

BONE CANCER RESEARCH TRUST

MINUTES OF MEETING OF TRUSTEES

held on Saturday 2nd February 2008

at the Leicester Hilton Hotel.

1. PRESENT

Trustees:- Mike Francis (Chairman), John Dealey (Deputy Chairman), Ian Lewis, Gill Pilcher, Patricia Smith, Nick Bones, Patrick Hardman.

Officers:- Ros Francis (Clerk to the Trustees), Kate Connor (Administrator), David Fisher (Head of Fundraising), Alan Johnston (Website Manager).

Supporters:- Chris Smith, Chris Wickham.

APOLOGIES

Trustee:- Rob Grimer.

Supporter:- Marian Dealey.

2. MINUTES

Minutes of the Meeting of Trustees held on 17th September 2007 were agreed and signed.

3. MATTERS ARISING FROM THE MINUTES of 17th November 2007.

Matters not covered by later Agenda items:-

3.1 An Information Officer. Ian Lewis reminded Trustees of a previous discussion (See Minutes 17.11.07; 6.5) around the possible need for a part-time Information Officer for the Bone Cancer Research Trust (BCRT). He felt that this was becoming more necessary and it was agreed that David Fisher (BCRT's Fundraiser) should research possible funding for such a post. Information on funding of projects by Children in Need was passed to him by the Clerk.

ACTION - David

4. CORRESPONDENCE

4.1 Requests received by BCRT to support "research". The Clerk reported on a request from the Royal College of Paediatrics and Child Health concerning the aim to produce a communication training tool for paediatricians working with young people. Ian Lewis reminded all present of the principle of care in checking legitimacy in any response to such requests for any kind of involvement.

4.2 Macmillan Cancer Support merger with Cancerbackup. The Chairman drew attention to possible changes through which Macmillan might not continue to support children.

4.3 NACCPO (National Alliance of Childhood Cancer Parent Organisations). Mike Francis drew Trustees' attention to future meetings that he would be attending.

4.4 ICCPO (International Confederation of Childhood Cancer Parent Organisations). A copy of this organisation's recent Newsletter was circulated.

4.5 Social Economy. The latest quarterly edition of information for charities was circulated.

4.6 Request for funding. This had been received from a 4th year medical student at Birmingham University requesting support for his research in Brazil into replacement bones. It was agreed that BCRT was not yet in a position to help with this kind of project. The Administrator to write.

ACTION - Kate

Ian Lewis suggested that in the future BCRT might consider offering annual bursaries to support education and research into bone cancer by medical students within the funding considerations carried out by BCRT's Scientific Advisory Panel (SAP).

4.7 Further letters and comments from Debbie McCartney and Gill Callar which had been received were passed on, assuring the Trustees of their future support of BCRT.

5. FINANCIAL AND ADMINISTRATIVE BUSINESS

5.1 Statement of Accounts. Statements were presented for the main account and for the now seven dedicated accounts, the total amount to 31.01.08 standing at £395,941.13. All Trustees agreed that the accounts be accepted. Requested expenditure for the purchase and setting up of the IT equipment, phone and broadband for the BCRT office, was approved.

5.2 Dedicated Accounts. There was discussion concerning arrangements for the management of these named, memorial accounts. It was decided that once the new accounting package is in place, procedures for their administration will be clarified.

5.3 Approval of Expenditure. Trustees revisited the roles and responsibilities of Trustees and Officers in respect of financial matters. With the retirement of Debbie McCartney from trusteeship and who had also been a signatory, it was agreed that Gill Pilcher with her forthcoming increased involvement in the financial side of BCRT, should become the new signatory. It was reiterated that the authorisation of online payments, the signing off of purchases and the signature of cheques should always include a trustee and not just be carried out by officers.

The following two sections (5.4, 5.5) report on work carried out for BCRT by the trustee Gill Pilcher contributing her skills in accountancy. It was noted that BCRT has grown unexpectedly fast resulting in it becoming hard to keep pace with all the different facets of financial activity. It was agreed that some reorganisation was required to increase efficiency and to make the task of the Administrator easier.

5.4 Budget Statements. Using information given to her by the Administrator, Gill presented a summary for the financial year ending 30.06.08 and a summary for the financial year July 08-June 09. These provided a useful overview and will be a monitoring tool for the Trustees.

5.5 An Accounts Package. Following her research into accounts packages and having previously sent the Trustees the web address for the Paxton Accounts Package that she felt she could recommend for BCRT's needs, Gill took further questions. The package is specifically for charities, it will deal with gift aid and can record income from donations, fundraising and merchandise sales separately. It was agreed that this package should be purchased.

ACTION - Gill

5.6 The Opening of the BCRT Office. The small office with space for two desks, situated in the outskirts of Leeds in a Georgian building, housing a number of other business and charity offices, was opened on 2nd January 2008. This meant that the part-time Administrator, Kate Connor, could stop working from home and coincided with David Fisher taking up his post as BCRT's full-time Head of Fundraising.

