

## **BONE CANCER RESEARCH TRUST**

### **MINUTES OF MEETING OF TRUSTEES held on Saturday 17<sup>th</sup> November 2007 at the Leicester Hilton Hotel.**

#### **1. PRESENT**

**Trustees:-** Mike Francis (Chairman), John Dealey (Deputy Chairman), Ian Lewis, Gill Pilcher, Patricia Smith, Nick Bones.

**Officers:-** Ros Francis (Clerk to the Trustees), Alan Johnston (Website Manager).

**Supporters:-** Chris Smith.

#### **APOLOGIES**

**Trustees:-** Rob Grimer, Patrick Hardman.

**Officer:-** Kate Connor ( Administrator)

**Supporter:-** Marian Dealey.

#### **2. MINUTES**

Minutes of the Meeting of Trustees held on 8<sup>th</sup> September 2007 were agreed and signed.

#### **3. MATTERS ARISING FROM THE MINUTES of 8<sup>th</sup> September 2007.**

Matters not covered by later Agenda items:-

**See 3.1** Report of the Professionals' Conference now on the website but without photographs.

**See 3.2** Emma and Katie had completed their trek in Peru having raised over £4,000 with more still to come in.

**See 4.2** No-one had been free to attend the Wrigleys Governance Seminar.

**3.1** As requested, the Clerk had sent a letter to Teresa Thompson.

#### **4. CORRESPONDENCE**

None.

#### **5. FINANCIAL AND ADMINISTRATIVE BUSINESS:-**

**5.1 Statement of Accounts.** In the absence of the Administrator, Trustees received and accepted a brief summary on financial activity since their last meeting in September. The amount in all the BCRT accounts to 8.11.07 totalled £381,879.24.

**5.2 A format for the on-going representation of the accounts** still being considered.

**ACTION – All**

**5.3 Expenditure.** Approval was given for major expenditures since the last meeting including payments towards two of the current research projects and also for the advertising and interviewing costs around the selection of a professional fundraiser for BCRT.

**5.4 Audited Accounts.** Trustees received final copies of the Audited Accounts to 30<sup>th</sup> June 2007 which they checked for accuracy. Gross income for the year was £166,265 (2006 - £176,144). Expenditure for the year was £89,522 ( 2006 - £5,728) of which £80,189 was dedicated to three research grants as follows:-

Dr. John Anderson, Institute of Child Health, Great Ormond Street Children's Hospital, "*The Development of Clinical Protocols for Ewing's Sarcoma Treatment Using Gene Transfer of T Cell Receptors*". £34,5000.

Dr. Richard McNally, University of Newcastle, “*An Epidemiological Study of Bone Tumours in Children and Young Adults*”. £29,985.

“*International Consensus Meeting on Local Control of Ewing’s Sarcoma*”. £15,704.

The net balance carried forward into 2007/08 was £247,159 (2006/07 - £170,416).

It was proposed by John Dealey and seconded by Ian Lewis that these should be accepted and this was carried unanimously. The three copies were signed by Mike Francis, Chairman and Gill Pilcher, Trustee with responsibility for Finance.

**5.5 A proposed Budget to June 2008** was presented by Gill Pilcher for feedback. It was suggested that expenses could be arranged under three main headings covering:- running costs, the work of the charity and research grants. **ACTION - Gill**

**5.6 Donation.** Trustees were pleased to receive a cheque from Patricia Smith for €8,000 as a result of her further fundraising efforts in Ireland.

