

BONE CANCER RESEARCH TRUST

MINUTES OF MEETING OF TRUSTEES held on Saturday 26th September 2009 at the Hilton Hotel, Leicester.

1. PRESENT

- Trustees:-** Mike Francis (Chairman), John Dealey (Deputy Chairman), Gill Pilcher, Roger Paul, Ian Lewis.
- Volunteers:-** Ros Francis (Clerk to the Trustees), Alan Johnston (Website Manager).
- Employees:-** David Fisher (Head of Fundraising), Lauren Heslop (Administrator), Maggy Barnes (Accounting Technician).

APOLOGIES

- Trustees:-** Patrick Hardman, Patricia Smith, Fiona Foley, Sally Hurst, Nick Bones.

A MEETING OF THE TRUSTEES ONLY was held prior to the main meeting.

2. MINUTES OF THE MAIN MEETING OF TRUSTEES held on 28th June 2009.

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

3. MATTERS ARISING FROM THE MINUTES

3.1 Patrons. Trustees were delighted that two people had agreed to join Mark Woods, paralympic gold medal swimmer, in becoming patrons of BCRT. Sir Alan Craft, Emeritus Professor, Northern Institute for Cancer Research, Newcastle University joins with eminent medical and research experience. Nick Bones, a founding member of BCRT and out-going Trustee joins with his personal experience of osteosarcoma; playing football in the England amputee team for nine years; and also his on-going work in disability benefits.

3.2 Two Conferences had been attended with the BCRT Display Stand:-

- **British Association of Health in Higher Education Conference held in Sheffield from 15th - 17th July attended by Chris Copland (a parent and supporter) and Ros Francis.** Thanks are due to Chris Copland for spotting this opportunity to raise awareness of bone cancer at this conference mainly attended by GPs who work in universities across the country. A cancellation had been obtained for their 3rd day providing space for the BCRT Display Stand. This was very well received and useful contacts were made. One of their lectures had been on “Knees” from an orthopaedic surgeon – should we try to encourage them to extend this topic with a speaker on bone cancer awareness next year?
- **Paediatric Oncology Nurses Forum held at York University attended on 20th July by Mike Francis and on 21st July by Ros Francis.** Again, a good opportunity for awareness raising, much interest in the research side of BCRT and some useful contacts made. During a workshop led by the “Teenagers and Young Adults Cancer” group (TYAC) with which BCRT has a link, Ros had seen the excellent DVD “*Sometimes it’s Cancer*” made for Christie’s Hospital, Manchester by *jimmyteenstv*, Leeds. This had been made by young cancer patients and survivors to be shown to young people to raise awareness. In another session, late diagnosis came up in discussion and gave Ros the opportunity to draw attention to BCRT’s Awareness Week theme and aims and also to ensure that all present had a poster with BCRT contact details included.

- Gill Pilcher made Trustees aware that she had a copy of the DVD mentioned above for Trustees' use.

3.3 Notice was given of the next NACCPO Conference – to be held in Oxford on 19th June 2010.

3.4 Pfizer Excellence in Oncology Awards. It had been decided that BCRT would not enter this year but might consider it in the future.

4. CORRESPONDENCE

4.1 Notice given of the next Wrigleys Charity Governance Seminar – 22nd. October 2009 in York.

4.2 June – August edition of Social Economy bulletin circulated.

4.3 Copies of the Autumn edition of Contact Magazine available for those who wanted one.

4.4 Other e-bulletins etc received to be posted on the Trustees section on the server.

5. SCIENTIFIC ADVISORY PANEL

5.1 Decisions on the fifth round of grant applications.

- Ian Lewis reported that the number of applications received had gradually increased, this time there had been six. About 20 independent reviewers had been involved and it had not been easy to find enough people who were available to do this. There had then been some delay in receiving back all the responses. He reminded Trustees of the scoring system as follows:- Over 3.5 – internationally competitive; 3 nationally competitive; 2-3 not good enough. Further questions had been asked of some applicants and they had replied quickly as they were hoping to be accepted.
- The SAP recommended to Trustees that 5 of the 6 research projects should be accepted for their aims and quality of presentation. This totalled £161,821, averaging approximately £30,000 each which BCRT is currently offering. Members of the Finance Committee were confident that this amount could be committed to research but it was decided by all Trustees that the next opportunity to apply for research grants should not be offered until Spring 2010.
- Ian felt that BCRT had become a bit stuck on funding pump-priming research so that the range was not as wide as he had hoped. He thought that next time maybe the amount offered per grant could be raised to £100,000. If this was to be done he said more advice would be needed than just from himself, Rob Grimer and Jeremy Whelan. Ian felt there was also the possibility of doing commissioned research and would like to attract other areas. He suggested, for example, a serious piece of commissioned work focused on times to diagnosis.

