

BONE CANCER RESEARCH TRUST

MINUTES OF MEETING OF TRUSTEES held on Saturday 3rd May 2008 at the Leicester Hilton Hotel.

1. PRESENT

Trustees:- Mike Francis (Chairman), John Dealey (Deputy Chairman), Ian Lewis, Gill Pilcher, Patricia Smith, Patrick Hardman, Fiona Foley, Sally Hurst.
Officers:- Ros Francis (Clerk to the Trustees), Kate Connor (Administrator), David Fisher (Head of Fundraising), Alan Johnston (Website Manager).

APOLOGIES

Trustee:- Nick Bones.
Supporter:- Marian Dealey.

The Chairman welcomed the two new Trustees Fiona Foley and Sally Hurst to their first meeting. He also congratulated Ian Lewis on becoming an Honorary Professor of Cancer Studies in Children and Young People at the University of Leeds.

2. MINUTES OF MEETING OF TRUSTEES held on 2nd February 2008.

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

3. MINUTES OF THE SPECIAL MEETING held on 2nd February 2008.

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

4. MATTERS ARISING FROM BOTH THE ABOVE SETS OF MINUTES, not covered by Agenda items.

There were no matters arising from either sets of Minutes.

5. CORRESPONDENCE

5.1 Draft “guidelines manual” from NICE – discussion on this was deferred.

5.2 Information received on a new quarterly magazine called “Understanding and Coping With Cancer” was discussed. It was agreed that the first edition should be obtained and considered before deciding whether BCRT would contribute. **ACTION - Ros**

5.3 Trustees were reminded about the Trustee Conference being held in London on 26th June in case anyone was interested in attending.

5.4 A seminar on Employment Law for Charities to be held on York on 10th June was publicised. Mike said he hoped to attend. **ACTION - Mike**

5.5 Email correspondence had been received from the Parents’ Association for Seriously Ill Children (PASIC) concerning support for young people up to the age of 24 (as being discussed in the NICE Guidelines). BCRT’s interest and concerns about provision for teenagers from 16 – 24 had been contributed. It was noted that this was a matter being discussed on BCRT’s Parents’ Forum. Trustees suggested that BCRT could perhaps, in the future, become actively involved in offering, for example, advice on access to sports facilities after treatment for this age group, possibly setting up a network of physiotherapists, information on horse riding, football etc. BCRT’s interest to be passed on into the discussion. **ACTION - Ros**

5.6 It was noted that BCRT's Conference had been added to the diary of international sarcoma events listed by the Liddy Shriver Sarcoma Initiative.

5.7 A letter published in a doctor's advice column in a local newspaper about a 14 year old boy with a swollen and painful knee and the doctor's reply was read to Trustees. All present were greatly concerned that it was merely put down to "growing pains". **ACTION - Ros**

6. FINANCIAL AND ADMINISTRATIVE BUSINESS

6.1 Current Financial Statement.

The statement including the main account and the seven dedicated accounts to 2.05.08 totalled £468,260. It was agreed that all but the odd pounds and pence in each dedicated account should be transferred into the main account thus benefiting from a higher rate of interest but that an on-going record of funds raised in each account should be maintained.

6.2 Approval of Expenditure. The following were presented and approved:- Invoice from Skyline for the cycle challenge £2,200; invoice from Dr. Grigoriadis, Kings College, London for £21,322.01 for the period 01/10/07 – 31/03/08 for his research project; 1000 copies of the general BCRT poster £210; the printing of the Newsletter £753 with VAT to be added.

6.3 Gift Aid. It was noted that a significant amount of work was needed to claim the gift aid from the many completed sponsor forms that had been received. A plan to deal with this to be considered. **ACTION - Gill**

6.4 Justgiving. The statement for income received via online justgiving sites to 2/05/08 was received. Including gift aid, this showed £38,082.42. Trustees were delighted to see the effectiveness of this method of giving.

6.5 Annual Return to the Charity Commission 2007. An explanation of the way this had been presented in line with Charity Commission procedures had been explained by Mike Francis via a previously circulated paper. There were no further questions.

7. STAFFING

7.1 Information Officer. It was felt that this part-time post, possibly one day a week, should be considered with more urgency so that BCRT can provide up-to-date information (not advice). It would need someone with library and research skills. Ideas to be gleaned from other charities. Possible funding avenues are emerging but an actual proposal of the role and costings will be required.

ACTION – All, David

8. TRUSTEES' MATTERS

- **8.1 Deed of Indemnity for the Outgoing Trustees.** This had been prepared by solicitors Brooke North as agreed at the last meeting (2.2.08 Section 7.1). It was circulated for signature by all trustees present and will be posted out to the remaining four. **ACTION - Ros**
- The need for **on-going indemnity insurance for the Trustees** was discussed. Gill Pilcher presented three quotes including varying amounts and cover. John offered to look at them in detail with an appropriately skilled colleague to decide on the most suitable. **ACTION - John**

ACTION - John

8.2 A Potential New Trustee. The CV from this interested person had been circulated amongst the Trustees for consideration and they were looking forward to meeting him and his wife at the BCRT Conference.

