



BONE CANCER RESEARCH TRUST

MINUTES OF MEETING OF TRUSTEES held on Saturday 2nd May 2009 at the Leicester Hilton Hotel

1. PRESENT

- Trustees:-** Mike Francis (Chairman), John Dealey (Deputy Chairman), Fiona Foley, Patrick Hardman, Ian Lewis, Roger Paul.
- Officers:-** Ros Francis (Clerk to the Trustees), David Fisher (Head of Fundraising).
Kate Connor (Administrator).
Trustees welcomed Lauren Heslop as Administrator during Kate's maternity leave.

APOLOGIES

- Trustees:-** Gill Pilcher, Patricia Smith, Sally Hurst, Nick Bones.
- Officers:-** Alan Johnston(Website Manager).

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

None.

THE AGENDA. It was noted that an experimental attempt had been made to rearrange the Agenda to incorporate reports from all the newly formed committees. It was recognised that some had not yet started to meet, that some topics may have been incorrectly assigned to committees and that some matters fell under the remit of several committees.

4. CORRESPONDENCE. The following had been received:-

- 4.1** Notice of Wrigley Employment Law Seminar to be held in Leeds on 9th June 2009.
- 4.2** Social Economy bulletin Issue March-May 2009.
- 4.3** A reminder about the NACCPO Conference to be held in Bournemouth on 20th June 2009. It was noted that Gill Pilcher and Alan Johnston will be attending to represent BCRT.
- The Clerk pointed out that in future, correspondence received that may be of interest to Trustees, will be posted on the server in the Trustees' section.
- 4.4** Ian Lewis drew Trustees attention to a request from the Children's Cancer and Leukaemia Group (CCLG) concerning Contact Magazine.
- He reported that changes were taking place in the structure and roles of CCLG and also that CLIC Sargent would no longer be co-funding Contact Magazine. Several Trustees expressed their

sadness about this situation as much support had been received from the organisation by them and their families on their cancer journeys. Ian felt it was also an important organisation for professionals.

- Groups like BCRT were being asked to fund one edition of Contact a year at a cost of approx. £6,000 and provide a page, linked with the theme of that copy, about its charity.
- Approximate costings were carried out relating this possible expenditure to the current cost of publishing two BCRT Newsletters a year full of our own news and Trustees felt they had to decide that it would not be good value for money for BCRT to support this request.

ACTION – Mike to reply.

5. STRATEGIC PLANNING COMMITTEE

5.1 An update. The committee had been unable to hold its proposed 3rd meeting since the previous full Trustees' Meeting.

David Fisher talked Trustees through his draft Business Plan dated 1.05.09.

- It was noted that as the other newly formed committees begin their work, the operational aims of each should be written up and objectives stated from these. **ACTION - All Committees**
- Pages 12 – 15 included the four main aspects of fundraising. It was said that each of these needed to have specific targets added and could then be included in the final Business Plan.
- It was thought that appendices could be included showing the links between committees on certain areas and, in particular, clarity of the need for specific matters to be referred by committees to the Finance Committee according to the possible powers to be delegated to that committee by the full Board of Trustees.
- All the above to be ratified by the full Board of Trustees before becoming fully operational.

5.2 Draft Terms of Reference for All Committees of BCRT.

- This had been written by Ros Francis as Clerk to the Trustees with advice from Roger Paul, Trustee, as a starting point for procedures for all the committees as they start their work.
- This was adopted in principle.
- It was stated that each committee would also need its own Terms of Reference. Roger circulated a draft of one as an example, that he had started ready for the Finance Committee.
- All Committees' Terms of Reference to be submitted to the full Board of Trustees as well as the overall draft one as above with the additions made by Ros, ready to be adopted at the next meeting.

ACTION – All Committee Chairmen, Ros.

6. FINANCE COMMITTEE

6.1 The Current Situation. Trustees celebrated the fact that BCRT had raised £1m since the signing of the Deed of Trust in December 2005.

6.2 Appointment of Accounting Technician – This to be dealt with by the Finance Committee. Interviews to be held on 22nd June.

6.3 Accountants – Thomas Coombs, Leeds. It was agreed that Mr. Christopher Darwin, ACA of Thomas Coombs should be re-appointed for the next year.

7. FUNDRAISING

7.1 Report from the Head of Fundraising.

- David Fisher responded to questions about the various runs. A question had been submitted by a few keen runners - could they take up BCRT places on runs without raising the suggested amount of funds? This would be because they wanted to use them as training exercises whilst raising

awareness, towards longer runs for which they would be raising funds. It was agreed that as only a small number of people would want to do this, it would be acceptable.