**5.7 Reports from Other Meetings.** Mike had attended the NACCPO Executive Committee Meeting and brought several points of interest to the Trustees:-

- CRUK may be interested in providing support funding for groups who are funding research.
- The NACCPO Annual Conference to be on 26<sup>th</sup> April 2008 at Donna’s Dream House in Blackpool.
- The current rearrangement of Children’s Cancer Centres was discussed, for example the four in London had combined to form two larger centres. This promoted discussion around Parent Advocacy and BCRT’s role in supporting parents. Trustees were grateful for Ian Lewis’s expertise in advising them on areas that might be important to pursue. He said that ITCC (Innovative Therapies for Children with Cancer) has a process for evaluating change. To counter the feeling often heard that “nothing is happening” – it was suggested that an article on this subject might be included in BCRT’s next Newsletter.
- It was agreed that BCRT should pay this year’s subscription of £30 to NACCPO to continue to be in touch with other parents’ groups. **ACTION - Ros**
- It was considered to be important to continue to be aware of developments in other organisations but that BCRT should maintain its independence.

## 6. STAFFING

**This section includes the appointment of a Fundraiser, the setting up of the Office and further clarification of the role of the Administrator. Several aspects of these areas and the essential formal arrangements cover combinations of all three so are not necessarily recorded here under the three separate headings.**

### 6.1 Interviews for a Professional Fundraiser.

- Six candidates had been shortlisted from the 17 applications received using a scoring system. On the day 4 attended for interview. The panel included five trustees as well as Stuart Andrew, Fundraiser for Martin House Hospice to whom the Trustees are grateful for his professional advice throughout the procedure. David Fisher, currently a Professional Fundraiser for Epilepsy Action, was appointed and will take up the post in January 2008.

### 6.2 Formalities and Arrangements.

- Gill Pilcher presented HR information and a Service Level Agreement for 12 months. Contracts to be drawn up for both the Fundraiser and the Administrator. Gill to continue to be the point of contact for these matters.
- Gill Pilcher dealing with employers’ and public liability insurances. **ACTION - Gill**
- Arrangements to be made for CRB checks to be put in place even though it was thought to be unlikely that the two members of staff would be working on their own with children or vulnerable adults.
- Both members of staff to be responsible to Mike Francis, Chairman, on a day-to-day basis.

- Both members of staff to submit a weekly diary sheet of their activities to Mike and Gill and send expenses claims to Gill.
- Inservice training had been included in the budget for both members of staff. Suggested topics:- an Institute of Fundraising Strategies Course for the Fundraiser and possibly training on the setting up of data bases for the Administrator.

### **6.3 The Administrator.**

- A job description to be drawn up clarifying roles and responsibilities. **ACTION - Mike**
- Monitoring of working hours to be continued and clarified once the Fundraiser is in place. Currently two days with a third added for specific reasons.

### **6.4 The Office.**

- To be a one year contract with occupancy from 5<sup>th</sup> December 2007.
- A budget for furniture, computer equipment, fax/ telephone etc. £4,225.00 was presented by Gill Pilcher.
- A trading company, Bone Cancer Research Trust Ltd to be registered at Companies' House. On completion, the entire shareholding will be transferred to BCRT as a charity and all the Trustees will be appointed Directors. The annual accounts of the trading company will be fully incorporated into the charity's accounts to ensure favourable taxation terms.
- Essential that information on the office computers is backed up very regularly and stored off site.

**6.5A staffing suggestion for the future** was made by Ian Lewis. A part-time post for an Information Officer / Librarian would extend BCRT's aim to become a respected source of up-to-date information for patients and families. Information gathering through online searches etc could include:- drug developments, conferences, trials, newly published research, etc.

- It was noted that Children in Need fund for specific reasons and maybe the above post would be considered. **ACTION - Ros**

## **7. TRUSTEES**

**7.1 Out-going Trustees.** With regret, the resignations of Gill Callar and Debbie McCartney had been accepted. See 7.1 in Minutes 8.9.07.