5.2 Arrangements for the sixth round of grant applications.

The next applications to be invited for a closing date in April 2010. Ian felt that maybe only a couple of projects might be funded then but they may be bigger. The website to invite enquirers to watch for further details in January.

ACTION – Lauren, Alan

5.3 Completed and on-going research projects. Ian was asked how we should be publicising our research other than in medical circles. A suggestion was that a group of projects could be focused on during Awareness Week.

5.4 A strategic planning meeting for the members of the SAP.

See Minutes dated 28th June 2009, Section 13.5, where Ian had proposed holding this meeting and Trustees agreed to fund it with £2,000. It will be held on Tuesday 8th and Wednesday 9th December either in Leicester or Birmingham. Points for discussion will include:- where should BCRT go with its funding strategy? What emphasis should be put on

which types of research – translational, clinical etc?

5.5 The National Institute for Health Research (NIHR).

- Ian announced that BCRT had met the criteria for NIHR partnership status for its Project and Pump Priming Grant funding stream. He explained that if BCRT is funding a clinical trial, the NHS would support certain costs, i.e. if 100 people had to have an x ray every 3 weeks as part of the research, this cost would not need to be included in BCRT's funding. Researchers will need to know about this so amounts are adjusted accordingly and appropriate arrangements made.
- It was agreed that Lauren should ask NIHR for permission to put its logo on our website to show that BCRT is now in this partnership. **ACTION – Lauren**

5.6 The appointment of Dr. John Newby, Information Officer.

- Ian Lewis was delighted that Dr. John Newby would be starting in the post of Information Officer from 1st October. He would be making his first visit to the Office on 6th October for a meeting with Ian to establish his work plan.
- He will be working from home, coming into the office once a month.
- Work can now begin towards BCRT becoming the known authority and source of information on bone cancer.

5.7 Mifamurtide.

- With Takeda Pharmaceuticals Ltd. involvement, Ian was hopeful of a launch in January 2010.
- He said that BCRT would be listed as a Community Stakeholder in Takeda's Annual Report. This could possibly lead to funding from them.

5.8 Update on the next Local Therapy in Ewing's Sarcoma Meeting.

This is due to take place in France and will probably be early next year.

6. TRUSTEES

6.1 Planning for additional Trustees.

- Ian Lewis reported that he had not been able to make progress with finding a potential Trustee with a medical background. There are professionals who are very supportive of BCRT and its aims and would be / are pleased to contribute to the research side but would not be able to give up time to the on-going running of the charity.
- It was decided that an advertisement should be put in the forthcoming Newsletter and on the website. **ACTION – Lauren, Ros, Alan**
- Two interested GPs known to Trustees to be contacted to alert them to the advert. **ACTION – David**

6.2 Visit from Natalie Townsend who was shortly to be holding a charity event for Ewing's Sarcoma in Leicester. Natalie reported that she had made some excellent contacts whilst publicising the event and asked for help to make the most of these.

David to follow up with British Gas, Leeds.

ACTION –David

Lauren to be in close contact to support Natalie.

ACTION - Lauren

6.3 Dates for BCRT meetings and events in 2010 were agreed:-

There will be four full Trustees' meetings in the year with Awareness Week moving to 18th-25th September and the Patients' and Supporters' Conference to be held on Saturday 9th October.

6.4 On-line Calendars.

Two on-line calendars were proposed for Trustees and Employees' use.

One for all Trustees and Employees. The intention is that everyone should learn to access this themselves and refer to it regularly - the Trustees to show when they will not be available and the Employees to show when leave and holidays are booked. Gill to send out user information.

ACTION - Gill

- See 8.6 below for details of the second calendar.

6.5 Draft Terms of Reference for Committees (TORs).

It was noted that there was not enough time to study the seven draft TORs. These would therefore be taken as a priority for discussion and agreement at the next meeting. Ros to ensure from all Chairmen, that their draft TOR had been agreed by members of the committees and were ready.

