

APPG on Stem Cell Transplantation meeting – 3rd September
Minutes



Attendees

Mark Tami MP

David Burrowes MP

Chris Ruane MP

Paul Goggins MP

Rebecca Roberts, Cells4Life
Jo Taylor, Cells4Life
Rosemary Exton, Royal College of Midwives
Orin Lewis, ACLT and the NBTA
Ann O'Leary, Anthony Nolan
Jonni Berger
Dr Paul Veys, Great Ormond Street Hospital
Professor John Goldman, Anthony Nolan
Julie Frohlich, Guy's and St. Thomas' Trust
Patrick Ojeer, Sickle Cell Society
Jai Patel, NHS Blood and Transplant
Emyr Harries, Department of Health
Nula Clark, Department of Health
Catherine Simpson, Department of Health

Lawrence Quaeh
Katherine Gayford
Ros Williams, University of York
Gurch Randhawa, NBTA
Ed McRandal, Insight PA
Julia Jenkins, Human Tissue Authority
Ulrike Paulus, SNBTS
Dr Maria Gilleece, Leeds NHS
David Fanthorpe, Future Health Biobank
Guy Parkes, NHS Blood and Transplant
Professor Stephen Mackinnon, UCL
Caroline Harris, Anthony Nolan
Chiara De Biase, Anthony Nolan
Susana Gomez, Anthony Nolan
Katie Begg, Anthony Nolan
Victoria Moffett, Anthony Nolan
Iana Vidal, Anthony Nolan

Mark Tami MP opened the meeting and introduced the topic of discussion; meeting the stem cell transplant need for patients from ethnic minority backgrounds.

Orin Lewis, National BAME Transplant Alliance

Orin Lewis presented in his capacity as co-chair of the National Black Asian and Minority Ethnic (BAME) Transplant Alliance, a coalition of charities, universities, government bodies and the Department of Health working to improve transplant provision for patients from ethnic minority backgrounds. The NBTA focuses on stem cell and organ donation as many of the issues and challenges apply to both forms of donation.

The group's main aim is to identify the difficulties in recruiting ethnic minority stem cell and organ donors, and work with the relevant agencies to build a strategy for engagement and recruitment. The members are due to meet soon to review the organisation's first year in operation. By April 2015 they aim to have increased the number of committed ethnic minority donors and built awareness in ethnic minority communities.

The group operates as a coordinating and influential voice at the highest level in strategy and planning for transplant provision. It has built an online presence over the past year and is due to review the recommendations it set out in two reports published earlier this year on stem cell and organ donation in BAME communities.

Orin highlighted a number of issues that the group would be addressing to help improve outcomes for patients from ethnic minority backgrounds. One issue is that there are many gaps in reporting the ethnicity of both donors and patients. It is difficult to quantify the unmet need and this figure is crucial to not only communicating why donation is important but also planning recruitment strategies. He said that both registries and transplant centres need to work together to build a consistent plan for data collection and use.

More information about the NBTA including access to the reports mentioned can be found here: <http://www.nbta-uk.org.uk/>

Ann O'Leary, Anthony Nolan

Ann O'Leary, Head of Register Development at Anthony Nolan, presented on the charity's current recruitment strategy and its future plans to increase BAME stem cell transplant provision. Ann identified three major reasons why only 40% of patients from ethnic minority backgrounds are able to find a stem cell match; small numbers of BAME donors on the register, small or no registers in key regions abroad such as Africa and South Asia, and the complexity in matching tissue types for ethnic minority patients and donors.

Anthony Nolan has taken a three-stage approach to devising a BAME strategy. This consists of continued investment in adult recruitment, increased investment in public cord blood banking and a strategy to build relationships with registries abroad that operate in areas that match the ethnic diversity of the UK.

In terms of adult recruitment, Anthony Nolan currently works on targeted recruitment, patient appeals, with recruitment partners like the Army and ACLT, and on campaigns like the recent 'six percent' campaign focused on recruiting Asian Indian donors. Ann highlighted that in the future Anthony Nolan would be considering how to work with specific recruitment partners and community groups to address different ethnic minority groups. Messaging cannot be 'one size fits all' and recruitment agencies need to think about how they appeal to people from different communities and regions in the UK.

Dr Paul Veys, Great Ormond Street Hospital (GOSH)

Dr Paul Veys, bone marrow transplant unit director at GOSH, explained the process of deciding the best course of treatment for an ethnic minority patient who needs a transplant.

He explained that there is a 1 in 4 chance of a suitable match being found in the family. If this cannot be found, other options are explored. In some cases like treatment for sickle cell anaemia, the medical team may deem alternatives that have a degree of mismatch to be too risky and will not opt for transplant at all. After sibling/family donor searches, transplant clinicians will search for an unrelated donor. If this cannot be found, a matching cord blood unit will also be considered.

