

BONE CANCER RESEARCH TRUST

**MINUTES OF MEETING OF TRUSTEES
held on Saturday 22nd November 2008
at the Leicester Hilton Hotel**

1. PRESENT

- Trustees:-** Mike Francis (Chairman), John Dealey (Deputy Chairman), Gill Pilcher, Patrick Hardman, Patricia Smith, Fiona Foley, Nick Bones, Ian Lewis.
- New Trustee:-** Roger Paul was welcomed following the Special Meeting at which he was appointed –see separate Minutes.
- Officers:-** Ros Francis (Clerk to the Trustees), David Fisher (Head of Fundraising).
Kate Connor (Administrator), Alan Johnston (Website Manager),

APOLOGIES

- Trustees:-** Rob Grimer, Sally Hurst.

2. MINUTES OF MEETING OF TRUSTEES held on 13th September 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.

There were none.

4. CORRESPONDENCE The following had been received by the Clerk and were circulated for Trustees' interest:-

- 4.1** Copy of **Social Economy** – the quarterly bulletin for charities, Sept – Nov. issue.
- 4.2** Copy of the **Directory of Social Change – DSC e-news**, November.
- 4.3** Copy of the **National Council for Voluntary Organisations (NVCO)** – November.
- 4.4** Copy of **Cancer Research UK (CRUK)** November's e-newsletter.
- 4.5** Information on the petition concerning "**Conquer Childhood Cancer Act**" which some Trustees had signed and the Government's response to this received 21.11.08.
- 4.6 An update on the National Alliance of Childhood Cancer Parent Organisations (NACCPO).** It was reported that plans are underway for the 2009 Conference, the next committee meeting being held in January with others carried out by phone conference. Mike Francis tries to join in these for BCRT. NACCPO has become involved with NICE consultations on Malignant Melanoma and End of Life Care Strategies. All groups in NACCPO have been asked to contribute to information gathering concerning 16-24 year olds for the Steering Group on Children and Young People – Improving Outcome Guidance. NACCPO is currently trying to find innovative fund-raising ideas for itself as the member groups tend to be busy raising funds for their own stated aims.

5. TRUSTEES' MEMBERSHIP

5.1 An Additional Trustee. Roger Paul, appointed by resolution at a Special Meeting of Trustees (recorded separately), attended his first meeting bringing his expertise in investment matters. The number of Trustees was increased from ten to eleven.

5.2 End of Term of Office for two trustees.

Both Rob Grimer and Nick Bones are coming to the end of their three year term of office as Trustees. They would both be eligible for re-election at the forthcoming AGM.

Rob Grimer. Trustees were sorry to receive a letter of resignation from Rob due to future additional responsibilities within his professional roles. Much appreciation was expressed for all that Rob has contributed towards the establishing of BCRT and in particular, his expertise on the Scientific Advisory Panel.

Nick Bones. Nick advised that he would be happy to stand for re-election for a further term of office.

5.3 BCRT's Annual General Meeting. To be held on Saturday 21st February 2009 at the Leicester Hilton Hotel as a separate meeting before the regular Trustees' Meeting.

5.4 Recommendations on Indemnity Insurance. All Trustees agreed that this insurance should be in place for their protection. It was decided that John Dealey should obtain definite charges for cover for £1m and £5m from the insurance company he was recommending and that there will be an email vote for a decision on the information circulated. **ACTION – John**

5.5 Up-date on the Deed of Retirement and Appointment. Ros Francis informed trustees that this had still not been signed by everyone and that she was actively attempting to secure its return. **ACTION – Ros**

5.6 Report from Wrigleys Annual Autumn Charity Governance Seminar (28th October 2008 in York) attended by MF.

- Mike reported on proposed changes due in December 2009 to the structure for incorporated unincorporated groups and the running of a limited company in parallel. He will watch out for relevant information for BCRT.
- There is to be change of status for trustees which will make it possible for them to be paid to carry out a specific duty (public bodies already do this).
- It will become necessary to maintain a “register of substantial donors” setting out amounts received, during, ie over a year, 6 years. The amount suggested is £25,000 and would be able to be treated differently for taxation.
- The importance of maintaining an accurate record of donations was stressed.
- The interpretation of the definition of the status of a charity is being examined. This should be “for public benefit”.
- Annual Report. This must include a well written account for the Charity Commission on the year's work and there is now a web-based rating system to monitor these. It is important for a charity to “sell itself” with detail about all that it does including charts, good presentation etc It was decided that Mike will work with David and Kate and also with Gill and the Auditor to prepare a draft report. This will be emailed to all Trustees before the A

6 STRATEGIC PLANNING – THE FUTURE OF BCRT.

6.1 “Fundraising Strategy 2008-2011”. David Fisher talked Trustees through his document which had been circulated previously.