**7.2 New Trustees.** The Trustees conducted a brief skills audit amongst themselves and listed the following areas of expertise which could be useful additions:- in PR, legal knowledge and investment experience. Three names were suggested and it was decided that they should all be approached. **ACTION – Mike, John**

**7.3 Trustees in Ireland.** Patricia Smith explained to Trustees that she was keen for a branch of BCRT to be officially set up in Ireland to give credibility and to support her in her fundraising. She presented formal information as to how this might be done. This would require two directors, one being the company secretary using her house as the designated office and 7 other named people. Trustees agreed to this in principle. The process, legal and financial implications to be clarified with the Charity Commissioners. **ACTION – Mike**

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

**8.1 The first BCRT Newsletter.** Trustees agreed that this looked professional and summed up the rapid and positive growth of the charity during its first eighteen months. Very favourable comments had been received by all present. Thanks were recorded to Kate Connor for all the hard work she put into its production. An initial 1000 were being sent out to everyone on the current lists of contacts including batches to the hospitals, groups and individuals who have raised and contributed funds. A further 2000 had been ordered for distribution and to be available for publicity until the next edition, probably in 6 months time. A list was started of ideas for items to be included.

## 8.2 Patrons.

- The role of patrons was further discussed and additional names put forward for consideration. These included notable sportsmen, cancer specialists and people who might interest and inspire young people. All to continue to think about this area of support for BCRT. **ACTION - All**
- Trustees were grateful to have received a donation via Marc Woods, BCRT's first patron, in lieu of his fee for a talk given to a national sports' association.

## 8.3 Forthcoming Events.

- London – Paris Cycle Ride in July 2008. Three people have said they will be taking part and raising funds for BCRT.
- Leeds 10K Run in June 2008. BCRT has booked 150 places and names are coming in.
- The Valentine's Masked Ball in February 2008 being organised by people from Leeds and York. Tickets are now on sale and Kate is dealing with this side of the event directly through the main BCRT office. There was discussion around arrangements for this event as it was not actually a main BCRT event planned by the Trustees but happened to be taking place in Leeds where the office is situated. Trustees were grateful for Kate's enthusiasm for this and the Leeds 10K Run but noted that her time is for administrative work for BCRT, in particular the research grants and for centrally planned activities such as the Conference and the Newsletter.

## 8.4 Publicity.

- **Sally Young / Hurst.** The Trustees registered their delight at the birth of Sally and Pete's daughter Holly and congratulated them on the television interview they gave.
- **Megan Blunt.** Several of the Trustees had seen Megan receive her Pride of Britain award on television and recorded their congratulations to her.
- It was noted that both the above had been involved with bone cancer but had not been able to give really strong publicity to BCRT through their recent interviews.
- Consideration to be given to getting up-to-date articles about BCRT into a future edition of Contact Magazine and into the Candlelighters' Magazine.

## 9. SCIENTIFIC ADVISORY PANEL

### 9.1 Second Round of Bids.

Information on the three research applications for grants that were agreed by Trustees has been put on the website.

### 9.2 Third Round of Bids.

- Ian Lewis reported that five applications had been received:- three from people new to BCRT, one who had applied before and one that BCRT is already funding. Of these, one dealt with osteosarcoma, one with Ewing's sarcoma and the other three were relevant to both bone cancers.
- The SAP had decided to increase the number of referees from two to three relevant experts with reports being completed and returned by early January. It was felt that everything was unlikely to be in place for the Trustees' meeting in January so the SAP would probably report back at the following meeting.

**9.3 Development of Drugs.** Ian Lewis highlighted several developing drugs which may have potential for the treatment of bone cancer.

**9.4 BSG Conference.** Notice was given of this event to be held at the Sheffield Hilton Hotel on Thursday 31<sup>st</sup> January and Friday 1<sup>st</sup> February 2008. Trustees agreed that a place should be booked for the BCRT display stand. Several Trustees expressed an interest in attending one of the days.

Registration form to be sent out to them.

**ACTION – Ros**

## 10. WEBSITE MANAGEMENT

There had been 7325 hits to date.

**10.1 Publication of Trustees' Minutes** – As previously agreed, Ros to prepare the Minutes, having been agreed and signed at each meeting, for publication and send the final copy to Kate for the website.