- **Belgium to Berlin Cycle Challenge to take place 15th-17th May 2009.** David reported that 6 teams were signed up for this event organised by himself for BCRT.
- **Bake a Cake.** Much gratitude was expressed to Andy Greig for all that he had done in creating the posters for Awareness Week in spite of being back on treatment. Celebrities' photos and recipes would be included in the Fund Raising Guide. 30 requests had been received to date. Following sponsorship from Premier Foods - Mr. Kipling, for which Trustees were very grateful, all secondary schools had been sent the Bake a Cake posters and there had been 10 responses so far. It was noted that unfortunately by Awareness Week the Year 11s would have left.
- **Future celebrity support.** Roger Paul suggested that we should plan well ahead for the support of celebrities and also that an area for awareness raising could be through sports clubs.
- **Supporter Fundraising.** David had listed events that had taken place since his last report.

8. MANAGEMENT COMMITTEE

8.1 Interim Administrator during Kate's maternity leave. This to be from 14th May 2009 – January 2010 with a hand-over period at each end. Interviews had been conducted by John Dealey resulting in Lauren Heslop being appointed. The Trustees were grateful for all that the Management Committee had done in gathering together HR advice and procedures, the job description etc.

8.2 Information Officer. Ian agreed a job description for this 1.5 day post. Trustees agreed to go ahead, office staff to seek out the best places for advertising. **ACTION – office staff**

8.3 Voluntary Help for Awareness Week. The office staff had continued to try to attract PR students with the addition of an "honorarium". (Gill Pilcher checking with HR that arrangements are appropriate). They had appointed a PR student in her final year at Huddersfield University, to start on 19th May for 8 weeks to include time for follow up work after Awareness Week.

8.4 Staff Annual Appraisals. John Dealey reported back to a meeting of Trustees' only, having carried out the appraisals.

8.5 CRB checks for staff. Following David Fisher's recent visit to speak at a school, it was felt that all staff should be covered. Mike gave Kate information needed to put this in place. **ACTION-Kate**

8.6 Further development of the office:-

- Whilst cleaning, Ros Francis had noticed that the fire extinguishers had not been checked since 2007. It was therefore questioned as to whether checks were the responsibility of the landlord or of the tenant.
ACTION – Kate to ask the Landlord.
- Telephones – As agreed, extra extensions had been added as well as a phone put into the Meeting Room with a conferencing facility.

9. CAMPAIGNING

9.1 The political side of Awareness Week.

- Tribute was paid to former patient Nick Bojas whose work for last year's Awareness Week had obtained an early day motion about BCRT which had been signed by 82 MPs. Mike Francis reported that he and Nick had been discussing the best political approach to take this year when bone cancer devastatingly returned and Nick had died on 17th April. Gill Pilcher had represented BCRT at Nick's funeral and his family had generously opened a justgiving page in his memory.

Mike Francis reported on an extremely helpful and productive conversation with Jean Mossman, the former chief executive of Cancerbackup and now an independent consultant on health issues. Jean had asked "do we know what our purpose is?" On reading this year's Awareness Week poster with 5 good points on it her question was "what do you want me to do?" It was not clear.

- Jean felt that our thinking was too short term. She suggested that this year's efforts should be similar to last year but that we begin planning for 2010 now.

- If BCRT is on its own, she feels the NHS will ostracise it, working with others will add more weight, give a united front. We know we already have good links with Sarcoma UK, The Teenage Cancer Trust (TCT) and the Rarer Cancers Forum.
- We must bear in mind a possible change of government.
- The political approach for this year to be made to supporters from 1st June. Mike working on this and making contacts. **ACTION - Mike**
- Jean felt that contacts with the media was successful last year with family stories but would be more effective if a local bone cancer story/family and the local MP were linked.
- Jean suggested that the best time to have BCRT's Awareness Week would be in September so that it does not clash with other awareness weeks and is separate from our Conference. Fiona Foley was delighted as this timing would link well with cancer awareness in Ireland, she will look at Northern Ireland and it is also America's "child cancer month". Late September 2010 would also be a good time as by then the General Election will have taken place.
- Jean felt that politicians – and GPs – hold the key. Promotion within sport and with parents also important.

John Dealey had realised that his local MP is a Shadow Minister for Health, it was agreed that he should try to book him to speak briefly at the BCRT Conference, particularly as it was being held in his area. **ACTION - John**

Ian Lewis spoke to link this political approach with the important progress made towards the availability of Mifamurtide.

- **It was agreed by all that Bone Cancer Awareness Week should be moved to September in 2010.**
- **It was agreed by all that BCRT should accept Jean Mossman's helpful and substantial support. Mike to update TCT, Sarcoma UK and the Rarer Cancers Forum.**

ACTION - Mike

9.2 National Sarcoma Register

Mike Francis reported that the committee was now underway and that the Steering Group would be meeting in a few weeks. He would check whether one or two places were available for BCRT representatives.