5.7 The British Sarcoma Group Conference (BSG). This two day conference was held in Sheffield at the end of January. Rob Grimer, a Trustee of BCRT, is also the secretary of BSG. There was much interest in BCRT's stand displaying information on current research, fundraising and notice of the forthcoming conference. The first day was attended by Mike Francis and David Fisher and on the second day Ros Francis joined Mike. Ian Lewis suggested that it might be possible for there to be a BCRT session at next year's BSG Conference in Glasgow to present research data. He said this could perhaps be a two hour session with leaders of research projects funded by BCRT reporting on their work.

6 MARKETING, PUBLICITY AND FUNDRAISING

6.1 Report from David Fisher, Head of Fundraising.

- David presented a budget for fundraising activities from February 2008 – June 2009. This was heavily based on a range of Runs around the country as well as other potential participants in treks, climbs, bike rides etc. Recruiting for these seemed to be gathering momentum and it was helpful for Trustees to see the breakdown of associated expenditure and possible income from such sponsorship. Ian suggested that there should be specific publicity within the cancer centres and hospitals in the areas of the Runs. Contacts and promotional visits to be considered. **ACTION – David, Ian**
- David explained the online Weather Lottery and suggested that BCRT should join. It was agreed that he should set this up to start in March. **ACTION – David**
- Fundraising through the use of Every Click by BCRT supporters was also suggested. Trustees asked David to prepare a simple registering and users' guide. **ACTION - David**
- Permission was given for David to take out an annual subscription to two organisations through which he would be able to access databases of charitable trusts and of company giving in the UK. **ACTION - David**

6.2 Christmas Cards. Trustees agreed that BCRT should again have two new styles of Christmas Cards as well as the remainder of the previous packs of cards to sell this year. David to email a small selection of a range of cards for comments from the Trustees. To aim for them to be available for sale at the Conference in June. **ACTION - David**

6.3 Fundraising Events. It was reported that funds raised by Peter Franklin with his adult Nativity Play and from the Adam Panther event and auction had been received. It was noted that the two teams (from Yorkshire and from Wales) were about to climb Kilimanjaro, the Ball in Cornwall was about to take place and Sherbourne Boys School would be holding three fundraising events before Easter. Plans were being made for several Gigs around the country, two people were preparing to run the London Marathon as well as numerous others entering the Runs mentioned in 6.1. Several Trustees said they would be attending the Ball in Ireland in memory of Blathnaid Foley and Gill Pilcher gave notice of the Ball to be held on 14th June in memory of Anthony.

6.4 Newsletter. It was agreed that the second BCRT Newsletter should be prepared for distribution at the end of April and some ideas about the layout were presented by David and Kate. All agreed that the Conference should be clearly advertised and there should be a feature on the input from Ireland. It was noted that the slip on the back page for ways to subscribe to BCRT, should be adjusted to include payments from Ireland. Further ideas for items to be sent to the office. **ACTION - All**

6.5 Leaflets. It was noted that the stock of leaflets was now very low and that the information included needed up-dating. Trustees were asked to prepare ideas to bring to the next meeting.

ACTION – All

6.6 T-Shirts It was agreed that these should be re-ordered.

ACTION - Kate

7 TRUSTEES' MEMBERSHIP

7.1 Procedures for the change of Trustees.

- See separate record attached of the Special Meeting held earlier during which a resolution was signed by the quorate number of Trustees present concerning the two outgoing Trustees, Gill Callar and Debbie McCartney and officially adding the two incoming Trustees Sally Hurst and Fiona Foley.
- Bank forms were signed by all Trustees removing Debbie McCartney as a signatory and adding Gill Pilcher ready for her increased involvement with the management of BCRT's finance.
- A formal document to be prepared by BCRT's solicitor to indemnify the out going Trustees from any financial matters during their time of office. **ACTION - Ros**
- The Clerk reported that she was preparing an Induction Pack for the two incoming Trustees and had asked them to prepare a short introduction to themselves for the Trustees section on the website.

7.2 **A potential new Trustee.** John Dealey recommended someone who was interested and would be willing to bring his experience in investment to add to the range of Trustees' skills. He had offered to submit a CV and John will circulate this to Trustees when he receives it. It was hoped he would be able to attend the Conference so that Trustees could meet him then.

ACTION – John

7.3 **BCRT in Ireland.** It was agreed by all that there should be a more formal arrangement for BCRT in Ireland but that further research into the most appropriate way of doing this should be undertaken so that it is set up correctly and in the most advantageous way to carry out BCRT's aims. More needs to be known about membership of a possible Board in Ireland, arrangements for the transfer of funds and clarification of any risks involved.

