

BONE CANCER RESEARCH TRUST

MINUTES OF MEETING OF TRUSTEES held on Saturday 13th September 2008 at the Leicester Hilton Hotel

1. PRESENT

Trustees:- Mike Francis (Chairman), John Dealey (Deputy Chairman), Gill Pilcher, Patrick Hardman, Patricia Smith, Sally Hurst.

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

APOLOGIES

Trustees:- Rob Grimer, Ian Lewis, Fiona Foley, Nick Bones.

Officer:- David Fisher (Head of Fundraising). The Trustees sent congratulations to David and Victoria on the birth of their second daughter, Alice.

2. MINUTES OF MEETING OF TRUSTEES held on 29th June 2008.

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

3. MATTERS ARISING FROM THE MINUTES not covered by Agenda items.

3.1 Geoff Thaxter. (See 3.1 – 29.06.08). A card with the Trustees' condolences had been sent to Geoff's family. Mike Francis said that Geoff had worked tirelessly to foster the recognition of children's cancer at international level. He would be a great loss and hard to replace.

3.2 The Bone and Sarcoma National Database – now called the National Sarcoma Register Steering Group. (See 3.2 – 29.06.08). Mike said he hoped to attend the next meeting on 30th September to continue the potentially worthwhile link with this development. He hope that Hannah Millington might also be able to attend as a former patient. **ACTION - Mike**

3.3 Emily Blunt. (See 5.1 – 29.06.08). Mike said that he had written expressing BCRT's gratitude and admiration for all that Emily and her family had done in support of BCRT's Awareness Week at such a dreadful time in their lives.

3.4 Paralympic Games 2012. (See 5.2 – 29.06.08). It was reiterated that BCRT should explore possible involvement with these games and that Marc Woods, BCRT's Patron, should be asked for advice. It was agreed that this would be on the Agenda for the next meeting of Trustees.

ACTION – John, David

3.5 BCRT Office.(See 6.6 – 29.06.08). Kate Connor reported that there was no possibility of a larger office in the same building at the moment but the other occupants were aware of BCRT's interest if they were to be vacating. The deadline for renewing our occupancy is 4th December.

3.6 BCRT Leaflets. (See 8.3 – 29.06.08). Sally Hurst expressed an interest in putting together some ideas for the redesigning of BCRT's leaflets. The recent slight adjustment and small reprint had been a stop-gap as all agreed that BCRT has changed and developed greatly and now needs to be represented differently in the leaflet.(See also Section 9.4 below).

4. CORRESPONDENCE The following had been received by the Clerk and was distributed:-

4.1 Wrigley's Annual Seminar on Charity Governance. To be held in York on 28th October – Mike probably to attend. **ACTION - Mike**

4.2 The latest copy of **Social Economy**.

4.3 DSC e-news (Directory of Social Change) for information.

4.4 nvco (National Council for Voluntary Organisations) August email update and booklet about the support that membership could bring.

4.5 ESUN – the August edition of articles and information on sarcomas from Bruce Shriver.

ACTION – Sally, Patricia to find out more about this organisation.

4.6 The latest copy of Contact magazine was not available but a copy of Mike's speech at the Childhood Cancers Conference in Blackpool on 10th May that had been printed in it (with some alterations) was circulated. Copies to be obtained on a regular basis. **ACTION – Ros**

5. FINANCIAL AND ADMINISTRATIVE BUSINESS

5.1 Current Financial Statement.

At the date of the meeting, BCRT funds totalled £542,269.74 including the main account and the dedicated accounts.

Prior to the meeting, Trustees had received the Budget against Actual Figures and the budget for the current 8 research grants. Gill said she had sought advice from Alistair Cole of Morley and Scott Accountants about charity finance and limited company procedures:-

5.2 Limited Company. This had been set up 1) to protect the name; 2) for trading activity such as Christmas cards. This does not bring in enough at the moment to need to be VAT registered and to claim it back. It is not set up to provide liability insurance. Gill had been told that cover for all events would not be appropriate as each event needs to be specifically named and as yet, BCRT has not held any centrally organised events. (See Cycle Challenge in Section 9.6).

5.3 Financial year end audit - 30th June 2008. Gill reported that she was making good progress towards being ready for the audit to be carried out. It was realised that this year BCRT's financial activity had been much greater than previously so it was agreed that Gill should check the appropriateness of the Accountant currently being used. Kate to pass contact details to Gill.

ACTION – Kate, Gill

It was agreed that the description of BCRT in the financial report needs to be written by Trustees and not by the Accountant in order to give a realistic picture of BCRT, its aims and progress.

5.4 Gift Aid. Gill reported that the substantial task of recording information from sponsor forms, due to the back log, was proving difficult but progress was being made. It was reiterated that it should be made very clear to fund raisers that the information required on sponsor forms should be complete and legible. **ACTION - David**

5.5 Approval of Expenditure. The system currently in place is that Kate now emails both Mike and Gill for agreement for expenditure.