ACTION - Mike

9.3 BCRT in Ireland

- Fiona Foley was congratulated on the success of the recent Ball held in memory of Blathnaid.
- Fiona reported that she and Patricia Smith were planning to meet, saying that they know of 7 families who might want to become more involved.
- It was felt in Ireland that BCRT needs to be registered there as at the moment it is all too English and too distant. It needs to be more Irish, perhaps using Irish colours- green and orange instead of the blue and red but with the same words. It might be sensible to have an Irish address. **ACTION – Fiona - to see what needs to be done to register etc.**
- Fiona was very much in favour of the change to Awareness Week being held in September from 2010 and this would link well with events in Ireland.

10. INFORMATION COMMITTEE

This committee had not yet started to meet but the following points were made:-

10.1 The Spring edition of the Newsletter.

- It seemed that this had again been well received and that the centre fold items on "Getting Active after Treatment" had been very successful.
- It was noted that all the centres should now be restocked with copies of the Newsletter as there was a constant turnover of patients and this might also help to promote an interest in further bookings for the Conference. **ACTION - Office**

10.2 Initial ideas for the Autumn Newsletter. This was not discussed but it would be helpful if Trustees began to note any ideas they may have. **ACTION – All**

10.3 BCRT Conference.

- Trustees received an update on the programme with all speakers booked and an adjustment made to timings to try to avoid over running as much as had happened last year.
- It was proposed and agreed that Ian should ask Sir Alan Craft to become a patron of BCRT.

ACTION – Ian

- It was noted that Premier Foods - Mr. Kipling, had not only kindly sponsored Awareness Week which was being used to provide all secondary schools in the country with information about awareness of bone cancer and the Bake a Cake events, but had also now provided a further amount for the Conference.

10.4 A new leaflet. Deferred for the moment.

10.5 Report from the BSG Conference. Mike Francis had attended with the BCRT stand and found a good welcome for and recognition of BCRT. Ian had delivered the final talk of the two days and had woven all that he wanted to say around BCRT. Next year's BSC Conference to be held in London from 4th- 5th February 2010.

11.0. SUPPORT NETWORK COMMITTEE

This was deferred in the absence of Sally Hurst and also as this committee had not yet started work.

12. SCIENTIFIC ADVISORY PANEL

12.1 Update on the fifth round of applications for research funding from BCRT:-

- Ian Lewis reported that there had been 6 applications. The range of the projects included those dealing with Ewing's sarcoma, osteosarcoma and relevance to both and included biological targets and an epidemiological approach.
- Ian felt that BCRT was getting close to "raising the bar" for the type of research and researchers to attract, by considering raising the suggested amount of funding on offer per project. It was decided that this might be looked at to take effect next year.
- These applications would go out to reviewers shortly. Ian said he was looking for more reviewers as several of his regular people had been applicants themselves this time.
- He felt that the system of feedback from the reviewers followed by further questions to the potential researchers, replies and re-submission request if necessary all worked well to encourage good research.
- Feedback for Trustees should be ready for the next meeting on Sunday 28th June 2009.
- The closing date for the sixth round of applications to be decided at that meeting.

12.2 Update on on-going research projects.

Trustees asked whether any further project was nearing completion and whether any on-going, intermediate reports had been received. Kate was asked to check on progress for Trustees.

ACTION - Kate

12.3 Local Therapy in Ewing's Sarcoma - meeting of professionals funded by BCRT two years ago.

Ian reported that the French team had obtained funding and was working to move this forward. He said there will probably be a follow up conference in France and suggested that BCRT might consider funding the British contingent to attend. Trustees expressed an interest in this – Ian to report back when appropriate.

ACTION - Ian

13. TRUSTEES

13.1 Nick Bones. Trustees were saddened to receive a letter of resignation from Nick Bones as a trustee. They expressed their gratitude for all that he had brought to the role as a former patient and in particular his fantastic effort in taking part in 2 Leeds 10k Runs and also in providing information on disability benefits for other patients. They were glad of his reassurance that he will continue to do all he can to further the aims of BCRT.

During later discussion, it was proposed that Nick should be asked to be a patron of BCRT – it was agreed that Mike should ask him.

ACTION - Mike

13.2 Replacement Trustees. As mentioned at the last meeting, Ian continues to find a trustee with medical expertise. Further names were suggested with skills to bring to BCRT as well as the idea that we might contact patients / former patients over 18 on BCRT's database.

13.3 Trustees' Indemnity Insurance. John Dealey reported that this was now in place.

14. WEBSITE

14.1 Remote Access Details. Mike Francis to send out individual passwords to all. He reminded everyone to only log off themselves otherwise they will be shutting down the office and also that if they ask to print – it will do so in the office! The way to print for one self would be to save to a stick and load onto ones own computer.

15. DATES OF FUTURE MEETINGS IN 2009 WERE CONFIRMED.