



**MINUTES OF THE MEETING OF TRUSTEES
HELD ON SATURDAY 28TH NOVEMBER 2009
at the Hilton Hotel, Leicester.**

1. PRESENT

- Trustees:-** Mike Francis (Chairman), John Dealey (Deputy Chairman), Patricia Smith, Fiona Foley, Roger Paul, Ian Lewis, Gill Pilcher, Patrick Hardman.
- Volunteers:-** Ros Francis (Clerk to the Trustees), Alan Johnston (Website Manager).
- Employees:-** David Fisher (Head of Fundraising), Maggy Barnes (Accounting Technician), Kate Connor (Administrator preparing to return from maternity leave in January).

APOLOGIES

- Trustees:-** Nick Bones, Sally Hurst.
- Employees:-** John Newby (Information Officer), Lauren Heslop (Administrator providing maternity cover).

A MEETING OF THE TRUSTEES ONLY had been held prior to this main meeting.

2. MINUTES OF THE MAIN MEETING OF TRUSTEES held on 26th September 2009.

Following agreement by all Trustees present, these Minutes were signed by the Chairman.

3. MATTERS ARISING FROM THE MINUTES

3.1 Mr. Kipling sponsor money. Following many communications, it looked as though the £11,000 in support of Awareness Week and the Conference, would be gratefully received the next week.

3.2 Badges for Trustees, Key Volunteers and Employees to wear at events. It was decided that it was not necessary to have specially made ones but to all be sent their BCRT Conference badges.

ACTION – David

3.3 Associated Conferences. Notice was given of:-

- The British Sarcoma Group (BSG) Conference to be held in London on 4th, 5th February 2010.
- The National Association for Childhood Cancer Parents Organisations (NACCPO) to be held in Oxford on 19th June 2010 with the AGM the previous afternoon.

4. CORRESPONDENCE

None other than items to be included within Agenda headings.

5. INFORMATION GIVEN TO THE EMPLOYEES FOLLOWING THE TRUSTEES' ONLY MEETING:-

5.1 BCRT Committees. A re-adjustment of three of the existing committees had been agreed. The full list of eight committees would now be:- Strategic Planning; Campaigning and Marketing; Finance; Fundraising; Ireland; Management; Research and Information; Support. The Terms of Reference (TORs) of six of these had been agreed, the other two were being re-written to be in line with the re-formed committees. The TORs and Table of Membership of the Committees to be readjusted as had been agreed and sent out to all by the Clerk.

ACTION - The Clerk

5.2 A Marketing Officer. It had been decided by the Trustees that Lauren Heslop would take on the role of Marketing Officer for the three months following the ending of her role in mid January of providing

maternity cover as Administrator. The basis of her new role would be to visit the cancer centres to find out who/which departments would be most interested in BCRT and all that it can offer them and their patients and to write up reports with all the information gathered for future use.

6. FINANCE COMMITTEE

6.1 Current Statement. The balance of all the bank accounts at the end of November was £798,000.

6.2 The Accounts. The Trustees expressed their thanks to Maggy Barnes (Accounting Technician) for the rapid progress she had made in entering the transactions for the financial year 2007 – 2008 onto the Paxton System. Maggy said that there were still some queries to be solved but that she planned to meet the Accountant on 16th December. It was hoped that the draft accounts would then be ready for the next Trustee Meeting on 6th March 2010. Trustees took the opportunity to ask questions of Maggy about the system. These included explanations of the presentation of grants accruals, of what constituted governance costs, of how allocated but not yet called for research grant funds were shown. Ian Lewis discussed the heading “charitable activities costs” and Trustees felt they would like more information on the titling of other sections.

6.3 Bank Account. Gill Pilcher reported that, as agreed, she had opened an account with the Charities Aid Foundation Bank (CAF) and was awaiting receipt of a cheque book.

