



BONE CANCER RESEARCH TRUST

MINUTES OF MEETING OF TRUSTEES held on Saturday 21st February 2009 at the Leicester Hilton Hotel

1. PRESENT

Trustees:- Mike Francis (Chairman), John Dealey (Deputy Chairman), Gill Pilcher, Ian Lewis, Sally Hurst, Roger Paul.

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

APOLOGIES

Trustees:- Patrick Hardman, Fiona Foley, Patricia Smith, Nick Bones.

2. MINUTES OF SPECIAL MEETING OF TRUSTEES held on 22nd November 2008.

Following agreement by all Trustees present, these Minutes were signed by the Chairman.
There were no Matters Arising.

3. MINUTES OF MEETING OF TRUSTEES held on 22nd November 2008.

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

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

4.1 Report from the meeting of the National Alliance of Childhood Cancer Parent Organisations (NACCPO) attended by Mike Francis on 31st January 2009.

- Mike reported that the organisation was working hard to become larger and more widely established. The Operations Manager was now working full time and so able to encourage more groups to join and to put in place a wider range of fundraising possibilities.
- NACCPO also aims to become more strategic and more European.
- Concern had been expressed about the lack of patient / parent input into clinical trials.
- There had been discussion around National Children's Cancer Month – it was felt that a month could be more effective than a day or week.
- The NACCPO Conference is to be held on 21st June in Bournemouth this year. Gill Pilcher and Alan Johnston said they would be able to attend with the BCRT stand. **ACTION – Gill, Alan.**

5. CORRESPONDENCE The following had been received by the Clerk and were circulated for Trustees' interest. It was stated that in future most of these will be posted on the server so that Trustees can look for themselves:-

5.1 Social Economy bulletin December 08 – February 09 issue.

5.2 Information on the Children and Young People's Advisory Group.

5.3 Copies of Contact Magazine – Winter 2008 and International issue 2009

5.4 Winter issue of The Global Eye / Daisy's Eye Cancer Fund news.

5.5 Summary of Teenage Cancer Trust news February 2009.

5.6 Summary of the February issue of ESUN from Bruce Shriver

5.7 National Council for Voluntary Organisations information January 2009.

6. FINANCIAL AND ADMINISTRATIVE BUSINESS

6.1 Draft Report of the Trustees to 30th June 2008. Mike Francis drew Trustees attention to the fact that in previous reports accompanying the publishing of the year end accounts, only brief comments had been included about BCRT's activities and development. Gathering information from Trustees, the Minutes and other relevant sources, he had endeavoured to tell the full story of the Trust from Day 1 to 30th June 2008. Needless to say this had made it very lengthy on this occasion but in future years it would form the basis from which to simply pick out activity in certain areas and to add new aspects. He had done this partly to accurately record the history of BCRT but also in readiness to satisfy the Charity Commission's new requirements and grading system of reports and to provide full information for potential grant makers.

Trustees adopted the format of the draft report. It was stated that once completed, the final draft would be circulated and agreed by email so that this, with the audited accounts, could meet the deadline of 30th April for submission to the Charity Commission as BCRT's Annual Return. **ACTION – Mike.**

6.2 Draft Year End Accounts to 30th June 2008. Gill Pilcher had worked closely with the Auditor and had pointed out various errors that she had found in the draft copy.

ACTION – Gill, The Auditor.

6.3 Current Financial Statement.

At the date of the meeting, BCRT funds totalled £227,998.34 with £400,000 invested in 6 months bonds.

6.4 Funds raised in Ireland.

Concern continues about the amount that is lost through the exchange rate and bank charges when euros are transferred to pounds. It was suggested that BCRT might have a euro bank account where euros could be held and only transferred when the exchange rate was seen to be favourable.

Gill to investigate. John to discuss this with Patricia and Fiona.

ACTION – Gill, John.

6.5 Equipment for the New Office.

The Fundraiser and Administrator were settled into the new and larger office but attention was required to acquiring more appropriate and extra furniture as well as kitchen and cleaning equipment.

