

The All-Party Parliamentary Group on Stem Cell Transplantation

## **Effective, Affordable, Sustainable: A strategy for unrelated donor stem cell transplantation in the UK**

Tuesday 10 March 2015

### NOTE OF MEETING

On 10 March 2015 the All-Party Parliamentary Group on Stem Cell Transplantation hosted a meeting to discuss current and future strategy for the development of an effective, affordable and sustainable UK-based unrelated donor stem cell transplantation service.

The meeting was an opportunity for the UK Stem Cell Strategy Oversight Committee to present the findings and recommendations of their new report, *Unrelated Donor Stem Cell Transplantation in the UK: Effective, Affordable, Sustainable*. This new report examines progress made over the last five years and outlines the Committee's on-going commitment to building a fully sustainable UK unrelated donor stem cell transplantation service.

The APPG also presented their new progress report, *Cord Blood Transplantation: Meeting the Unmet Demand – Progress Review*, into recent progress made in the use of umbilical cord blood in saving lives. In the context of the new Committee report, the APPG made a number of revised recommendations to government and stakeholders to ensure that momentum is maintained and the full potential of cord blood is realised.

The meeting brought together a wide range of parliamentarians, government officials, clinicians, charities and industry stakeholders to discuss the findings of both reports, and the need for on-going collaboration between all groups to realise the ambitions and challenges presented.

This note is a record of the meeting and does not necessarily represent the views of the APPG on Stem Cell Transplantation or its secretariat organisation, Anthony Nolan.

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### **Findings and recommendations of the Stem Cell Strategic Oversight Committee report 'Effective, Affordable, Sustainable: A strategy for unrelated donor stem cell transplantation in the UK'**

*Ian Trenholm, Chief Executive, NHS Blood and Transplant & Professor Charles Craddock, Chair of the Committee*

Ian Trenholm introduced the report and stressed the need, and the on-going commitment of NHS Blood and Transplant (NHSBT), to building a fully effective and sustainable UK unrelated donor stem cell transplantation service.

Professor Charles Craddock then took the group through the findings and recommendations of the report, in particular focusing on the continuing need to grow and develop both the Anthony Nolan and NHS Stem Cell Registry and UK cord blood inventory to ensure that every patient in need of a transplant is able to find a perfectly matched donor. He also stressed the need for on-going integration, and to develop new and existing research and knowledge bases.

## **Findings and recommendations of the APPG's new report '*Umbilical Cord Transplantation: Meeting the Unmet Demand – Progress Report*'**

*Simon Butler, Policy and Public Affairs Manager, Anthony Nolan*

Simon Butler summarised the content of the APPG's new report which welcomed the progress made in the use of umbilical cord blood-derived stem cells in transplantation since the publication of *Meeting the Unmet Demand*, in 2012. In particular, there have been significant increases in cord banking rates and the number of cord blood units sourced domestically.

In light of this progress, and in the context of the new Oversight Committee report, Simon presented the APPG's revised recommendations for fully realising the potential of cord blood. These called on government, the Oversight Committee and other stakeholders to continue to collaborate to this end, and stressed the need to develop further research and innovation via a national stem cell transplantation trials network.

### **Discussion:**

A number of key issues were addressed during the discussion by the speakers and the meeting attendees:

#### *Black and minority ethnic (BAME) donors and patients:*

- The group acknowledged the increase in the percentage of BAME patients able to find a well matched donor – from 40% in 2010 to 60% in 2014.
- The reasons for this percentage increase are an increased number of adult donors on the UK registers from BAME backgrounds, together with increased availability of cord blood units for transplantation.
- Ensuring patient access to cord blood transplants, particularly in the case of BAME patients who have a lower chance of finding a well matched unrelated adult donor, is key.
- Growing the donor Fit Panel, and expanding the UK cord blood inventory to the numbers recommended in the Oversight Committee report, could potentially save an extra 220 lives per annum.

#### *Meeting the target of 30,000 banked cord blood units by 2018:*

- If NHSBT and Anthony Nolan continue to bank cord blood units as they are doing at the moment, there will be no need for an expansion of the cord collection programme needed to reach the 30,000 target by 2018.
- By 2018, enough revenue should be being made through the sales and export of cord blood units to guarantee the sustainable development of the UK cord blood bank until 2020 and beyond.
- Focus is now being placed on ensuring that only cord blood units with a TNC count equivalent to at least  $14 \times 10^8$  are banked. This will increase utilisation rates.

#### *Current unmet need:*

- It was reiterated that the current survival rates for patients who receive a stem cell transplant are 50-60% for adults.
- Much more needs to be done to ensure that every patient receives a perfectly matched donor, and that all patients have equality of access.

*Developing a tariff for stem cell transplantation:*

- It was acknowledged that the recent decision to approve the commissioning of double cord transplants means that cord transplants can now be routinely commissioned for adults.
- Second stem cell transplants, offered as a curative therapy for patients who relapse after receiving their first transplant, are still not being routinely commissioned by NHS England.
- It is paramount that any tariff for stem cell transplantation sufficiently remunerates transplant centres.

*Educating mothers on public and private cord donation:*

- There is a need to ensure that expectant parents are given correct, unbiased information about the benefits of public and private cord blood banking.
- Regulators such as the Human Tissue Authority (HTA) should consider regulating the information made available to expectant parents.
- An upcoming information campaign from the HTA, which will feature primarily on their website, will aim to inform expectant parents about cord blood banking. The public will be able to access information about the public and private cord blood banks, and date will be published to inform choices. The HTA will also develop a list of questions for expectant parents to ask when they are considering whether to bank their cord.
- It is key that stakeholders work with midwives and maternity units to ensure that they have the right information and support to educate expectant parents on cord blood banking.

*Patient data:*

- There is often insufficient data collected in hospitals on patients, particularly prior to transplant, making it very hard to track full patient pathways.
- Hospitals and data registries must receive the resources and support needed to ensure adequate data collection.

*Clinical trials:*

- Progress has been made in recent months towards developing a stem cell transplantation trials network, led by the British Society of Blood and Marrow Transplantation and supported by Anthony Nolan, Leukaemia and Lymphoma Research and NHSBT.
- A trials network would not only lead to better transplant outcomes, it will also create jobs and stimulate investment from the international pharmaceutical industry.
- There is a need to ensure full support for clinical trials from the clinical community. Hospitals participating in trials must follow strict trial protocol to ensure high quality data collection.