6.4 Budget. Roger Paul reported that this was in hand.

6.5 Processes and Procedures. During her work, Maggy had seen the need for various processes to become properly established, understood and carried out by all. The first three had been previously circulated:- Purchase Orders and Invoices Sign Off; Petty Cash; Expenses for Employees, Trustees, Volunteers. These were welcomed and agreed by all Trustees and would be implemented immediately.

7. TRUSTEES

7.1 Resignation. Trustees had been very sorry to receive a letter of resignation as a Trustee from Sally Hurst. However, they were delighted to learn that she is willing to continue to speak for BCRT as a representative of patients and wants to use her journalistic skills where-ever appropriate. The Chairman had sent a letter on behalf of the Trustees.

7.2 Potential new Trustees. The Clerk distributed a table with initial information sent in by the 13 people who had expressed an interest in becoming a trustee having responded to the advertisement in the Newsletter and on the website. She explained that working with Mike Francis and Ian Lewis, she had prepared a sheet about the role of a trustee detailing essential and desirable qualities, a sheet about the charity itself and an application form. These would be sent to all applicants for return by 8th January 2010 and with contact details for phone discussion if wanted. The covering letter explained that one or two trustees would then be in touch to meet people and it was hoped that all might be settled by the next Trustees’ meeting on 6th March.

It was also noted that some people may feel that being a full trustee might not be for them but could contribute to BCRT by being on committees or working parties for particular reasons or events etc. It was suggested that a conference call for Trustees might be arranged once all the applications are in.

7.3 Length of term of office for Trustees. The Charity Commission had advised the Clerk that BCRT should now agree a set number of years for the office of Trustee (this had initially been staggered to establish a rolling programme of changes as recorded in the Trust Deed). This set term would be relevant for Trustees standing for re-election and also for newly elected Trustees. It was decided that the period would be four years with the understanding that Trustees could submit a letter of resignation at any time. This was proposed by Mike Francis, seconded by Gill Pilcher and agreed by all Trustees present.

8. STRATEGIC PLANNING COMMITTEE

This committee had met in London on 4th November but the Minutes had only been circulated to committee members a few days before this 28th November full meeting. There had therefore not been time for the content to be agreed by committee members ready for discussion with the full board of Trustees. As a result, progress on the work of this committee was deferred.

9. SCIENTIFIC ADVISORY PANEL (SAP).

9.1 Update on the five grant applications accepted at the last meeting of Trustees.

- A table was distributed providing Trustees with current information available on each research project.
- As BCRT had met the criteria for partner status with the National Institute for Health Research (NIHR), the NHS would support certain costs, for example for clinical trials, so this information had been added to the BCRT website Research Grant section so that applicants were aware of this possible funding support.
- Trustees were pleased to receive a four page document detailing all the current BCRT research projects and their progress. It was noted that this was all interim information and so could not be published on the website etc.

9.2 Mifamurtide. Ian Lewis reported that the next NICE appraisal hearing would be in March 2010

9.3 SAP Strategic Planning Meeting. Ian reported that he had changed the date of this to link with the National Bone Tumour Group meeting to be in Leeds as many relevant people would be attending both meetings. This would now take place on 25th and 26th February with half of the time being for BCRT's specific meeting. He said he would be using BCRT's Administrator to help to organise this event.

10. PRESENTATION BY DR. JOHN NEWBY, INFORMATION OFFICER.

- In his absence due to illness, John Newby had sent his presentation so that Ian Lewis could speak to it for him as they had been working closely on defining the role of BCRT's Information Officer.
- Trustees were impressed by the range of possibilities listed and by the progress already made.
- John had been invited to join relevant groups including the National Cancer Pathway – Improving Outcomes Guidance National Programme with BCRT being a partner organisation.

11. FUNDRAISING COMMITTEE

11.1 Report from the Head of Fundraising. David Fisher presented his report showing the main income sources for the year.