- Mike and Ros had visited and discussed ideas with Kate and David about the layout, use of the space and the need for time for them to unpack and store everything.
- Trustees agreed to a budget of £1,000 for expenditure on the above mentioned needs in the office. Liaising with Kate and David, Mike to get quotes for furniture including larger desks for the office, also folding tables and stacking chairs for the meeting room. It was agreed that Scott Connor should be asked to put up shelving at one end of the meeting room for storage of T-shirts and other items of BCRT stock.
- Kate and Ros to explore the possibility of employing the cleaner who comes into the building or to make other appropriate arrangements.
- It was agreed that Kate and David should be given half a day "settling in" time.
- Trustees were grateful to John for kindly finding an extra computer which could be used by volunteers helping in the office. Alan had checked it over and passed it to David to install.

ACTION - Mike, Ros, Kate, David.

7. STAFFING (The Head of Fundraising and the Administrator left the room for this item).

7.1 Arrangements for Kate Connor's maternity leave.

- This to be from 14th May 2009 – January 2010 with a hand-over period at each end.
- Trustees revisited the priorities of the role and the job description. The newly formed Management Committee (see Section 8 below) to finalise the job description and person specification for this 3 days a week, fixed term contract, and with Kate to advertise the post appropriately.

ACTION – Management Committee, Kate

- Interviews to take place at the office on 1st April. John to take the lead as Chairman of the Management Committee but it was confirmed that all Trustees can choose to attend and to be involved with committee matters if they so wish.
- Gill, with her links with HR for BCRT, stated that there were certain rules that applied regarding Kate's official break from the role after the initial handover period with which both Kate and the Trustees must comply. Gill to keep all advised. **ACTION - Gill**

7.2 Staff Annual Appraisals

- Performance and pay reviews to be carried out for the Head of Fundraising and the Administrator at the office on the same day as the above interviews.
- An evaluation form to be completed by David and Kate and returned before the interview. This to include how they view their roles and possible targets for the next year.

7.3 Accounting Technician

- Trustees were reminded of the tremendous work done by Gill in putting BCRT's financial information to 30th June 2008 in place and on Paxton ready for the publishing of the Annual Accounts. It was agreed that it all needs to be right up to date before the Accounting Technician starts this proposed 1 day a week post.
- As previously mentioned, Mike proposed that accountant Steve Boothman be asked to bring the 2008/09 accounts up to date. He would be able to do this after Easter. The new post holder could then start around the start of the new financial year – 1st July 2009.

7.4 Information Officer – see in Section 11.8 of these Minutes.

At this point David and Kate were asked to return and the main points of the above were passed on to them.

7.5 Volunteer during the run up to and following Awareness Week.

- David informed Trustees that an advertisement for this voluntary position for eight weeks had been placed at the Leeds Metropolitan University for students on the Events Management / PR courses. The response had not been as hoped but he was considering asking to go in and actually speak to groups about this offer of experience rather than leaving it to lecturers' own possibly variable interest in passing it on to the students.

8. STRATEGIC PLANNING

The second meeting of this group of Trustees led by the Head of Fundraising had been held three days before so it was appreciated that there had been little time for some Trustees to familiarise themselves with the contents of the Minutes. David Fisher took the meeting through the main points covered:-

Trustee Committees.

- A table was discussed which listed 8 proposed committees:- Strategic Planning, Management, Research, Information, Support Network, Finance, Campaigning and Fundraising. The possible division of Trustees amongst them was shown and some additions and alterations were made with the lead Trustee being identified for most of them. As stated in the Minutes, supporters / volunteers with particular interests and expertise can also become involved and some potential names were added.
- With the geographical spread of BCRT's Trustees, it was realised that some of these groups may not be able to meet face to face. Email discussion and voting will be very important.
- Ros Francis, Clerk to the Trustees, had checked the relevant statements in the Trust Deed relating to committees and will put together a draft document of Terms of Reference for BCRT Committees for comment at the next full meeting of Trustees. **ACTION - Ros**

BCRT's Vision and Mission statements. David reported that the reconsideration and possible rewording of these had continued but had still not been conclusive. He asked for **ACTION FROM ALL** so these can be agreed.

