

**APPG on Stem Cell Transplantation**  
**Meeting minutes – 15<sup>th</sup> January 2013**



**Attendees:** Mark Tami MP, David Burrowes MP

**Speakers – representatives of the Stem Cell Strategic Forum (SCSF) Oversight Committee**

Professor Charles Craddock, Chair of SCSF

Andrew Hadley, General Manager, Specialist Services Operations at NHS Blood and Transplant (NHSBT)

Rob Bradburn, Finance Director at NHSBT (in place of Lynda Hamlyn, Chief Executive)

Henny Braund, Chief Executive at Anthony Nolan

Guy Parkes, Head of Special Projects at Anthony Nolan

**Observers**

Mil Vukovic, Leukaemia and Lymphoma Research

Paula Claytonsmith, Anthony Nolan

Susana Gomez, Anthony Nolan

Steve Baines, Future Health

Roger Dainty, Future Health

Rebecca Roberts, Cells4Life

Abid Shah, Royal College of Obstetricians and Gynaecologists (RCOG)

Malcom Griffiths, RCOG

Dr. Robert Lown, Anthony Nolan

Breedagh Hughes, Royal College of Midwives (RCM)

Lorna Watson, Smart Cells

Rosemary Exton, RCM

Lionel Salama, Umbilical

Orin Lewis, African Caribbean Leukaemia Trust

Dr. Ulrike Paulus, Scottish National Blood Transfusion Service

Martin Guttridge, NHSBT

Dr Paul Veys, Great Ormond Street Hospital

Prof. Tony Pagliuca, King's College Hospital

Jai Patel, NHSBT

Dr. David Hutchon

Katie Begg, Anthony Nolan

Victoria Moffett, Anthony Nolan

Iana Vidal, Anthony Nolan

**Review of the recommendations of the cord report published by the APPG in January 2012**

Guy Parkes provided the group with a summary of the impact and achievements of the aligned register and cord blood banks. He also discussed patient outcomes, emphasising the fact that public data is due to be released shortly.

Professor Charlie Craddock highlighted the fact that patients who would previously have been considered incurable are now surviving long term. Disease relapse is still an issue in the first 100 days but this can be addressed by clinical trials networks.

**Background**

David Burrowes summarised the first three background recommendations of the cord report, and said that he recognised that the Stem Cell Strategic Forum (SCSF) Oversight Committee are in the process of applying for funding for a secretariat to help meet these review-based objectives.

Prof. Tony Pagliuca said that he supported this idea as currently groups such as the SCSF Oversight Committee and clinical reference groups are functioning with little to no administrative support and this is problematic.

David Burrowes also said that the APPG was prepared to submit a response to the NHS Commissioning Board's consultation on service specifications for transplants. Prof. Pagliuca

said that it would be helpful to have the APPG's influence on this, particularly regarding the references in the consultation document to double cord transplants. As the consultation closes on the 25<sup>th</sup> January, the timeline is short but any support the APPG could offer would be appreciated.

Katie Begg noted that the patient outcomes data would be useful for this, and Prof. Pagliuca emphasised the importance of the cord data available, commenting that the Commissioning Board have asked the CRG to investigate whether double cord blood transplants are the right way to go. Dr Paul Veys said that the data is good and that cords are often selected over adult donors; it needs to be made publicly available.

Rosemary Exton said the RCM would be reviewing the data and information available to the public. The college gets a number of queries from mothers about cord blood donation; are there plans to roll out the programme to more hospitals? David Burrowes said that this question was more appropriate for the next section of the meeting. He emphasised the fact that the issue of a secretariat is still pertinent and the APPG wishes to be updated on the progress of this action, in case it can offer assistance.

David Burrowes asked that the group keep the APPG informed on the application to DoH for funding for a secretariat.

### **Cord**

David Burrowes summarised the recommendations relating to cord and asked for updates on progress in this area. Guy Parkes said that we now have 11 collection sites and Anthony Nolan is looking at the budget for opening further centres. In answer to Rosemary Exton's question, the best hospitals are those that cover large, ethnically-diverse populations. It is not economically viable to have a collection centre in every single hospital which is why Anthony Nolan and NHSBT only work in selected hospitals.

David Burrowes enquired about the funding needed to meet the targets set in the SCSF report. Guy Parkes stated that they have secured three year funding but would like long-term investment. Since the report was published the TNC count thresholds have been raised for cord which means that there is now a smaller inventory of banked cords that are viable for clinical use. David Burrowes asked if in light of this, the targets were still relevant. Guy Parkes explained that they were but that the focus was now also on improving the quality of cords, as well as growing the inventory. There are plans to introduce secondary banding for cord in selection that would include information on cost, reputation of bank and other factors.

