

**BONE CANCER RESEARCH TRUST**

**MINUTES OF MEETING OF TRUSTEES  
held on Sunday 28<sup>th</sup> June 2009  
at Sopwell House, St.Albans.**

**1. PRESENT**

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

**Officers:-** Ros Francis (Clerk to the Trustees), David Fisher ( Head of Fundraising).  
Lauren Heslop (Administrator), Alan Johnston (Website Manager).

**APOLOGIES**

**Trustees:-** Patricia Smith, Nick Bones, Sally Hurst.

**A MEETING OF THE TRUSTEES ONLY had been held prior to the main meeting.**  
The main points from this meeting were circulated to Trustees as Action Points the next day.

**2. MINUTES OF MEETING OF TRUSTEES held on 2<sup>nd</sup> May 2009.**

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

**3. MATTERS ARISING FROM THE MINUTES not covered by Agenda items.**

**3.1 The appointment of Patrons.** Following agreement at the last meeting that Nick Bones should be invited to become a patron of BCRT, Mike Francis reported that Nick had been delighted to accept. It was proposed that following his well received contribution to the Conference, Professor Sir Alan Craft should also be invited to become a patron. It was agreed that Mike would contact him once the idea had been agreed by the two absent trustees. **ACTION - Mike**

**3.2 Presentation from Newman's Own Foundation.** Due to the initiative of a friend of Guy Francis and work done by David Fisher on completing the application form, BCRT had been presented with a cheque for \$10,000 at a prestigious reception in London attended by Mike and Ros Francis.

**3.3 Dollar and Euro Accounts.** Gill Pilcher presented the paperwork for trustees' signatures towards opening these accounts so that monies received can be saved there until the exchange rate is favourable. **ACTION - Gill**

**3.4 The Reporting of Meetings.** Gill Pilcher had not been present at the May meeting (the first she had missed). She commented on the fact that in spite of the full content of the Minutes and talking to fellow trustees, she appreciated how hard it is to keep up to date with all BCRT's business when you have missed a meeting.

All Trustees agreed that an Action Sheet sent out by the Clerk immediately after a meeting, was very helpful and effective. **ACTION - Ros**

**4. CORRESPONDENCE**

None. The Clerk reported that once the computer system is ready and all the Trustees are able to access the Trustees' section, any relevant correspondence received will be posted there.

## **5. TRUSTEES**

**5.1 The Appointment of Trustees.** It was agreed that Ian Lewis should continue to search for a professional to take the place of Rob Grimer as a trustee with medical expertise.

**ACTION - Ian**

All Trustees to continue to think of prospective trustees with areas of expertise that could enhance the effectiveness of the current team.

**ACTION – All**

**5.2 The Constitution of BCRT Committees.** The draft table of committees and their membership was re-examined with amendments made since the last meeting and was agreed by all Trustees present.

**5.3 Terms of Reference (TOR) for Committees.** The draft overall TOR for all BCRT Committees was re-examined with amendments made since the last meeting and was agreed by all Trustees present. It had been decided at the previous meeting that each committee should prepare its own individualised TOR with reference to the overall TOR but these were not ready. It was decided that the Chairmen of each committee should submit a draft TOR for their committees by 1<sup>st</sup> August to form part of the preparation for the next Strategic Planning Meeting to be held at the end of August. It was agreed that the Clerk should have sight of all these to ensure their compatibility with the main, overall TOR and that all these drafts should be ratified at the next full meeting of Trustees.

**ACTION – all Committee Chairmen**

## **6. STRATEGIC PLANNING COMMITTEE**

The Head of Fundraising was continuing to work on the five year Business Plan.

As noted in Section 3.4 above, it was decided to aim for the next meeting to be held at the end of August.

**ACTION – David**

## **7. FINANCE COMMITTEE**

**7.1 Bank Balances.** The total, within the current accounts, the 14 day and the deposit accounts at 25<sup>th</sup> June - £704,917.11.

**7.2 Deposit Accounts** Following the decision made on 4.12.08 to open investment accounts for 6 months, Gill Pilcher had notified Trustees by email on 11.05.09 that this period was coming to an end. Having ensured that there were sufficient funds available for the on-going running of the charity, 5 Trustees had replied agreeing that the money be put into new accounts for the same period of 6 months. It was suggested that a longer term strategy should be discussed at the next full meeting of Trustees.

**ACTION -**

**Gill**

**7.3 Appointment of Accounting Technician.** It was reported that Maggy Barnes had been appointed and would be working one day a week but initially 2/3 days. Gill Pilcher to be in the office to lead Maggy's induction on her first two days – 3<sup>rd</sup>, 4<sup>th</sup> August. It was agreed that with Gill's guidance, Maggy would be responsible for setting up and running all the systems that she deems necessary to establish the efficient and effective management of BCRT's finances.