8.3 BCRT in Ireland. Further information offered by Fiona Foley and Patricia Smith as well as from Mike Francis who had been making enquiries in England. **ACTION - Mike**

8.4 “Trustee Voices”. Both Ian Lewis and Mike Francis felt that there were some good and relevant articles in this magazine. Mike informed Trustees that he had put it into the Pooled Resources section of the BCRT system for all to access.

9. PUBLICITY, FUNDRAISING AND MARKETING

9.1 The Second Newsletter. These have been sent out to all on BCRT’s database. Supportive comments had been coming in. Trustees were pleased to receive copies to take back to their areas. It was noted that the format had been very similar to the first Newsletter and that maybe a Newsletter Planning Group for the third would add to the range of ideas and presentation.

9.2 BCRT’s Second Conference for Patients and Supporters.

- The draft programme had been received by all Trustees.
- Fiona Foley and Patricia Smith both gave their apologies for the Conference and the Trustees’ meeting to be held the next day.

Ian Lewis reported that he had obtained sponsorship of approx £4,000. Trustees were grateful for this but all to continue to look for further support of about the same amount if possible.

ACTION - All
ACTION – All

- All to encourage more supporters to register to attend.
The Conference Planning Group to meet again shortly in Leeds.
- It was suggested that there might be a session on Complementary Medicines next time.

9.3 Bone Cancer Awareness Week to be from 21st-28th June 2008 ending with the Conference. This had been suggested by David Fisher with the theme of delayed diagnosis. Awareness posters (a copy was shown) being sent out with Awareness Week packs to hospitals, politicians, radio stations etc. Sally Hurst supporting through writing a press release and advising on strategies to use in order to be noticed by the media. Tim Eden being asked to provide statistics. Relevant case studies being obtained for use. John Dealey said that he and his son will be speaking on their local radio.

9.4 Fundraising Report from David Fisher. Trustees where pleased to see information on the wide range and amount of all that has been, is and will be taking place including details of Supporter Fundraising Activity between January and the end of April and a long list of future events already planned. They found it helpful to see the projected minimum income from the high number of places that had been bought for 6 major runs taking place around the country. Two items mentioned in particular were that more places in the Royal Parks Run were needed thanks to the publicity given for this by John Dealey and the potentially big contact made with a company in Hamburg for their sponsored run.

9.5 Merchandise. New additions of car stickers, balloons and posters were shown. More badges to be ordered. Environmentally friendly bags being investigated but with our relatively small numbers and cost implications, this may not be viable.

9.6 National Alliance of Childhood Cancer Parent Organisations (NACCPO). Ros Francis to attend the AGM, Committee Meeting and Support Workers’ Meetings the day before the Blackpool Conference (see below).

9.7 Annual Conference of Childhood Cancer Charities and Support Groups in Blackpool – Saturday 10th May. Ros and Mike Francis to attend with the BCRT Display Stand. Mike reported that following a cancellation, he had been invited to speak on “Challenging Consultants”. He said he would be basing this on the Belfry Consensus Meeting of professionals.

9.8 Events Insurance. Gill Pilcher had made enquiries about this and found that it was only appropriate to insure events set up and run centrally by BCRT. At the moment, the only such event is the Conference and insurance for this is covered by the Hilton Hotel. When BCRT buys places on Runs, these are covered by the Run Organisers’ insurance.

This means that people holding their own events but sending funds raised to BCRT, MUST INSURE THEIR OWN EVENTS.

It was noted that this should be made clear on all publicity material and fundraising advice sent out by BCRT.

10. SCIENTIFIC ADVISORY PANEL

10.1 The Third Round of Research Grant Applications.

- At the last meeting (2.02.08) it had been reported that 5 bids had been received. Three were recommended for approval pending further information and Trustees agreed that Ian Lewis could accept them if the responses were satisfactory. Ian reported that this had been the case. These were as follows:-

Main Applicant	Institution	Title	Additional Information
2. Professor Nicholas Athanasou	University of Oxford – Nuffield Orthopaedic Centre.	Effect of hypoxia on growth, apoptosis and angiogenic capacity of Osteosarcoma and Ewing’s Sarcoma cells: regulation by Hypoxia-Inducible Factor.	£27,213 Project length 24 months
4. Professor Josef Vormoor	Newcastle University	Molecular mechanisms of organ-specific Ewing’s sarcoma metastasis.	£31,772 Project length 12 months
5. Dr. Richard McNally	Newcastle University	Environmental contributions to the aetiology of bone tumours in young people: small area analyses.	£30,601 Project length 12 months

- It was noted that No.5 came from Dr. Richard McNally who was coming to the end of his first project funded by BCRT and would be speaking about it at BCRT’s Conference.
- It was noted that Annual Reports should now be received from the first projects granted. These to be requested. **ACTION - Kate**
- John Dealey and David Fisher reported they had been pleased to visit Dr. John Anderson at the Institute of Child Health in London to hear about his BCRT funded research.