11.2 Report from the Fundraising Committee Meeting which had been held by conference call on 25th November.

- Roger Paul felt this had been a good first meeting of the committee providing a platform for progress in the new year. Possible ideas to explore were:- extending Golf Days and Sports Dinners, the promotion of running events, the use of Ambassadors for the charity.
- It was felt that BCRT should stress more strongly and emotively that it is children and young people who are mostly affected by bone cancer and yet they do not figure in the title. This led to discussion about producing a BCRT DVD. Further thoughts and enquiries to be made around this idea. **ACTION - All**
- Roger said that the audio conferencing had worked well. He was asked to write up how he had organised it and to distribute this information for other committees use. **ACTION - Roger**
Other possible facilities suggested were Skype and Community Network.
- Roger said he had produced a fundraising diagram which he would send out and asked for further ideas to be added.

11.3 A report on the Berlin to Belgium Cycle Ride was received. David assured Trustees that he was still chasing up the remaining amount of promised sponsor money.

11.4 A paper on a proposed Corporate Supporter Scheme was discussed. It was felt that there was a basis of some good ideas. It was felt that it would be best to keep to local companies initially. This scheme was approved and the response to it would be monitored.

11.5 Bake a Cake for Bone Cancer. A report on this had been received. It had been successful but all felt that it could be built on and improved further. There was discussion as to whether it necessarily needed to take place in Awareness Week. Could it be launched with relevant publicity material etc sent out earlier in the year and people then holding events when it suits them? This would still raise awareness and funds. There was again discussion around the best time to circulate schools and when schools would

be most likely to hold events within their year's timetable. The importance of getting celebrities etc on board early was stressed. It was also felt that the publicity around the celebrities should go out in the initial mailing as it would have greater impact to enthuse and encourage rather than the Guide having to be requested.

12. CAMPAIGNING COMMITTEE

12.1 Awareness Week -18th - 25th September 2010.

- Initial thoughts were that it would be best to extend the focus already given to mis /delayed diagnosis as this continues to be a frequent and concerning issue.
- It was suggested that an objective might be to get the BCRT DVD envisaged by the Fundraising Committee made and to launch it in Awareness Week. All to actively consider people with the skills to write, produce, film this etc

ACTION – All

12.2 EuroBoneT. Mike Francis asked that links with relevant organisations such as this be checked as to whether there were reciprocal links on websites.

ACTION – Alan

12.3 Report from the meeting of the National Cancer Intelligence Network (NCIN), Sarcoma Site-Specific Clinical Reference Group attended by Mike Francis in Birmingham on 15th October. Mike reported that this had been an extremely interesting meeting. The chairman is Rob Grimer and Mike will circulate the Minutes when he receives them. They are considering holding a conference in 2010 and would like everyone to think about the many questions there are around service provision that might be explored. One issue discussed was around when patients sign consent forms for tissue to be use – who may get it and where from?

12.4 Report from the Credit Suisse Charity Day attended by Mike Francis in London on 14th October with the BCRT Display Stand. It appeared that the organisers had not explained the nature of this event clearly but even so it had raised some awareness and it was thought that BCRT might be one of its charities again next year.

13. INFORMATION AND MEDIA COMMITTEE

13.1 BCRT Newsletter – Autumn 2009 issue.

- Many favourable comments had been received. These included support for the range of the overall content, interest in the medical articles, news of the many amazing challenges people take on etc. It was clear that people like to see themselves, their family and friends. The heading of “News in Brief” had been changed to “Thank You” and readers really do scour this for their events. This emphasised the importance of making sure that ALL events / donations whatever the size, are shown somehow within the Newsletter.
- There was discussion as to whether to add another 4 pages so that more could be included. Costings to be obtained.
- It was agreed that BCRT in Ireland should have at least a whole page next time and including its own colours.