**ACTION – Gill**

It was also agreed that the Finance and Management Committees would liaise to carry out on-going support and reviewing.

**ACTION – Finance and Management Committees**

**7.4 Reporting of BCRT's Financial Matters to Trustees.** It was hoped that by the November meeting, with Maggy Barnes in post and the on-going use of the Paxton system, it may be possible to have a clearer picture. Trustees agreed that as soon as the systems are in place, they would like to

receive monthly reports. It was also felt to be important that consideration should then be given to the way the accounts are presented.

**7.5 The Budget.** Roger Paul to continue to work on this and to liaise with relevant others.

**ACTION – Roger**

## **8. FUNDRAISING COMMITTEE**

**8.1 Head of Fundraising's Report.** This had been received by Trustees ten days prior to the meeting giving time for questions to be asked and for David Fisher to reply to all via email.

- Reporting of fundraising income. David explained that fundraising amounts are reported in two groups – 1) from trustees' charities and groups 2) supporter groups. He said that like all trustees and staff, he awaited the availability of reports from the Paxton system in order to be able to give and receive a clearer picture.
- Leeds 10k Run. Trustees expressed disappointment that BCRT's entry this year had dropped from 150 to 50 runners. It seemed that all charities had struggled to sell places so the overall entry had been down but it was agreed that efforts must be made to turn this round for BCRT next year in order to try to gain recognition as one of the official charities and so that no loss is incurred by purchasing places and t-shirts that are unused.
- Berlin to Belgium Cycle Ride. David assured Trustees that he would circulate a full report on this event once all the funds raised have been received. **ACTION – David**
- London Marathon 2010. David reported that a number of people had contacted BCRT asking for places. He reminded Trustees that the cost of places is prohibitive.

**8.2 A Recognised BCRT Annual Event.** Gill Pilcher laid down a challenge to all trustees and staff to try to think of an event that could become annual and widely accepted as specifically about BCRT.

**ACTION – All**

## **9. MANAGEMENT COMMITTEE**

**9.1 Information Officer** Interviews to be held on 4<sup>th</sup> August for this 1-1.5 day a week post. This would probably involve remote working with possibly one day a month in the office. Ian Lewis to lead the interviews with two other trustees. Ian asked all trustees to become involved in what BCRT wants and to send him their thoughts about the role and specimen questions that might be asked of the candidates.

**ACTION - All**

**9.2 Communication.** It was reiterated that communication is not easy between all those with on-going involvement in BCRT and the systems available need to be used well by all. The custom of "reply to all" emails helps in that those involved can carry out a conversation and know the views and points raised by others. It was suggested that greater use should be made of adding "response by" to certain items. It was felt that some system should be set up so that all staff and trustees can be aware of when anyone is on holiday / not in the office and so is unable to respond.

**9.3 Voluntary Helpers.** It was noted that Tabitha Hazeldine, PR student, had made a valuable contribution in supporting the office staff with preparation for Awareness Week and was continuing with the follow up work. She was enjoying being part of the team.

### **9.4 Office Matters.**

- **See Section 7.1 for appointment of the Accounting Technician.**
- **Office equipment.** It was stated that the third desk in the main office was now fully operational and being used by volunteers. It was agreed that Gill Pilcher / Ros Francis would purchase a fourth computer from "Computers for Charity" and other relevant equipment to set up the desk in the Meeting Room ready for the Accounting Technician.

This would be funded from the budget previously agreed by trustees as part of the move into the larger suite of offices.

- **Feedback on Staff Appraisals** was carried out during the “Trustees Only” meeting held before the main meeting.

## **10. CAMPAIGNING COMMITTEE**

**10.1 Awareness Week meeting with MPs.** Mike Francis and John Dealey had previously reported to Trustees that they attended a meeting in London with Mike Penning MP, Shadow Health Minister and Paul Harrison, Parliamentary Researcher. It had been a valuable meeting in raising awareness of bone cancer and of BCRT, particularly in the light of a possible General Election next year. They were happy to receive an updated Early Day Motion which read as follows:

*“That this House supports Bone Cancer Awareness Week from 20<sup>th</sup>. to 27<sup>th</sup>. June 2009, coordinated by the Bone Cancer Research Trust which promotes research into the causes and treatment of Primary Bone Cancer; notes that this disease most commonly affects children, teenagers and young adults and that research published in 2009 shows that UK survival for childhood bone cancer has not improved for 20 years; further notes that early treatment for bone cancer can improve the outcomes for patients but that the disease is often misdiagnosed as growing pains or a sports injury by Medical Professionals and GPs; and urges that, when effective new treatments are licensed, they should be made available as a matter of urgency; and congratulates the Bone Cancer Research Trust in its endeavours to raise awareness to ensure that this life-threatening illness affecting over 400 children and young people every year, is given the priority in the NHS that these vulnerable patients deserve.”*

Unfortunately it had not been possible for this to be presented in the House as last year but all the 82 MPs who signed last time had been recontacted to keep BCRT in their minds.

