

## **BONE CANCER RESEARCH TRUST**

### **MINUTES OF MEETING OF TRUSTEES held on Saturday 8<sup>th</sup> September 2007 at the Leicester Hilton Hotel.**

#### **1. PRESENT**

**Trustees:-** Mike Francis (Chairman), John Dealey (Deputy Chairman), Ian Lewis, Gill Pilcher, Patrick Hardman.

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

#### **APOLOGIES**

**Trustees:-** Rob Grimer, Patricia Smith, Nick Bones, Gill Callar, Debbie McCartney.

#### **2. MINUTES**

Minutes of the Meeting of Trustees held on 15<sup>th</sup> July 2007 were agreed and signed.

#### **3. MATTERS ARISING FROM THE MINUTES OF 15TH JULY 2007.**

Matters not covered by later Agenda items:-

**See 3.1 Conference for Professionals.** A report to go onto the website - Kate Connor still awaiting photographs to accompany it. Ian Lewis and Lee Jays were continuing to work on writing up the findings of the whole event.

In response to a Trustee's question on consensus around treatment decisions in this country, Ian answered with the question the professionals are trying to solve "How do you run a National Advisory Group"? The ideal would be for x-rays to be online so they could be seen and discussed together by teams from different hospitals. This, with video conferencing at set times would be effective but demanding of time. To be explored further. Meetings between professionals from some of the other countries who attended the Conference have been also planned.

**See 3.2 Trek to Machu Pichu.** Further funds raised by Emma and Katie had been received ahead of their trip.

**See 3.6 The exchange rate.** Kate reported that normal rates apply at the time of receiving euros from Ireland into BCRT.

**See 5.3 Audited Accounts.** Kate reported that the Charity Commissioners were now ready to receive BCRT's Accounts for the part year following registration plus the first full year.

**New Item 3.1** On behalf of the Trustees, Mike Francis paid tribute to the fortitude and achievement of Jane Tomlinson who had recently lost her battle with cancer.

#### **4. CORRESPONDENCE**

**4.1** The recent edition of Social Economy was passed round for Trustees to read.

**4.2** Notice was received of the Annual Wrigleys Governance Seminar to be held on 6<sup>th</sup> November. It was thought to be worthwhile for BCRT if someone could attend.

#### **4. Correspondence – continued.**

**4.3 Contact Magazine.** It was noted that two people involved with BCRT were already on the editorial board – Trustee Patricia Smith and Supporter Andrew Belshaw. It was reported that The Patient Advocacy Committee would like a former patient to join the group. Trustees suggested possible people known to them. Information to be gained concerning venue of meetings in the country and the possibility of expenses.

### **5. FINANCE**

#### **5.1 Statement of Accounts.**

- Statements were presented for the main account and for the now five dedicated accounts, the total amount to 07.09.07 standing at £384,049.80. All Trustees agreed that the accounts be accepted.

#### **5.2 Dedicated Accounts.**

- Income for the current Dedicated Accounts had mostly been interest during this period. A fifth had been opened in the name “Matt’s Beacon” with the cheque for £40,000 presented at the Conference in memory of Matthew Arrowsmith. The possibility of others to be opened was discussed.

#### **5.3 Research Funding.**

- The first claim had been received from one of the research projects which BCRT had agreed to fund from the first round of bids.

#### **5.4 Presentation of account details for Trustees and for wider accountability.**

- All agreed that it is necessary to show committed funds on the Account Summary especially as it is the custom of researchers to claim at unspecified intervals.
- It was also felt important to be able to show movement of funds from the Dedicated Accounts for accountability, to show supporters that their hard won funds are actually funding research.
- The importance of coming up with a format to clearly show all this information as soon as possible was stressed. **ACTION – Mike, Gill P, Kate.**

#### **5.5 Investment Advice.**

- Trustees agreed that they should consider setting up an Investment Advisory Group. An appropriate speaker on investment of charity funds to be sought, possibly for the next meeting. **ACTION - Ian.**

### **6. STAFFING**

**6.1 An Office.** The search was continuing for an office in Leeds with space for 2/3 desks. All to look out for possible sponsorship.

**6.2 The Administrator.** It was agreed that Kate should purchase a new printer now as this was needed, rather than wait for the move into an office. Mike reminded Trustees that Kate had been working extra hours to cope with the work load around the Conference, research bids, the production of the newsletter and the advertising for a professional fundraiser. Trustees agreed that Kate should keep a record of extra hours and claim for phone calls etc.

**6.3 A Professional Fundraiser.** There was much discussion around what BCRT really expects from someone in this role in order to finalise the job description, advert, application procedure etc. Stuart Andrew, fundraiser for Martin House Hospice, had kindly provided advice and support. It was decided that the advert should be placed in the “Third Sector Jobs” magazine which specialises in charity posts with the closing date set at 8<sup>th</sup> October. Interviews to take place in Leeds, probably on 5<sup>th</sup> November. The interviewing panel to include:- Stuart Andrew, Mike Francis, John Dealey, Ian Lewis, Gill Pilcher and Patrick Hardman.