**10.2 The Stories.** Ros drew attention to the list of “common themes” at the top of each of the two sets of Story pages. She suggested that they omitted any guidance to readers that they do not only include factual information but also contain much personal and emotional content about the patients and their family's experience. Ros to draft the wording. **ACTION - Ros**

This prompted discussion on **the way that BCRT responds to new contacts** which requires great sensitivity for people who are often going through challenging and painful times. It was decided that Kate should pass contacts on to an identified list of trustees and others who are having or have had similar experiences so they could make the link in ways that are as well matched and appropriate as possible.

**10.3 The Forum.** (See also 10.4 in last Minutes) To date there were 21 members of the main BCRT Forum site and 10 members of the patients' forum, providing a way for them to link up and support each other.

**10.4 The BCRT Online Shop.** Thanks were recorded to Kate and Alan for setting this up with orders now coming in for the 3 styles of Christmas cards, badges, T-shirts, sweatshirts, hoodies and Sheila Belshaw's book.

**10.5 Spam.** Recipients of emails via the [info@bonecancerresearch.org.uk](mailto:info@bonecancerresearch.org.uk) all reported that they were also receiving a large amount of inappropriate spam. Alan offered to try to reduce this.

**ACTION - Alan**

## 11. PATIENTS' AND SUPPORTERS' CONFERENCE

### 11.1 The Findings from the Morning and Afternoon Discussion Groups – Conference 2007.

- Trustees and some delegates had been disappointed that there had not been enough time for feedback during the day but it was agreed that it would have been inappropriate to cut short other aspects of the programme that were so well received. This to be considered when planning the next conference programme.
- It had been hard after the event to collect notes on the feedback from all the group facilitators. Could a system be built in to make this easier for them another time?
- Having collated the feedback, Ros reported that there had been three main areas about which all the groups had been concerned and hoped for support from BCRT:-

**Area 1. Education.** The universal question “why?”, numerous incidents of delayed diagnosis and the search for greater understanding for themselves, their families and medical practitioners. The many interesting suggestions made for educating medical personnel and the general public will be examined thoroughly by BCRT's Trustees.

**Area 2. Practical Support.** Difficulties in finding appropriate support to get back to normal life as affected by postcode variation within education, benefits, equipment, social support and counselling. A harder area for BCRT to influence but it was suggested that the charity might provide channels through which patients and families could share procedures and the outcome of their actions.

**Area 3. Emotional Support.** The common need to meet and share the whole experience with others (patients, parents, extended family and friends), who are going / or have been through it. A clear role for BCRT to provide ways for people to link up with suggestions of online blogs, forums etc.

- Trustees to study suggestions made by each group ready for the next meeting. **ACTION - All**

**11.2 The Findings from individual Evaluation Sheets – Conference 2007,** Ros reported that:- a total of 20 evaluation sheets had been returned, of these 1 was anonymous and 1 was filled in by two people together, 17 were completed on the day and 3 were returned later.

The findings from these helped Trustees to make the decision to hold another Conference next year.

### **11.3 BCRT Patients' and Supporters' Conference 2008.**

- **Date** To try for the similar time in July, as this year.
- **Venue** Trustee and delegate feedback felt that Leicester was well placed geographically and that the Hilton Hotel had served us well – so to repeat this format.

**ACTION – Ros** to investigate availability.

- **Content** It was agreed that the following aspects should be repeated:- to include personal stories (possibly 4 rather than 6 this time), to receive a report on one of the pieces of research that BCRT is funding, to provide time and opportunity for people to meet informally and to ensure time for group feedback to all.
- **Topics** It was noted that care must be taken to prepare speakers to present their subject appropriately for the type of audience. A number of topics were suggested for consideration and exploration:-

Amputation and limb fitting ( the speaker had been unable to attend this year),

Side effects of chemo etc.

Information on how and from where to get support, benefits etc.

New Drugs,

Fundraising,

Delayed Diagnosis to follow up on this year,

Advocacy.

- **A Motivational Speaker** to end the day was favoured as this had been so successful. A few suggestions were made.

**ACTION – All**

### **12. ANY OTHER BUSINESS**

None.