ACTION – Lauren

13.2 IT in the Office.

- It was proposed that a support agreement should be set up with Main Systems in Leeds so that there is a named person to call out directly when problems occur. It was said that this would be at a cost of £57 per month. This was agreed by all Trustees.
- It was proposed that Lauren Heslop would need a laptop in her new role as Marketing Officer. This was agreed. In the light of some of the problems there have been with the computers, it was decided that in future, new equipment should be bought rather than reconditioned items as the later two computers had been.
- Alan Johnston asked that the Management Committee should keep him in touch with all IT matters, particularly when there are changes or additions to personnel needing access codes, authorisation to relevant parts of the server etc so that he can activate these when required.

13.3 The Website.

- It was noted that some sections of the Website were out of date and that there seemed to be delays in new items being added. It was noted that it is extremely important to families that stories sent in are added as quickly as possible and when people hold events they search within the first two or three weeks expecting to see what they have sent in. Mike Francis reported that the committee had been endeavouring to unpick this situation and some reorganisation of the system was in hand. He said he would report back to Trustees as this develops. **ACTION – Mike**
- It was reported that there had been several requests from supporters to advertise the sale of items on the Website – sales that would benefit the charity. Trustees were happy for this to be done but it appeared to be difficult to see how these could easily be found on the Website. Alan Johnston said he would think about the best way for these to be seen. **ACTION – Alan**

13.4 Google Calendars. These were again discussed. Gill tried to explain some aspects to Trustees but it is hard to envisage without actually doing it. A request was made for an “idiot’s guide” to take them from stage to stage in order to master it. **ACTION - Alan**

13.5 BCRT Conference. To be on Saturday 9th October 2010 at Sopwell House, St. Albans. Not to be in June/July this year due to difficulties around the availability of the venue following the decision made to hold the conference there for a second time.

The Planning Committee to meet early in the New Year to consider themes and speakers following Ian Lewis’s advice that October is not the best time of year for medical professionals to be easily available.

14. IRELAND COMMITTEE

Trustees were delighted to hear the progress that this Committee had made towards becoming established. Fiona Foley reported that they were starting from nothing so there was much to put in place.

The most important aspect was to have a clear Irish identity:-

- They need to have an Irish website link which is not .uk but .ie. This should go straight into the Irish section with the Irish colours. Alan Johnston to book the domain names for them. **ACTION - Alan**
- They must have an Irish legal framework. They need 3 Trustees and the majority must always be Irish.
- A database of contacts in Ireland should be started.
- They need to open a Bank Account there.
- There should be one, maybe two pages devoted to Ireland in the next Newsletter.
- Patrick proposed that there should be a biannual meeting held in Ireland.

Some aspects would be the same as already set up for BCRT:-

- The Terms of Reference matched well with the other BCRT TORs and the adjustments as agreed would be made and circulated. **ACTION - Ros**
- The Objectives had been received from Fiona and added to the Draft Business Plan.
- It was said that the system for grant applications and the SAP would be the same.

There were some questions to be answered:-

- How would the Accounting System be organised?
- Would they be covered by a Trust Deed like the main BCRT one, will it be separate or different?
It was agreed that advice was need to check the legal aspects for registration as a charity.

15. SUPPORT COMMITTEE

15.1 Gill Pilcher reported that discussion and investigation was on-going within the Committee around information gathering, the storage of information on databases and the organisational practicalities of the role of committee members.

15.2 It was agreed that an email address support@bcrt.org.uk should be set up.

15.3 It was agreed that the Support Committee should have a page on the website.

15.4 It was thought that it could be useful to begin to gather information on other organisations to have to

hand to recommend to people as appropriate.

15.5 It was suggested that the Committee would meet via Conference Call early in the New Year.

16. MANAGEMENT COMMITTEE

16.1 CRB Checks. It was reported that the forms for this had been received in the office but no further action had been taken. There continued to be indecision as to whether any employees or Trustees needed this cover within their work for the charity. Further advice to be obtained.

17. THE DATE OF THE NEXT MEETING WAS CONFIRMED.