs. Online sign-up generally had a lower attrition rate than recruitment events.

Mark Tami MP closed the discussion.