After these options, consultants may consider other alternatives. Due to advances in technology, clinicians are more open to considering haploidentical transplants from a parent; the degree of risk is higher than with matched family, cord or unrelated donors as the match is only 50%, but developments in transplant medicine have allowed doctors to gain confidence in such procedures.

In rare cases, a [saviour sibling](#) may be used. GOSH recently carried out the first transplant of this kind for the hospital on a child born with the rare disorder, Wiskott Aldrich syndrome. Alternatively, clinicians can opt for gene therapy, which will involve treatment and transplantation of a patient's own stem cells.

Dr Veys explained that cord is increasingly seen as the preferred option for treating BME patients because the a greater degree of mismatch can be tolerated and due to strategic planning by Anthony Nolan and NHS Blood and Transplant, cord donations in this country are very ethnically diverse. In 2010, GOSH carried out more cord transplants than donor transplants and this reflects the ethnic diversity of the children being treated at the unit.

He showed the group an example of a chart that would be used to evaluate the best transplant option for a patient.

Jonni Berger

Jonni Berger presented on his family's perspective and experiences whilst waiting for a matching donor for his mother Sharon, earlier this year. Jonni described his feelings on learning that there wasn't a suitable match for his mother and how this inspired him and his family to start the #spit4mum twitter campaign and organise recruitment events in the Jewish community. They used the Jewish holidays and Jewish philosophies about duty and community to inspire others to join the register. A match for his mother was found a few months later and she recently reached her 100 post-transplant milestone. Jonni explained that although he is very grateful to the transplant centre for saving his mother's life, he would have liked more information and support at the time to understand the difficulties in finding a match for an ethnic minority patient.

David Burrowes MP then opened the floor for questions.

Paul Goggins MP asked if the relevant agencies had a view on what the optimum number of cord collection sites should be.

Guy Parkes, Head of Stem Cell Donation and Transplant at NHS Blood and Transplant (NHSBT), said that the Stem Cell Supply Group (a coalition of transplant clinicians and registry staff) had been in discussions to ascertain an ideal inventory. In 2010, the Stem Cell Strategic Forum recommended that a target of 50,000 units was needed to meet the transplant need in the UK. The Department of Health (DoH) has committed annual funding of £4m to public collection and banking and the best use of this money is to turn existing sites into 24/7 operations so that we can collect from 40% of the births at each unit. The recent announcement of investment from the Regional Growth Fund into Anthony Nolan's cord collection activities will see three more centres opened outside of the South East. According to the terms of the award, these will have to be in areas of economic deprivation but this is a welcome investment in UK public cord banking. Ideally both Anthony Nolan and NHS Blood and Transplant would open 2 or 3 more collection sites each but the focus should be on quality, which will include the banking of ethnically diverse cords.

Mr Goggins highlighted that mothers in the Greater Manchester area are currently unable to donate their cords. Mr Burrowes said that decisions on the location of future collection sites would need to be made strategically and not just on a geographical basis.

Mr Goggins said that 40% of births at Central Manchester University Hospital are to BME mothers and the DoH needs to seriously consider investing in a collection site in Manchester.

Katie Begg, Head of Policy and Public Affairs at Anthony Nolan, thanked Mr Goggins for his commitment to raising this issue with the Public Health Minister and said that Anthony Nolan would continue to support his campaign. Mr Goggins also invited APPG members and stakeholders to support the campaign.

Mr Burrowes also asked when a proposed review into the revision of the 50,000 cord unit target would take place as the research has moved on since this was first agreed.

Guy Parkes said that NHSBT and Anthony Nolan are working with DoH and the Stem Cell Supply Group to review the current inventory needs. Guy stated that until the unmet need for BME patients is quantified it would be difficult to plan an accurate BAME stem cell provision strategy. The British Society of Blood and Marrow Transplantation does collect some data but it lacks the resource to do this to the standard required for these purposes. Ann O'Leary agreed and admitted that identifying the best places to recruit can be challenging without the data highlighting what the need is.

Mr Burrowes asked if this was a coding issue as Orin Lewis mentioned earlier. Orin agreed that in some ways, it was due to the inconsistency of transplant centre and registry coding over the years, although he admitted that this had improved recently.

Mr Burrowes asked if there was a more scientific way to identify a person's ethnicity, which would be preferable to the self-identification method currently used at recruitment stage. Dr Veys said that this is not scientifically possible, and that transplant centres need to work with the registries to accurately record and analyse the data that we gather on BAME patients and donors in the future.

The meeting was closed at 3pm due to room restrictions. Mr Burrowes thanked everyone for attending and asked that anyone with further comments or questions on the topic should send them to the APPG, and they would look into the issues raised.

Please send any queries or comments that were not covered in the meeting to Iana Vidal at iana.vidal@anthonymolan.org