

Minutes of the BSBMT Open Meeting

Thursday 15th May 2008, 9.30 – 10.30
Institute of Physics, 76 Portland Place, London

1.) President's report – David Marks

- 1.1: Incorporation: The BSBMT is now an incorporated society, which means its members are no longer individually liable.
- 1.2: Constitution: In accordance with the requirements for incorporation, our constitution is now called The Memorandum and Articles of Association, and will be placed on the website very soon.
- 1.3 Charity status: Good progress is being made for our application for charity status, which we expect to be finalised in around 3 months.
- 1.4: Lease for new Data Registry Offices at Guys: The lease for this has not yet been signed due to delays caused by Guy's lawyer. It will be signed as soon as he is ready
- 1.5: Reference Costs: It is likely that new reference costs for transplantations will be introduced in 2009-10. These costings need updating as the ones currently in use are strikingly varied and inaccurate. The BSBMT feels that this is a good opportunity to be involved in getting the new costings right, and is working to educate decision makers as to the complexities of procedures. Majid Kazmi is currently completing a costing exercise at Guys, and a few other large units have also been working out accurate ground up costings which so far have proved to be reassuringly uniform. These studies will form the basis of recommendations made to the commissioners. There will be a meeting in September for commissioners, transplant leads, and financial directors to discuss the matter further. Dates and venues will be advertised on the BSBMT website when finalised.
- 1.6: Indications table: There is a new, up to date BSBMT indications table available on the BSBMT website. All parts of the table have been reviewed by disease specific experts, and it aims to reflect up to date UK practice. There are still a few gaps which are being worked on. David Marks would appreciate any comments on the table. The Indications table committee will now form an adjudication group available to both individuals and the commissioners to help resolve disputes impartially.
- 1.7: Designated Cord units in London: The commissioners have asked for expert advice to determine which London centres should be able to perform cord blood transplantations. Out of the 8 possible units, 4 have so far submitted applications. David Marks and Nigel Russell are happy to develop a set of criteria to judge these applications, and oversee the process to make sure it is fair. There was some dissent from members of the meeting as to the value of limiting the number of centres performing cord transplants, the BSBMT's authority to judge in such matters, and the precedent being set for other regions and other types of transplant. David Marks reassured the meeting that limiting the number of centres in this way was a short term way of improving cord blood transplantation skills fast, and that once the processes had been evaluated and were being performed well more centres would be invited to undertake them. He stressed that the commissioners were definitely going to limit the numbers of centres performing this type of transplants, and if the

BSBMT refused to judge which centres would be most appropriate the commissioners would probably turn to international judges, who might know less about local circumstances. David Marks agreed to let the members view and comment on the criteria used to judge the centres before they were used. If anyone has any further comments on this issue please direct them to David Marks.

- 1.8: Outcome analyses: In return for increased funding from the commissioners for Data Registry staff, the BSBMT have promised to increase the amount of data available to them. This means we need to improve data in ProMISe, particularly follow up data.
- 1.9: The BSBMT is considering applying to join the ACCEA register of official specialist societies, in order to get both the society and individuals within it better recognition. If anyone has any reasons why we should not do this, please get in touch with David Marks asap. Becoming a registered specialist society will involve setting up a committee to judge applications. Any interested in being part of this committee should approach David Marks.

2.) Treasurer's report – Charles Crawley

- 2.1: The BSBMT's accounts from 2007 were presented. It was noted that last year saw additional expenses due to legal fees created by incorporation, charitable status, and the move to Guys.
- 2.1: The financial position in 2008 was discussed. This year should hopefully see an increase in income from Centre and Corporate subscriptions fees, and a reduction in extra legal costs. Overall our financial position is much improved from this time last year, but the society still has some way to go to achieve its aim of having enough reserves to fund us through a year of activity.
- 2.3: Income and expenditure was broken down by subcommittee, and the goal of each section of the society becoming financially self sustaining was discussed.
- 2.2: All were asked to take the time to speak to Pharma reps during the day, as they are important to us in terms of corporate funding.

3.) CTC / NCRN Report – Gordon Cook

- 3.1 An overview of the CTC's activity and core staff was given. The most recent meeting was Number 26, which had been a success with 19 attendees (average number of CTC attendees is 15)
- 3.2 Gordon Cook asked any that were not currently on the CTC emailing list who wished to be to get in touch with him, so he could ensure they were invited to meetings.
- 3.4 An overview was given of the very healthy number of studies published, being written, in progress, and proposed. The good number of prospective studies was noted.
- 3.5 A new study proposal pathway is currently being created. Anyone wishing to suggest a new study should contact Gordon Cook or Emma Morris to request a copy.
- 3.6: The CTC aims to increase its collaborations with other societies, and links are currently being made, for example with the NCRN.