- Part 1, based on a SWOT analysis showed the Strengths, Weaknesses, Opportunities and Threats concerning BCRT's current fundraising activities. Part 2 examined each area of fundraising looking at future plans for developing these and also for taking on additional fundraising approaches.
- Using this information, David emphasised the importance of developing a 3-5 year Business Plan identifying the goals of BCRT and clarifying how these are to be met.
- Trustees were grateful to David for this specific focus on the development of BCRT. It was felt that:- this analysis should be done on a yearly basis, that it was important that in future

a financial breakdown should be included within the SWOT sections and that the Trustees should contribute to the analysis.

- As most of the Founding Trustees had been parents, the following points were made concerning the continued development of the strengths gained from this aspect:- there had been a very positive profile and a large amount of funds available from early on, added to this, the establishing of the website and the extension of the profile into professional, medical circles had all contributed to the rapid growth of BCRT. Trustees were delighted that more survivors and patients are becoming involved but would like to continue to encourage the involvement of parents in a variety of ways. How to have the greatest impact was discussed, ie direct approach from BCRT or with the more personal touch of appealing in the name of a child or young person – it was felt that the latter should continue to be very relevant. The importance of BCRT being an easily accessible source of information was stressed – particularly around the time of diagnosis and on the wards. Fiona Foley suggested that the preparation of a booklet, rather than just a leaflet or newsletter as at present, possibly entitled “....So Your Child Has Been Diagnosed.....” should be considered. It was agreed that a question for the delegates at the next BCRT Conference should be “what would you like to see?” Patrick Hardman’s idea was that there should be a comments and suggestions page on the website. Other suggestions were that everyone involved should be enabled to increase the development of appropriate links with all the people who make contact with BCRT and that specific publicity around legacies should be put in place.

6.2 A Business Plan

- David gave a presentation suggesting how Trustees might look back at the vision and mission statements they used when originally registering as a charity and then identify their operational aims and objectives now. David proposed that a Strategic Planning Group should meet to do this work and then report back to the full board of Trustees for decisions.
- Trustees agreed that this would be a way forward. Comments made by Trustees included that:- “now is the time to put in place more of a business approach”, “we must start looking forward and not be playing catch up all the time”, this should be a living, breathing document – a journey, not a destination”.
- The initial group of Trustees to work on this was decided.

6.3 Report on the SANDS Befrienders’ Scheme. Item deferred to next meeting.

Minute from the meeting held on 13.09.08, 7.2 para 3 :- *“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 and support.”*

Having heard of this scheme, Sally Hurst had volunteered to investigate it and Ros Francis knew of other contact arrangements run by groups associated with the National Alliance of Childhood Cancer Parent Organisations (NACCPO).

7. FINANCIAL AND ADMINISTRATIVE BUSINESS

7.1 Current Financial Statement.

- At the date of the meeting, BCRT funds totalled £618,511.95 including the main account and the dedicated accounts. Trustees were investigating suitable possible arrangements for putting a proportion of funds into a deposit account.

7.2 On-Line Banking. The working of current arrangements were checked.

7.3 Employers’ Liability Insurance. Gill reported that there was no change in the amount quoted for the next year so Trustees agreed to continue with the same company.

7.4 Progress Report on the Paxton Accounts System. Gill reported that she was making progress as fast as possible with entering all the previous information and expected to have a draft copy of the accounts to 30th June 2008 ready for the AGM in February.

7.5 Restricted Funds. Patricia Smith stated that she felt it was important that funds raised by her in Ireland should be clearly allocated only to funding research so that she could say to supporters that “every penny is spent on research”. Other Trustees did not feel this to be as important in the presentation of information for their fundraising but it was agreed that Gill would set this up for Patricia.

8. FUNDRAISING, MARKETING AND PUBLICITY.

8.1 Report from the Head of Fundraising. Trustees were pleased to receive a more detailed report. Items specifically noted were:-

- The plan for **David’s visits to the main Cancer Centres** to be included in the Business Plan.
- **Training.** It was noted by Trustees that David had not yet attended relevant conferences or extension to the courses he had already completed. This to be looked at in 2009 for him.
- The first **Royal Parks Run.** Participation in this had been a great success for BCRT including the work done by the Adam Dealey Foundation with a gross income of £53,000, net £39,732. The publicity tent and banners had been well placed. It was felt that involvement in this event should be extended next year.