9. FUNDRAISING

9.1 Running Events. David responded to questions around the information on all the running events' places and the proposed income from these as listed in his previously circulated Fundraising Report. David reported that he had set up links between BCRT's 10 London Marathon Runners and that the BCRT running vests would be available in time for the event.

9.2 Belgium to Berlin Cycle Challenge, 15th – 17th May 2009. 5 teams had booked and another had expressed interested. David to do a recce in March of the route and check on accommodation, food options and costs, fearing that the budget could be tight at this time.

9.3 Updating of BCRT's Leaflet. Deferred – to be looked at by the Information Sub-Committee chaired by Sally Hurst, when it is ready to start. Immediate comments were that much needs updating due to the rapid development of BCRT.

9.4 Bone Cancer Awareness Week - 20th -27th June 2009.

- There was discussion around the focus. Thoughts included:- extending on from last year's attention to late diagnosis; findings from the first completed piece of research; the statement that there has been "little or no change in survival in 20 years in the UK".
- The Campaigning Sub-Committee led by Mike would be working on further progress with political contacts and MPs.
- Kate and David had been working on the fun and fundraising side of awareness raising through the Bake a Cake for Bone Cancer theme and trying to involve celebrities.
- Information packs to be prepared for cake bakers, for the media and possibly separately for politicians.
- As previously mentioned, student and volunteer help to be set up.

9.5 The 3rd. BCRT Conference – 27th June 2009, St. Albans.

- Having previously decided that the venue should be in a different part of the country this year – Sopwell House Hotel in St. Albans had been booked.
- Following a meeting of the Conference Committee a few days before, a draft programme was circulated for comment. Differences to last year :- alterations to the time to allow for change-over of speakers and slight over-runs; the facilitators of the morning discussion groups to work towards questions to be brought to an afternoon Question Time panel of speakers etc; Researchers of BCRT funded projects to be invited to attend with posters of their work and be available during the breaks for questions and discussion.
- It was decided that Kate would follow up the suggestion that Giles Long, paralympic swimmer, should be the motivational speaker at the end of the day.
- Sponsorship required - **ACTION – ALL.**

9.6 The 4th. BCRT Newsletter – Spring 2009.

- An almost final draft was circulated ready for printing a few days later.
- Volunteers to be in place for the week beginning 9th March for envelope stuffing so that the office staff can get on with their other work.

9.7 Paralympic Games Deferred until after the Conference.

10. SUPPORT NETWORK

Currently, BCRT sometimes makes arrangements for people in similar situations to link up or to meet at the conferences. Patients and families greatly value this contact and BCRT is aware it needs to do more of this putting people in touch with each other. The next aim of BCRT is to be able to provide support and in the long term, a counselling service.

- Sally Hurst gave information on a support network she had come across called Befrienders. She had looked into as a starting point for ideas of ways of supporting patients and families. She stressed that this is not counselling.
- The Befrienders have local groups but for us it would more likely be run using the phone and emails.
- They provide training which covers their aims, communication skills and an understanding of the stages of grief.
- It was felt that people's needs are different during treatment, post treatment, post bereavement. We would need to know clear boundaries around the level of support to offer/ give and have clear procedures for matching people up.
- Ian suggested that at some stage, professional information from a nurse consultant, social worker etc might be helpful.
- Ros Francis said that through NACCPO she had come across several support groups. She said that when the Support Network Committee is ready to start this work she will gather together information on these groups so it can be studied for ideas as to how best to set up BCRT's approach.

10 WEBSITE MANAGEMENT

10.1 Online Access for Trustees. Mike to circulate the codes to everyone and to check the access arrangements.

ACTION – Mike

11. SCIENTIFIC ADVISORY PANEL

11.1 Report from the NICE Appraisal Meeting concerning Mifamurtide held on 18th February 2009. As agreed at the last meeting- 22.11.08 section 9.5, three representatives of BCRT had attended to make statements from their experience and within defined roles:- Mike Francis the Parent/ Carer Expert”, Sally Hurst the Patient Expert and Professor Tim Eden the Medical Expert. All represented both BCRT and Sarcoma UK. Ian Lewis also attended, full of hope and enthusiasm for the progress of this new drug that has been proved to improve survival rates for Osteosarcoma sufferers. No date was suggested for the announcement of the meeting's findings.