Lionel Salama asked if the figure of 8,000 cords at the start of the project (as shown on the presentation) was correct, and if so, what had happened to the figure of 14,000 that NHSBT had. Andrew Hadley explained that these cords are still in the bank but they are rarely issued because of the low cell counts. They are still useful in research. Guy Parkes suggested that they could be useful in the future for research into cell amplification.

Lionel Salama pointed out that the average annual collection should be 5,000 cords if the 50,000 target is to be met within the agreed timeframe. He asked what the current average is. Martin Guttridge (NHS Cord Blood Bank Manager) estimated that this is between two and two and half thousand per year.

Lionel Salama asked what plans were in place to reach the 50,000 target given that cords are being collected at less than 50% of the review's objective and whether additional funding beyond what had been provided by the Department of Health would be required. Guy Parkes said that the UK would struggle to meet that target in the original time limit but we are now banking the best quality cords, with utilisation rates increasing as a result. There could be a review of optimum inventory size and process. David Burrowes stated that 50,000 target

might not be best figure in light of scientific developments but research needs to be released to support this. We need to know what the current target should be and how many cords we still need to bank in order to reach that amount. Guy Parkes suggested that this needs to be evaluated in terms of the adult register, and supply and demand.

Lionel Salama asked if the Department of Health funding meets the current need. Henny Braund said that it did not and we are looking into funding from the voluntary sector or a further bid to the DoH. Lionel Salama asked if it is known how much money is needed, and Andrew Hadley explained that NHSBT and Anthony Nolan do not have these figures.

David Burrowes asked how the Oversight Committee would address this. Charlie Craddock explained that this again highlighted the fact that the Oversight Committee needs a secretariat. It has now been two years since the original SCSF report was published; now would be a good time to review progress and identify areas that need more attention.

Prof. Pagliuca noted that the proportion of high quality cords banked worldwide has dropped as science has developed. The continued banking of high quality UK cords will also have a significant impact on export. Guy Parkes explained that the utilisation rates could exceed 2% next year due to the change to thresholds, compared to the 1% recommended by the SCSF. This can help generate more funding for future investment.

On engagement and donor selection, David Burrowes asked if the organisations had encountered any problems. Henny Braund explained that general recruitment is not an issue, but that recruiting ethnic minority donors has always been a challenge. Through the DoH and the National BAME Transplant Alliance, both organisations are working to improve the provision for ethnic minority patients.

### **Commissioning**

David Burrowes asked what work is being done to educate commissioners about the efficiency of UK cord. Guy Parkes explained that the Cord Blood Working Group, a sub-committee of the BSBMT made up of clinicians and providers, are communicating with commissioners. It was re-established to focus expertise in one resource, and enable the sharing of clinical experience. Professor Craddock noted that it signified a movement towards consensus informed by best practice.

Dr Paul Veys explained that practice varies between centres, and there is a need to encourage consistency – this could be led by commissioners. His own transplant centre focuses on quality so prefers to use UK donors and cord when the option is provided.

David Burrowes suggested that the APPG write to the Secretary of State about the success of cord and the Anthony Nolan/NHSBT partnership. He asked what progress had been made in establishing a clinical trials network. Professor Craddock explained the distinction between early and late phase clinical trials and suggested that with the critical mass available and correct regulatory environment, the UK has the potential to become a global leader in transplantation networks. He is currently speaking to the NIHR, the universities of Cambridge and Oxford and other scientists about developing this. When asked how he expected this to be funded, he suggested that a ‘patchwork’ of funding would be secured from a variety of sources. Prof. Pagliuca noted that applying to the Innovation Fund is one avenue that could be explored although this would have to be a joint bid with a pharmaceutical company or large research charity but this would not be clear for another few months. David Burrowes asked that the Oversight Committee keep the APPG updated on developments as this has wide-reaching implications.

David Hutchon welcomed the earlier comments on expansion techniques for cord blood as this will be a greater need for such techniques as delayed clamping is implemented; he would like to know what research is being done in this area.

Lionel Salama commented that he was disappointed that Anthony Nolan and NHSBT wouldn't collaborate with other organisations towards a global fundraising body for funding cord.

David Burrowes thanked the SCSF Oversight Committee for presenting to the APPG and for their work in the area. He said that a growing concern was the need for information to be accessible to the public. As a priority, he offered the support of the APPG to the Oversight Committee in its efforts to appoint a secretariat and prepare business cases.

He suggested that there be a review of the previous projections and targets, and offered help on commissioning issues.