8.2 The Belgium to Berlin Cycle Ride, 15th-17th May 2009.

- David reported that fliers had been distributed with the recent Newsletter and to date two prospective teams had made contact. Trustees asked what support might be needed. David felt this would be minimal but would keep Trustees in touch as planning develops. He said the teams would largely be responsible for themselves with their own backup arrangements, first aid etc.
- **Insurance for the event.** It was reported that suitable arrangements had now been made.

8.3 Report of meeting with Simon Davies, Chief Executive of the Teenage Cancer Trust attended by John Dealey and Mike Francis on 2nd October 2008.

John reported that he and Mike felt it had been a very worthwhile meeting. It had involved a useful exchange of information and relationship building between the two charities. It was good to learn that two former bone cancer patients who have spoken at the BCRT Conferences, were to speak at the young people’s “Sense of Tumour” event at Centre Parcs.

8.4 Review of the Newsletter – Autumn 2008 edition.

- It was felt that Page 2 with the three articles on “Life after Treatment” was particularly good as well as the centre pages on the Conference and Fundraising News. Other useful comments were made and noted for the future.
- **The readers of the Newsletter.** It was agreed that the content should appeal to everyone – patients, family members, supporters, medical staff and all ages and should be very positive.
- **The next edition** – to be published in March 2009 so that Awareness Week can be promoted ready for June 20th -27th. It was agreed that a working group should be set up and start to meet in good time.

8.5 Review of Marketing Communications – the leaflet. Deferred until the next meeting in the absence of Sally Hurst who has started to look at it. **ACTION – ALL** to bring ideas for updating the leaflet.

8.6 BCRT Conference 2009 including evaluation of alternative venues.

To be held on Saturday 27th June 2009.

Kate Connor circulated a map showing from where delegates had travelled to the two previous conferences held in Leicester. Information from a visit to the two possible venues in Birmingham was examined but Trustees felt that Sopwell House in St. Albans would be better. John Dealey, who has used the venue for events, to make a provisional booking and Kate to visit to check out the details.

8.7 Awareness Week 2009. To be 20th – 27th June 2009.

- There was discussion about the theme :- it was felt that the focus should be about the disease and not about money, it should be on an aspect of the classic pathway that patients follow, it could be an extension of late diagnosis from this year. **ACTION – ALL** to continue to think about this.
- Sally Hurst to be asked to be involved on the journalistic side of communications.
- Mike Francis to work with some interested parents on the parliamentary aspect of raising awareness using the 82 MPs as a start, being signatories to this year's Early Day Motion.

8.8 Paralympic Games 2012.

Early thoughts as to BCRT's possible involvement:-

- Try to find someone who is training to qualify then aim to film their story, their progress and to follow them right through.....
- Through John Dealey's son – radio impact.
- Seek advice from BCRT's patron Marc Woods.
- Nick Bones to make contact with amputee football teams etc to seek out anyone hoping to take part.

9. SCIENTIFIC ADVISORY PANEL (SAP)

9.1 Report on the National Sarcoma Register Meeting at West Midlands Cancer Intelligence Unit, University of Birmingham (30th September 2008) attended by Mike Francis and former patient Hannah Millington.

- Mike Francis reported that Rob Grimer will be heading the new committee nationally.
- It will be a mandatory requirement for all hospitals in England to contribute to the database. Arrangements for Wales and Scotland being discussed by the appropriate bodies in those countries, although it is hoped they will adopt the English format.
- There was much discussion as to the starting point of the records. It was initially thought to be from when a patient is first seen by a specialist but this was felt by BCRT and Sarcoma UK to be too late. They suggested it should ideally be when the person is first seen by a GP and to include details of the initial diagnosis. Alternatively, it should be from first presentation at hospital (which might not be with an Oncology Specialist), again with diagnosis. It was thought by several of the medical professionals that this could not be done; however, the Intelligence Unit revealed details of some trial data covering this subject which is being explored further. Hannah Millington described her own experience of desperately seeking professional help and this had a significant effect on the meeting.
- A questionnaire for patients and parents is to be prepared. This will not be constrained by the Freedom of Information Act.

9.2 Up-date on the fourth round of applications for research grants.

- As was clearly noted at the last meeting (13.09.08 Section 10.2), the five applications received were all of a high standard and worthy of being funded but further questions needed to be asked for clarification. Ian Lewis reported that replies had been received and that it would now be appropriate to accept four, the fifth needing to be re-submitted showing alterations.