ACTION – Ros, Committee Chairmen

7. FINANCE COMMITTEE

7.1 Bank Balances. The total, within the current accounts, the 14 day and the deposit accounts at 25th September was £ 786,334.

7.2 Accounting Technician, Maggy Barnes was welcomed and reported to Trustees that she had been learning about the organisation and where to find the figures she needed for her work.

- She was coding and working to bring all BCRT's business up to date on the Paxton system. Many questions were arising and she was working closely with Roger, Chairman of the Finance Committee.
- At the same time, Maggy was beginning to put in place procedures and policies, subject to Trustees' approval, so that everyone would be able to move forward in a clear and consistent way.
- Trustees recorded their appreciation of all that Maggy was doing.

7.3 Budget 2009 – 2010.

Roger Paul had circulated this prior to the meeting. He said it was very much in draft and that he would welcome comments and ideas on the presentation before he and Maggy met for further work on it in a few weeks time.

ACTION - All

7.4 Discussion on a possible change of bank.

- Gill Pilcher reported further operational difficulties that had occurred with the Co-Operative Bank.
- Maggy advised on other banks with which she had been involved in her work and Gill had received comments from some of the charities in the NACCPO group about the banks they use.
- Gill had sent out information from her research into the CAF Bank asking all Trustees to look at the website and read the details with BCRT's needs in mind. It was said that the CAF Bank is only for charities and as it is a charity itself, some transactions are free of charge. The deposit accounts could be left where they are and the dollar and euro accounts could also be elsewhere. It was suggested that we could have an overlap between banks and gradually make the change. It was also said that now would be a good time to make the decision to change as Maggy is only just getting to grips with BCRT's situation. With her work and a new bank it could be good opportunity to really get BCRT's financial base in good order.
- It was agreed that Gill should open an account with the CAF Bank's required initial amount of £1,000.

ACTION – Gill

8. FUNDRAISING COMMITTEE

8.1 Report from the Head of Fundraising. This had been circulated previously.

- Trustees were pleased to see more information on all the fundraising activity but asked that some alterations should be made to the presentation for ease of reading. It was felt that the

online calendar that Alan is setting up onto which David should be able to enter every event that comes into the office, will be very helpful. This will help to ensure that all events are included and will enable Trustees to see whether anything is happening in their areas so they can attend and give support. **ACTION – Alan, David**

- Berlin to Brussels Cycle Challenge. A significant amount of sponsorship money appeared not to have been received to date and some teams had split funds raised with other charities. As he was still waiting for some of these funds David had not yet presented his final report on the organisation and outcomes of the event. Trustees asked that they should receive this by the end of the following week. **ACTION – David**
- Charitable Trusts. David reported that he had set up a database of Trusts that he had already or was planning to contact. He explained that the time from first contact to any response can be several months. Trustees asked to see the list of charitable trusts. **ACTION – David**

IAN LEWIS HAD TO LEAVE AT THIS POINT SO THERE WAS NO LONGER A QUORATE NUMBER OF TRUSTEES PRESENT.

- Companies. David reported that he was again working with a graduate team via Watson Wyatt who support 7/8 charities a year of which BCRT is one.
- The types of events being encouraged and held. Gill Picher suggested that instead of putting so much emphasis on runs, BCRT should try to also think of focusing on completely different types of events. David Fisher said that the Great Swims were now being developed. Lauren Heslop suggested that we should try to target ideas on specific population groups. It was noted that we had done that with the circulation to schools about Bake a Cake events but that June unfortunately had not been a good time for schools to cope. Ros Francis suggested some initial thoughts around food events i.e. Bones Barbecues, Bones Brunch, etc. Mike wondered whether any joint promotions could be set up with local hospitals etc . **ACTION - It was felt that time should be set aside at a future meeting for a focused brainstorming session by ALL.**
- Bake a Cake Events. These had raised £15,670. There seemed to be an assumption that Bake a Cake might be repeated next year. Decision about this and the best time of year to be made. **ACTION – All** John Dealey said he would be encouraging it at work again following the enthusiasm this year. It was noted that Trustees would be interested to see a list of the actual Bake a Cake events held with details of the types of supporters holding them, where in the country as well as the amount raised by each. **ACTION – David** It was felt that the lead time should be longer in order to involve celebrities and make the most of their support. The Bake a Cake Guide was a very good booklet and a lot of work had gone into it but sadly it had not been seen by enough people as it was only sent out on request following receipt of a taster poster. It was thought that the impact of the celebrity content etc could have attracted more people to want to join in if this had been the advertising and guide document all in one. It was noted that none of the Bake a Cake events had yet been added to the Recent Events Section of the website and / or to the Awareness Week 2009 section. **ACTION - David**
- Forthcoming Events mentioned:- Royal Parks Half-Marathon. David to ensure that all 100 runners and their supporters know where to find the BCRT area in the Charities' Marquee. **ACTION – David**
- Places for the London Marathon 2010. Further research had clarified that it is practically impossible for BCRT to get its own places as the cost is prohibitive. It is also very costly to advertise appropriately to try to pick up people who have a place but are looking for a charity to support.