ACTION - Mike, Ian, Patricia

8. SCIENTIFIC ADVISORY PANEL

8.1 Current research projects. Ian Lewis reported that the two applications that had been accepted in the first round of bids and the three from the second round, were all now up and running.

8.2. Decisions on the third round of Research Grant applications.

- Ian Lewis said that the Panel had been pleased to receive five applications and that the interest seemed to be widening as these were again new bids from different people, each asking for around £30,000 each. Of these, one dealt with osteosarcoma, one with Ewing's sarcoma and the other three were relevant to both bone cancers. They was also a range of types of research :- epidemiological, biological, psychological and qualitative.
- These applications had each been put out to 3 external reviewers. These included eminent professors, doctors, psychologists, radiologists and lecturers to whom thanks were recorded for their time and interest. Ian reminded Trustees of the scoring system used. The results of these had then been studied by Ian Lewis, Rob Grimer and Jeremy Whelan who felt that 3 of the 5 were worthy of serious consideration.
- Ian suggested that the Trustees might need to decide how much they should commit to research during this second year on small projects bearing in mind that there could be a situation later when they might want to commit a large amount to one bigger piece of research.

Having received explanation and advice from Ian, three applications were approved in principle pending further answers. Trustees gave Ian permission to then accept these if the responses were satisfactory.

8.3 The composition of the Scientific Advisory Panel. Ian said he would be looking to broaden the range of disciplines offered by the advisors. The list of reviewers and their institutions to be updated on the website.

ACTION – Ian, Kate, Alan

8.4 Speaker on research. It was agreed that Dr. Richard McNally might be invited to speak on his research project, funded by BCRT in the first round, at this year's BCRT Conference.

ACTION - Ian

8.5 The fourth round of bids for research grants from BCRT.

- Information to go on the website shortly with the closing date of 28th April 2008.
- Trustees agreed with Ian that the amount offered should continue to be £30,000 for this round.
- Information to be up-dated on the website.

ACTION – Kate, Alan

8.6 L-MTPPE – Mepact. This drug stimulates white blood cells to react against osteosarcoma giving 10% improvement in survival. A recent peer reviewed article had been published in the Journal of Clinical Oncology. Whilst the Trustees were mindful of Ian’s involvement in this process, there was strong support for the contention that this agent should be available for use in young people with osteosarcoma and that BCRT had an advocacy role to support patients. Data is being gathered prior to possible registration. BCRT had received an invitation from the National Institute for Clinical Excellence (NICE) with other organisations to comment at a Scoping Workshop in London on 26th February 2008. Ian said he would be attending and suggested that Mike also attends from BCRT. Gill Pilcher for the Anthony Pilcher Bone Cancer Research Trust had also been invited so may also attend with another supporter.

At this point, Patrick Hardman gave his apologies and left the meeting early. There still being a quorate number of trustees present, the meeting continued.

9. BCRT’S SECOND CONFERENCE FOR PATIENTS AND SUPPORTERS.

To be held on Saturday 28th June 2008 at the Hilton Hotel, Leicester.

- It was agreed by all present that following the success of last year’s conference, the format should be very similar.
- Reference was made to the individual delegates’ responses on evaluation sheets returned last year as well as the reports from those who chaired the discussion groups. It was clear that the speakers about their personal experiences, the provision of time to meet, talk and share with others, the motivational speaker and the accessible medical information dealt with, were all the main factors that had been appreciated.
- Several names of possible speakers and topics were suggested.
- It was agreed that there should be a Conference Planning sub-committee which would meet in Leeds and involve trustees, officers and volunteer supporters in that area.

10. WEBSITE MANAGEMENT

10.1 Up-date from Alan Johnston, Website Manager.

- Alan reported on on-going up-dates. Trustees reiterated the importance of keeping the site up-to-date and expressed their thanks to Alan.
- Alan said that he had been impressed by the high level of security offered by the Citrix Package on the main BCRT server. There was some discussion as to who would be able to access certain areas and whether there would be a Trustees’ site. All to be revisited at the next meeting.

10.2 Trustees access to online facilities – BCRT Forum, Facebook, Justgiving, Everyclick.

As a number of areas need to be covered to help Trustees with these skills, the item was deferred until the new Trustees are in place.

10.3 Headings for the stories. It was agreed that slight alterations should be made to the heading of both the Patients’ and the Families’ Stories sections. All the five bullet points giving guidance to the reader about the content of the stories to be replaced by a slightly differently worded set of six points which include the addition of personal and emotional factors as well. (See Stories on the website).
ACTION - Ros, Kate, Alan

12. ANY OTHER BUSINESS

12.1 Posters. In response to requests received, it was agreed that David should prepare drafts of two forms of poster – one printed with details about BCRT for display and one with a blank centre for details of events to be added by the user.
ACTION - David