5.6 Progress report on new accounts system. Gill felt that this was going well and she was doing her best to get everything recorded into the new package.

6. BCRT IN IRELAND

Patricia Smith, a Trustee from Ireland, said she felt that more should be established to support the raising of awareness and raising of funds in Ireland.

6.1 Publicity of BCRT in Ireland. It was noted that there is now a separate section on the BCRT website for information from Ireland including several stories and information on events there.

6.2 Banking. Patricia explained why she felt it was important that there should be a bank account in Ireland:-

- it would make it easier for Irish people to give into an Irish account;
- she continued to be concerned about losing money through the exchange rate and that euros could then be exchanged when the rate was advantageous or could gain interest and be used to pay out for possible future research in Ireland in euros.
- Reading from “The Wheel”, a resource for the community and voluntary sector in Ireland, Mike said it looked possible to satisfy the Irish Revenue Commissioners by opening the account as a charitable trust using BCRT’s Trust Deed.
- It was felt that further information was needed and it was decided that Ros (as Clerk) would ask the English Charity Commission for advice. **ACTION - Ros**

7. STAFFING

7.1 The Administrator. (Kate Connor was asked to leave the room) A review of the role had become necessary so that Trustees could decide whether to increase the job permanently from two days to three.

All agreed that Kate had put a tremendous amount of work and enthusiasm into the beginnings of BCRT and thanks were recorded to her. As the charity had evolved and grown so fast, the Administrator’s role had also developed.

The original and primary reason for her appointment had been to support the Scientific Advisory Panel (SAP) in all the work surrounding the research grant applications and it was agreed that this was still the case.

On Kate’s return to the room the following points were made by the Trustees:-

- approval was given that the Administrator’s role be increased to three permanent days;
- it was proposed that an additional person should be employed for ½ or 1 day a week to enter all the Finance business;
- that work for the SAP was a priority and to continue with the merchandise, the website and the shared role of keeping the database up to date;
- that Trustees would review the timing of events and the effect on work load but greatly value all that Kate does for the Conference, Awareness Week and the Newsletter;
- it was noted that there is a need for flexibility but care must be taken not to become too involved in matters that are clearly fundraising. It was appreciated the Kate had worked incredibly hard on Leeds 10K Run but Trustees asked that she should begin to gradually hand this over to the Head of Fundraising.

7.2 General Staff Matters.

- It was felt that communication and involvement between the Trustees and the office and vice versa, between the office and the Trustees, should be improved.
- There is and needs to be flexibility between the roles of the Administrator and the Head of Fundraising supporting each other and the tasks in hand. However, it was suggested that at times, voluntary help must be brought in ie. to support the Head of Fundraising with particular administrative work for his role, for repetitive tasks such as stuffing envelopes, making up conference packs etc to be done. This should involve local volunteers, trustees and other officers where it is geographically possible.
- As previously minuted, most of the Trustees said they would value knowing more about new contacts that are made with the office and were also willing to be “matched up” for a chat with people with whom they may have things in common ie. age group, part of the country, age of child/children, type of cancer, with a prosthetic limb, bereaved etc. All felt that appropriate personal contacts are valued by most people (see evaluation comments from the Conference) and could be arranged. This is not counselling but relationship building.

7.3 An Information Officer. As requested by the Trustees, the Head of Fundraising had investigated other charities and put together a form of job description. There had been some email discussion around the reason and need for this and this had been answered by Ian Lewis who had proposed the need for this role to be developed for BCRT. He saw it as possibly a day a week for someone with good library and computer skills to seek out current articles and publications to keep both BCRT's trustees, the website and enquirers informed and up to date on relevant matters.

Mike Francis had received some correspondence from the West Midlands Cancer Intelligence Unit suggesting that we might fund a joint post with them. Trustees felt that BCRT would prefer to fund its own person and be in control of the role and the information. A reply to be sent.

ACTION - Mike

8. TRUSTEES' MEMBERSHIP

8.1 A prospective new trustee. It was noted that number of Trustees would shortly be meeting this person. He is offering to bring his expertise in investment to BCRT and has the time to be able to become involved.

8.2 Indemnity Insurance. John Dealey has made some investigations.

ACTION – John

9. FUNDRAISING, MARKETING AND PUBLICITY.

9.1 Report from the Head of Fundraising. Trustees were interested to see details of income related to fundraising activities carried out by runners, by groups and individuals all over the country and lists of those that are planned for the Autumn. However, they felt that in future they would also like a report at the end of each month on what David Fisher himself is doing towards generating these results. For example, details of links he is forging with other charities, groups, individuals to raise awareness, to encourage and advise them. Trustees knew that David has visited the cancer centres in Leeds and Birmingham but would like to know his plans to make contact with the others.