## **11. INFORMATION AND MEDIA COMMITTEE**

Due to the pressure of time, some topics listed on the Agenda were carried forward to the next meeting.

**11.1 Reflections on the BCRT Conference held the previous day.** It was agreed that Sopwell House had been an excellent venue and that it might be an idea to return again next year. The delegates’ evaluation sheets to be collated and Ros Francis to send a separate sheet to all Trustees and staff to record their immediate thoughts so that all information will be available when planning for next year. **ACTION - Ros**

**11.2 The November Edition of the Newsletter.** Mike Francis and Lauren Heslop to meet to draw up a timetable of the stages of production which would be published to Trustees so that all who want to, can be involved and will know how the draft is developing towards distribution in November.

**ACTION – Mike, Lauren**

**11.3 BCRT presence at Conferences.**

- **Conference recently attended with the BCRT Display Stand-National Alliance of Childhood Cancer Parent Organisations (NACCPO) Conference held in Bournemouth on 20th June 2009, attended by Gill Pilcher and Alan Johnston.** Gill reported that several ex-patients had spoken about late diagnosis and she has a copy of a DVD made at Christie’s Hospital called “Sometimes it’s Cancer” – ask her if you would like to see it. There had been a question and answer session with Mark Simmonds, a shadow health minister, which was very positive and was confirmed by the meeting that John Dealey and Mike Francis had with another of the shadow health ministers. Sue Ablett had spoken, asking groups to consider sponsoring “Contact Magazine” after 2010. Gill is still trying to obtain a delegates list to follow up on contacts made.
- **British Association of Health in Higher Education Conference to be in Sheffield from 15<sup>th</sup>-17<sup>th</sup> July. Chris Copland (a parent and supporter) and Ros Francis hope to obtain a site for the Display Stand on one of the days.** Thanks are due to Chris Copland for

spotting this opportunity to raise awareness of bone cancer at this conference which will be attended by GPs and medical professionals who work in universities across the country.

- **Paediatric Oncology Nurses Forum to be held at York University and will be attended on 20<sup>th</sup> July by Mike Francis and on 21<sup>st</sup> July by Ros Francis.**

**11.4 Pfizer Excellence in Oncology Awards.** The possibility of entering this was again mentioned with the closing date being 31<sup>st</sup> August. It was left that all should think how / if BCRT might enter.

**ACTION - All**

## **12. SUPPORT COMMITTEE**

It had been agreed that Gill Pilcher will chair this group in Sally Hurst's absence for the time being. As for other committees, this group to begin to work on its Terms of Reference and objectives. Also to continue to examine the support systems run by other groups.

## **13. SCIENTIFIC ADVISORY PANEL**

### **13.1 Update on the fifth round of applications for research funding from BCRT.**

Ian Lewis reported that not all the reviewers had returned their comments and scores for the six applications that had been received. He felt that there may be four good projects but he was not yet able to make firm recommendations to the Trustees. As soon as he was in a position to do so, he would email these out and the Trustees could then discuss by email and make a decision on the financial implications.

**ACTION – Ian**

**13.2 Local Therapy in Ewing's Sarcoma.** At the last meeting Ian had suggested that it might be necessary for BCRT to fund the British contingent to attend the follow up conference in France. He reported that this may not be needed and will keep the Trustees in touch.

**ACTION – Ian**

### **13.3 Could BCRT “commission research” rather than “call for research”?**

- Ian suggested that our focus on “delayed diagnosis” might be good but maybe not enough to grab interest. A more positive approach could be “improving time to diagnosis – could this improve the outcome?” He wondered whether BCRT could do some focused work on this perhaps with joint funding with another charity – Trustees agreed that Ian should continue to investigate this idea. **ACTION - Ian**
- Ian suggested that another positive approach could also be in regard to Action Research around delayed diagnosis. He suggested that whilst working with GPs, we should be seeing them as the solution – not that they are the problem.
- Ian felt that BCRT could make a bigger impact if not working on its own. It was noted that BCRT already has a good relationship with Cancer 52, Sarcoma UK, TCT and the Rarer Cancers Forum.

### **13.4 A Strategy Meeting for BCRT's Scientific Advisory Panel proposed for the Autumn.**

Ian reported that he would like to set up this meeting for 10-15 people involved with the SAP and possibly some of the professional speakers from the Conference. Ian felt that he might not chair it as he would like to facilitate. He requested a budget for the event of £2,000. The Trustees welcomed this event and agreed to the amount. Ian to keep Trustees informed as the planning develops.

**ACTION - Ian**

**13.5 Mifamurtide.** Ian reported that now that IDM had been taken over by Takeda Millennium, the new company was preparing a further submission to NICE.

## **14. DATES OF FUTURE MEETINGS IN 2009 WERE CONFIRMED.**