- The total cost of the four projects would be approx. £160,000.
- The question was asked as to whether and where results from BCRT funded research could be published. The British Journal of Cancer was suggested as a possibility. It was felt that BCRT has a responsibility to report on its website.
- Kate was asked to chase up further up-dates on the progress of the on-going research projects. **ACTION – Kate.**

9.3 Minute of the result of the Trustees vote to delay the next call for applications until Spring 2009.

- See Minutes 13.09.08 where the SAP suggested that the Autumn call for applications could be delayed until Spring 2009. This proposal was due to the high quality of the fourth round applications and the fact that Trustees had voted unanimously to accept the SAP's recommendation that all five should be accepted and funded following further questions. Gill Pilcher agreed to update the budget to reflect the extent of this funding. It was decided that Trustees would vote by email concerning the proposal once they had had sight of the budget.
- By 29.09.08 replies had been received from a quorate number of trustees, all 5 being in favour of the next call for applications being delayed until the Spring.

9.5 NICE technology appraisal of Mifamurtide (Mepact / L-MTP-E) for the treatment of osteosarcoma. The Appraisal Committee Meeting is to be held on Wednesday 18th February 2009. Mike Francis asked for ratification for Sally Hurst to attend representing BCRT as “an Expert Patient” and himself in the category of “Expert Carer”.

- It was agreed that Sally and Mike would attend the meeting in these roles for BCRT as well as John Dealey and Gill Pilcher representing their own charities. Ian Lewis would be attending but not representing BCRT as he is involved with the company and Tim Eden would be present as a professional advisor.
- Ian Lewis expressed his delight that this drug had at last been approved at a meeting held during the previous week and as a result of a single large randomised trial in the US. It is clear that its use improved survival rates and Ian himself felt that it should become standard treatment. It is used alongside chemotherapy. Registration is the first step. Then NICE have to approve its cost effectiveness, its cost per year of life saved.

9.6 British Sarcoma Group (BSG) Conference in Glasgow, 18th-20th March 2009.

Ian had previously suggested that BCRT might be able to have a slot for reporting on research being funded. A draft programme has been published including Ian Lewis as a speaker and he will discuss this with the organisers. **ACTION - Ian**

9.7 Request to make a research application from Singapore. Ian reiterated that BCRT is only funding research in this country at the moment.

10. STAFFING.

10.1 Christmas holiday arrangements. This had been clarified by Gill Pilcher and HR. The office to be closed on Christmas Eve until 2nd January with a voice mail message diverting callers to David at home.

10.2 A larger office.

- In the Minutes of 13.09.08 it was recorded that there seemed to be no possibility of a larger office becoming available in the same building before the renewal of BCRT's current office was due on 4th December.
- On 6th November Kate notified trustees that a first floor suite, approx. three times the size of the current office had become available. She circulated details and comparative costings etc.
- Eight trustees carried out a useful discussion by “reply to all” emails around the length of the lease, the removal of a partition and the terms in the Tenancy Agreement. Kate was then

authorised by a quorate number of trustees (7) to arrange for the Tenancy Agreement to be ready for signature at the forthcoming Trustee Meeting. The agreement was checked and signed at the meeting.

10.3 Information Officer. Planning for an Information Officer to be continued within the Business Plan.

10.4 Financial support in the office. Once the Paxton Accounts system is in place, then an accounting technician can be sought.

10.5 BCRT's computer system. Trustees asked office staff for clarification on the backup arrangements and systems they operated in the office.

11. WEBSITE MANAGEMENT.

11.1 Kate to check on the possibility of further stories to be added.

11.2 Two Trustees to prepare a piece about themselves with a photograph for the Trustees' section.

12. BCRT IN IRELAND

12.1 Fiona Foley reported that their Ball had again been a great success and that more families were being contacted through the publicity.

12.2 Patricia Smith felt that there were still difficulties with the transfer into England of funds raised. She handed over a cheque she had recently received from a local family.

12.3 All agreed that they had been interested to see more stories from Ireland in the BCRT in Ireland section of the website.

13. ANY OTHER BUSINESS.

13.1 Medikidz, a contact made by John Dealey. John met Dr. Kate James who has been involved in the creation of a comic designed for up to 15 year olds using super heroes to help explain medical conditions including osteosarcoma. Trustees watched a presentation.

14. DATES OF NEXT AND FUTURE MEETINGS.

- Using a year planner dates were identified for all BCRT meetings to be held during 2009. Ros to check the availability of these and email them to Trustees.

ACTION - Ros.

- These included 5 Trustee meetings as usual, plus the Conference. It was suggested by Ian that once the Paxton system is in place, it may become possible to drop to 4 meetings a year in 2010, meeting perhaps in March, June, September and December (this would be in line with BCRT's Trust Deed).