## **7. TRUSTEES' MEMBERSHIP AND INFORMATION SHARING.**

### **7.1 Trustees.**

- Resignations had been received from two Trustees, Gill Callar and Debbie McCartney. For personal reasons both have been finding it increasingly difficult to attend meetings but assured fellow Trustees of their on-going support through fundraising and their efforts to raise the profile of BCRT and its aims, in their areas. The Trustees expressed their regret and also their gratitude for the valuable contribution that both Gill and Debbie had made in the establishing of the charity  
**ACTION - Mike**
- Two names were suggested as possible new Trustees with particular areas of expertise and were to be followed up.  
**ACTION – John, Mike**
- Notice of trustee vacancies to be put on the website.  
**ACTION – Kate, Alan**
- Information to be sought from the Charity Commissioners about procedures for changing Trustees.  
**ACTION - Ros**

### **7.2 Information Sharing.**

- It was agreed that the Minutes of 15<sup>th</sup> July, accepted and signed earlier in the meeting, would be the first to be published on the website.
- Planning for the first BCRT Newsletter was continuing. **See Section 12 below.**

## **8. MARKETING, PUBLICITY AND FUNDRAISING**

**8.1** Kate Connor and Alan Johnson confirmed that the website is regularly updated with information on the many fundraising events held and that they are always pleased to receive reports and photographs. The wide range of activities recently has included:- a wheelbarrow race, a slave auction, wing-walking, golf days, fashion shows, Halloween fun, gigs with local bands, mufti days and collections. As well as these, there has been a variety of challenges with walks, runs, swims, treks and mountain climbs taking place all over the country and in Ireland. Notice of events being planned is also welcomed so that wider publicity can be gained for the organisers through BCRT's website. Three particular future events are the Robin Hood Marathon, the climbing of Kilimanjaro and a Fancy Dress and Valentine's Ball.

**8.2** Gill Pilcher reported that all the Christmas Cards had been distributed so it was now down to everyone to sell them.

## **9. SCIENTIFIC ADVISORY PANEL**

**9.1** See also 6.1 on Pages 3,4 of last Minutes. Ian Lewis brought Trustees up-to-date on the progress of their decisions and requests for further information concerning the 5 applications that had been considered for the second round of funding for research.

1) This had been accepted and would probably be starting in November.

2) As requested, further information had been obtained and now 2 of the 3 reviewers were happy as well as Ian Lewis, Rob Grimer and Jeremy Whelan. As this research is already being funded by another body, clarification had been sought that BCRT's name would also be used. The Trustees accepted the recommendations and the result will be passed on to the applicant.

3) Additional information and pictures had been received and agreed by the referees. Trustees also accepted this recommendation.

4) and 5) had both received feedback as to why their applications had not been successful.

It was agreed that details of these three additional and successful research projects could be put on the website.

**9.2** The closing date for the next round of bids to be 22<sup>nd</sup> October with notification at the end of January 2007 / beginning of February 2008.

## **10. WEBSITE MANAGEMENT**

**10.1** As noted in 7.2 above, in future the Minutes of Trustees' Meetings, once approved and signed, will be put on the website to enable supporters to keep in touch with the on-going progress of BCRT.

**10.2** The way that the Stories are presented on the website was discussed further. **See also section 8, Page 5 of the last Minutes.** Alan reported that he had now split them into two sections – those written “by Patients” and those “by Families and Friends”. Consideration was continuing of the possibility of including other categories that might be helpful to readers.

**10.3** The use of Face Book was discussed with concerns being expressed around the risks attached but also with a recognition that its availability and character is ideal for young people. It was suggested that BCRT tried to use Yahoo instead which appears to be better protected.

**10.4** Thanks were given to Alan for his recent work in adding the Forum section with Yahoo. This provides a “virtual meeting point” in two sections – the Main BCRT Forum and the Bone Cancer Patients' Forum, a need that had been expressed by many during the Patients' and Supporters' Conference. Work was on-going towards setting up a shop with BCRT merchandise.

## **11. PATIENTS' AND SUPPORTERS' CONFERENCE**

It was decided that feedback from the discussion groups and the evaluation forms from delegates would be reported at the next meeting as some had still not been received.

**ACTION – Kate** to chase up the remaining group facilitators and to send out the evaluation form electronically to delegates who may not have responded on the day.

**ACTION – Ros** to collate and summarize the information.

## **12. ANY OTHER BUSINESS**

**12.1 The Newsletter.** Kate reported that there would be enough news and information to fill 8 pages on 2 A4 sheets. This would cost 87p per copy, £ 464 for a run of 1,000 copies.

It should be ready for distribution in late October / early November. She outlined the content including a mix of articles, brief items and photographs and a centre spread devoted to the Patients' and Supporters' Conference.

**12.2 The Leaflet.** Mike asked Trustees to begin to consider ideas for any changes needed to the leaflet as BCRT has moved on so much since it was produced and a re-print will be necessary before long as stocks are getting low.