9.2 Fundraising Strategy. David had submitted a Fundraising Strategy for 2008-2011. Trustees resolved to defer discussion about this until the next meeting when David would be present.

9.3 The Newsletter. There was discussion as to the purpose of the Newsletter. It was felt that it should be very positive and encouraging, light and lively. It should include at least a page each on research, the conference and awareness week, a section on activity in Ireland, a comprehensive list of ALL donations received since the previous Newsletter and advertise BCRT merchandise. Trustees said they wanted to be involved in the planning and that this should happen well before the print date to avoid a last minute rush. A draft layout of the next issue to be distributed in November was discussed and ideas shared.

9.4 BCRT's Annual Conference.

- Mike Francis reiterated that this year again, the Conference had been excellent. Prior to the meeting Trustees had received a copy of the main points made by each discussion group and a collation of comments from delegates on their evaluation forms and these proved useful for reference when starting to plan for 2009.
- It was agreed that the date should be Saturday 27th June 2009. As the possibility of a more southern venue had been suggested, Kate presented information on conference facilities in Birmingham and Buckinghamshire for discussion. It was agreed that she would obtain more details and email trustees for responses so that initial arrangements can be put on the website as soon as possible.

ACTION - Kate

9.5 Awareness Week.

- Trustees were grateful to David Fisher for the idea and although there had not been much time to plan, a tremendous amount had been achieved. There was discussion as to whether the timing had been right with the Leeds 10k and the Conference all needing work at the same time. However, it was agreed that the same should happen next year so Awareness Week will be 20th-27th June. 2009. All to think about a focus (this year it had been delayed/late diagnosis) and possibly an idea for the launch on the first Saturday (20th).

ACTION - All

- Mention was made of the Early Day Motion (See Minutes 29.06.08 Section 5) which had been signed by 82 MPs during Awareness Week. Particular interest in lobbying MPs etc had been expressed by Malcolm Matthews and Chris Copland and it was agreed that Mike Francis, who has some experience in parliamentary matters, would chair a sub-committee to work on this aspect of awareness next year.

9.6 Cycle Challenge - a BCRT event being organised by David Fisher for a relay cycle ride from Belgium to Berlin in May 2009.

Gill Pilcher reported that she had been concerned that there must be appropriate insurance cover for this event. Individuals would be covered by their travel insurance but any type of accident involving others would be the responsibility of BCRT. Having researched several companies, Gill presented a quote for Events Insurance. Trustees were in agreement that this should be in place and added to the costings for the event. It was agreed that Gill would obtain answers from David to all the questions raised and email Trustees for their approval.

ACTION – Gill, David

10. SCIENTIFIC ADVISORY PANEL (SAP)

10.1 Submission to the NICE Appraisal : Mifamurtide for the treatment of osteosarcoma.

Ian Lewis has said he will be responding to this linking with Sarcoma UK as a co-signatory. John Dealey had also received the paperwork but both Patrick Hardman and Gill Pilcher were mystified as to why they had not, all being in the “carer” and “ witness” categories and having been involved previously. Sarcoma UK had indicated that they do not have anyone in these categories to put forward and would endorse BCRT’s choice. Gill and John reiterated how they had valued attending the previous meeting and it was noted that the next one would be held in February 2009. **ACTION - Ian, John.** **ACTION – Mike to reply to Sarcoma UK**

10.2 Results of the fourth round of applications for research grants.

- As Ian Lewis had declared an interest in some of these applications, Rob Grimer had taken the lead this time and produced a detailed report for the trustees to consider in both their absence from the meeting.
- It was stated that the five applications received were of a higher standard than previously seen, each having been sent to two or three external reviewers and gaining high scores.
- The SAP felt that all five applications were potentially fundable but as usual, there were some significant questions to which satisfactory answers would be required before funding was agreed. The recommendation was that the first three should be funded, that the fourth was worthy of funding and that the fifth had scored highly enough but had significant questions to be answered.

It was proposed by Sally Hurst, seconded by Patrick Hardman and carried unanimously that BCRT should fund all five applications subject to the SAP receiving satisfactory replies to its questions.

The SAP had suggested that the Autumn call for applications could be delayed until Spring 2009. This to be decided by Trustees by email vote once the budget has been adjusted to include the funding of the above projects.

11. WEBSITE MANAGEMENT

11.1 Review. Everyone was happy with the maintenance and development of the website.

11.2 Headings for the “Links” section. All agreed that this section should be made into two parts, one headed “Blogs” and the other “Organisations”.

11.3 Website access and links for Trustees. Mike still working on this.

12, ANY OTHER BUSINESS

12.1 Business Plan submitted by David Fisher. In this plan, it was suggested that BCRT could benefit from having as a trustee someone who currently has, or has had, experience of running a charity. There was a further suggestion that someone with knowledge of charity law could be helpful.

13. ARRANGEMENTS WERE MADE FOR THE NEXT MEETING.