11.2. Support for a parent who contacted BCRT searching for information. This parent was questioning figures for survival etc and had found a discrepancy between the figures on BCRT's website and those on Wikipedia. Mike Francis reported that he had discussed it with Ian Lewis and replied to this father whose daughter is currently on treatment.

11.3 The completion of the first research project funded by BCRT – led by Dr.Richard McNally, “An epidemiological study of bone tumours in children and young adults”. This was a land mark for BCRT. A press release had gone out in January and an article had been published in the British Journal of Cancer. Ian Lewis told Trustees that this had been Part 1 using data from registries for 0-15 year olds. Work was now beginning on Part 2 for 0 – 49 year olds.

11.4 Update on approved research projects from the 4th. round. Ian reported that following satisfactory replies to certain questions, all 4 applications discussed at the last meeting had now been agreed. Ian said he was waiting for the 5th application from this 4th round, to be re-submitted.

11.5 5th round of grant applications for BCRT funded research – to close on 6th April 2009.

11.6 Current, on – going research projects – Ian informed Trustees that progress reports on some of these were now due. He said the SAP will review them and then feed back to Trustees as they are not written in lay language.

11.7 Information Officer

- Ian reiterated how important he feels this role to be for BCRT in its aim to be a respected source of up to date information. He explained that under its Patient Pathway Project, the Department of Health is aiming to collect information together for patients and families from established and respected sources. He felt that we should move fast to have an Information Officer in place so that BCRT can be recognised as the reliable source on bone cancer.
- It was suggested that the post would be for up to two days a week with flexible working time. A suggested salary range would be between £21,000 - £25,000 or possibly with on costs £40,000 over three years.
- It was said that David should explore the possibilities of obtaining a grant / charitable trusts to fund this post. **ACTION - David**
- At this point, the Trustees were not quorate but all present were in support of the above.

11.9 British Sarcoma Conference in Glasgow , 18th-20th March. Ian reported that it was not possible to include a section on BCRT's research projects this year but when he speaks on the second day he will include mention of both BCRT and Mifamurtide. Mike said he would probably be able to attend with the BCRT display stand.

12. TRUSTEES

12.1 Trustees' Indemnity Insurance. As decided at the meeting held on 22nd November 2008 – see Section 5.4, John Dealey had obtained and circulated prices for a range of cover. It was proposed by Sally Hurst and seconded by Gill Pilcher that the chosen insurance cover should be taken out. This was carried unanimously and John agreed to make the arrangements. **ACTION – John**

12.2 A trustee with medical expertise to replace Rob Grimer. Ian indicated that he had been giving this some thought and had someone in mind to approach. **ACTION - Ian**

12.3 Deed of Retirement and Appointment of new Trustees.

Following the loss in the post of this Deed as well as the amount of time that had elapsed, the Clerk had discussed the situation with BCRT's solicitor. The intention of the deed had been to provide indemnity for the two out-going trustees. Almost a year has passed since they retired from their posts and the two sets of accounts covering their period of office had been audited and accepted by the Charity Commission. The solicitor therefore suggested that the Deed was no longer needed as BCRT's financial matters during that time had been seen to be in order.

In addition, the solicitor made a gesture of goodwill and kindly reduced his charges.

During an email vote, there had been a quorate response of 5 from the Trustees that the Deed should be abandoned, that the invoice as presented be paid and the solicitor thanked. **ACTION – Kate, Ros**

13. ANY OTHER BUSINESS

13.1 BCRT Christmas Cards 2009. This item was dealt with in haste at the end of the meeting.

Kate reminded Trustees that this year's Christmas Cards must be chosen soon so that they could be ready for sale at the Conference in June.

Suggestion 1 - Trustees were shown a colourful drawing of a penguin done by Roger Paul's daughter.

Suggestion 2 - Trustees had previously been emailed a set of photographs taken in the snow by a patient for consideration.

There was brief mention as to whether a third new card was needed this year and the suggestion was made that one might have a religious theme to add to the range of cards that BCRT offers.

No decisions were made.

ACTION - All

14. THE DATES OF FUTURE MEETINGS IN 2009 WERE CONFIRMED.