10.2 The Fourth Round of Research Grant Applications.

- Ian Lewis reported that five bids had again been received. He said that the content was very encouraging but that as he had an interest in some of them, Rob Grimer would be closely involved in the work required to assess their viability.
- Recommendations will be given to the Trustees at their September meeting.
- Ian said he was working on up-dating the list of specialist advisors.

10.3 Report on the National Institute for Clinical Excellence (NICE) Scoping Meeting held in London on 26th February. Following the invitation to BCRT, three trustees had attended :- Ian Lewis, Gill Pilcher and John Dealey. The meeting was held to check support for the drug Mepact to become available in the UK as work is being carried out for it to be registered. John and Gill said they valued being able to attend to support Ian and the medical professionals and now found it easier to understand why NICE procedures seem to take so long. Trustees felt that being invited to attend this meeting showed significant recognition for BCRT. (See Minutes 2.02.08 for more information on Mepact).

10.4 The Bone and Sarcoma National Database. Ian explained that there are regional registries for all patients diagnosed with cancer. There is to be a reorganisation and The West Midlands Cancer Intelligence Unit, Birmingham is to become the centre for all bone sarcomas and soft tissues. This will be a useful source of information for BCRT. The invitation received to the meeting about this is a real opportunity for BCRT. It was decided that a previous patient would be asked if she would be interested and Mike Francis, a parent, said that he could attend. **ACTION – Mike**

10.5 Bone and Cancer Foundation. This is a programme of The Paget Foundation for Paget's disease of Bone and Related Disorders. An email had been received asking for a link with BCRT. Ian Lewis felt that this could be useful, Kate to follow up. **ACTION - Kate**

10.6 Bone Research Society. Request received for a link – Kate to get further information. **ACTION – Kate**

10.7 A research grant request from the US. Ian Lewis to asked Kate to send thanks for his enquiry and say that there is increasing research capacity in the UK at the moment. **ACTION - Kate**

10.8 Ian Lewis reported that a Ewing's Sarcoma Meeting is to be held in America. He felt that BCRT might consider giving a grant towards bringing people together to work on classification, common language etc. Ian to report back on developing arrangements. **ACTION – Ian**

11. WEBSITE MANAGEMENT

11.1 Alan Johnston, Website Manager, put a number of questions to the Trustees:-

Alan said that he is waiting for the two new trustees to send in their message and photo to go into the Trustees section.

- The list of research projects being funded to be up-dated with the new three now agreed. Kate to give Alan the information. **ACTION - Kate**
- Alan will up-date the list of peer reviewers on the Scientific Advisory Panel when it is ready. **ACTION - Ian**
- The fact that no new stories had been added for some time was discussed. Brief "stories are often seen on justgiving sites or in emails – how can we get permission to use the short versions they give us? How can we make it easy for people to write their stories for us? Should we publish some sort of guidelines on the Stories site?"

11.2 The Forum. It was noticed that it had gone rather quiet. Agreed there should be a publicity push at the Conference.

11.3 Facebook. Worries about the use of this continue. It was felt to be safe if only one's name and a few friends were linked.

11.4 The Weather Lottery. It was reported that leaflets had been sent out about how to join and there was a section about it in the Newsletter.

11.5 Everyclick. Several people were now using this although some had difficulty in making it become their home page.

12. ANY OTHER BUSINESS:-

12.1 Communication Arrangements.

All Trustees recognise geographical difficulties to meet together easily but some felt that they were not kept in touch with developments between meetings as much as they would like. It was felt that once the different areas and access to them are set up on the BCRT computer system, it will become easier.

When anyone posts anything onto the sites, the procedure should be to send out an email alerting Trustees to look at the appropriate site.

- Trustees felt they would like to read up-dates from Planning Groups (ie for the Conference, for Awareness Week) to be put on the Trustees site so that they could see the plans and progress being made. **ACTION - Ros**
- For Trustees' information and interest, proposals, for example, for new types of merchandise, could be posted on the Trustees site.

12.2 Head of Fundraising.

Trustees said they would appreciate it if David Fisher could focus on each of the Trustees in turn, looking at their part of the country, their fundraising approaches and possible needs. They felt this would help to widen their ideas and give David more of an overview as to what is being done around the country and in Ireland.

12.3 Packs sent out to Supporters.

Trustees said they would be interested to see what the various packs include ie. for Fundraising, for Awareness Week, for Runners etc. It was suggested that examples of these could be on show during the afternoon Fundraising session at the Conference. **ACTION - David**