4.) Registry/data issues / New Staff – Keiren Towlson

- 4.1: The Data Registry team has expanded, and now consists of a Head of Data Registry, a Senior Data Manager, a Data Coordinator, and a Statistician. All posts are fully funded by the specialist commissioners. An additional data manager, shared between ourselves and the Anthony Nolan Trust is due to start in the Autumn, funded by the ANT, and working solely on UD transplants. They will also begin to merge retrospective AN data with BSBMT data.
- 4.2: Data agreements with commissioners: In order to secure the increased funding for the staff described above, the BSBMT have agreed to increase the complexity of data it supplies to the commissioners, for example national data for each type of transplant. These new analyses can only be done using data in ProMISe so it is vital its data is complete and up to date, including follow ups. The database is currently missing about 60 % of 1 year follow ups so Keiren will be in touch!
- 4.3: Release of centre specific data: It is predicted that the commissioners will request data on individual centres. The transplant lead will have to give written permission before the Data Registry will release any centre specific data to the commissioners. A form for this is being devised by Keiren Towlson.
- 4.4: Appendix to Med A form: In March 2008 the EBMT and CIBMTR agreed an appendix to the Med A form. Currently filling in this appendix is voluntary for most centres, but it would be incredibly useful for upcoming studies if all centres could complete this section.
- 4.5: BSBMT help: David Marks asked that any centre struggling to submit data get in touch with him, and he would see if he could help, for example writing to their trust to stress the case for enough Data Manager hours.

5.) Meeting Report – Scientific Meeting – Ronjon Chakraverty

- 5.1: Previous Meetings: The last Scientific Subcommittee meeting had been in November 2007, titled ‘Cancer Immunotherapy – beyond the T cell’. It was a success with the full capacity of 60 attendees
- 5.2: Upcoming meetings: The next Scientific Subcommittee meeting will be on the 4th November 2008, titled ‘Cancer Immunology – targeting regulatory T cells’. Details will be advertised on the website in the near future.
- 5.3: LRF/BSBMT fellowship: There have been a number of applications for the award, and a winner will be announced in June. As it is an annual award it will be advertised again in Jan 2009, with a deadline in March.

6.) JACIE / Accreditation – Mark Lowdell

- 6.1: Current TAC activity: There have been 2 TAC Committee meetings in the last year. The TAC quality management group has also been helping several centres become accredited. An accreditation workshop was run in February and was very successful. Thanks to Chugai for sponsoring the meeting. The next accreditation meeting is planned for November 2009.
- 6.2: JACIE Update: At the last EBMT JACIE board meeting it was decided to increase the fees for inspections. However, as the frequency of inspections is going to be

reduced (from 4 yearly to 3 yearly) the fee increases will be cost neutral to individual centres.

- 6.3: Current situation: The UK has done well in terms of numbers of accredited centres, and has the best in Europe, although Germany is close behind. Auto only centres are not becoming accredited quite so quickly, probably due to a lack of resources.
- 6.4: BSBMT help: The BSBMT wish as many UK units as possible to become accredited, and is eager to help units in any way they can. Auto only centres can expect to hear from David Marks in the near future asking what challenges their particular centre faces in becoming accredited, and offering assistance such as writing to trust CEs stressing the need for Data Managers. Any centre that feels such assistance might make becoming accredited easier for them should contact David Marks immediately.
- 6.5: Inspector numbers: During the next year we have many centres hoping to become accredited and a huge shortage of UK inspectors. We desperately need more inspectors, and in an effort to solve this problem we hope to run a course in the near future offering free inspector training. It was stressed that this course is aimed at those willing to actually do inspections after they are trained, not just those interested in getting an insight into the inspection process – we cannot afford to fund those!

7.) Nuclear Preparedness – David Marks

- 7.1: Current UK level of preparedness: The UK is currently far behind the rest of Europe in terms of having policies for reacting to a nuclear incident. There is a lack of formal dialogue between the government and clinicians concerning plans for caring for victims. Currently there are only 5 transplanters in the UK who have been trained to deal with radiation victims.
- 7.2: BSBMT goals: The BSBMT feels its members will be asked to place a crucial role in the event of a nuclear incident; therefore they should be involved in developing policies. Each trust should have its own policy for dealing with nuclear accidents, and the BSBMT should be involved in developing the template for this.
- 7.3: Progress to date: David Marks, Tony Pagliuca, Jane Apperley and Ray Powles are meeting with the MOD and the DoH amongst others next week to discuss policy development. There is a training course running soon in the US to train clinicians to care for radiation victims, and if any BSBMT members wish to attend, the BSBMT is willing to help with funding.

8.) Elections – David Marks

- 8.1: The next elections for members of the Executive Committee including the post of President Elect will be held soon after the October 08 meeting. Efforts will be made to make this process more open and democratic than it has been in previous years. Please get in touch with David Marks or other Executive members if you wish to find out more about a role, or consider standing.

9.) Date of next meeting

16th October 2008