- Credit Suisse event at Canary Wharf with charity exhibitions – Mike Francis to be there with the BCRT Display Stand, John Dealey to try to join him for part of the time.
- David Fisher reported that he had now registered BCRT with Virgin Money Giving – similar to *justgiving.com* but with reduced charges.

8.2 Report on Awareness Week.

- It was felt that there had been less overall newspaper coverage than last year, partly due to the focus there had been on certain families in 2008.
- David felt that BCRT had been grateful for the support gained from Weiss Comm but wondered whether this could have been better co-ordinated with the office staff so that they would have focused more on local press coverage and the agency dealt with wider matters.
- It was agreed that much advanced, persistent planning is required with a great deal of follow-up in order to have a good impact.
- From the parliamentary side, the untimely and sad death of Nick Bojas had affected BCRT's ability to move political contacts forward this year. However, Mike Francis and John Dealey did have a very positive meeting in London with Mike Penning MP, Shadow Minister of Health, and his Parliamentary Researcher, Paul Harrison.
- It was noted that under the heading of Awareness Week 2009 on the website, it was still being advertised as a forthcoming event and needed updating. **ACTION - ?**

8.3 Christmas Cards. This year's three new cards were available for sale :-

Penguin drawn by Claudia Paul who lost her battle with Ewing's Sarcoma in 2006 aged 17;
Robin Feeding photographed by BCRT supporter Adam Gill;
Star by Matthew Henderson. Packs of last year's cards also for sale :- The Three Kings, Warm Welcome and Snowdrops.

- David Fisher distributed batches to Trustees who had requested them.
- It was decided that David would prepare a flyer /order form for these cards as well as the ones in stock from last year. This to be included in the forthcoming mailing out of the Newsletters. **ACTION – David**

8.4 T-Shirts and Running Vests.

- Trustees were asked to begin to think about the colour scheme of these for the future as they are currently not easy to spot amongst the crowd and consequently are not as good for awareness raising as they might be.
- It was agreed that David would try to distribute some of the surplus Leeds 10K 2009 t-shirts through the local Free-Cycle scheme.

8.5. Name Badges.

Roger Paul asked that badges stating name and roles should be given to all Trustees, key volunteers and employees to wear at events attended. **ACTION - David**

8.6 Events' Calendar.

(See also 6.4 above). A second calendar is being prepared by Alan Johnston, to be used by the Head of Fundraising for events. As soon as notice comes into the office of an event it will be put onto the calendar so that Trustees can see that something is taking place in their area and that they might be able to attend to add support. **ACTION – Alan, David**

9. SUPPORT COMMITTEE.

- Gill Pilcher reminded Trustees that the Support Committee will be looking for people willing to give support and for those who need support and details of these could all be stored on spreadsheets.

- Databases were discussed. Would the Support Committee need to have a separate one from the main office one? Could the office one be altered to take more categories of information and also in a way that particular groups could be seen on request?

ACTION – David, Alan to liaise.

- When ready, the Support Committee would like to have a page on the website.
- There was discussion about other support available. It was thought that there were not many people talking on the Forums but that those who did, valued it. Many BCRT supporters seemed to be on *Facebook*.

10. INFORMATION AND MEDIA COMMITTEE

10.1 Conference 2009.

- Ros Francis reported that she had collated two sets of evaluation sheets – one set from the conference delegates and the other from trustees, key volunteers and employees. She had also written a report on the discussion groups and Question Time. It was felt that these should be sent out to Trustees when planning for the next Conference is about to begin.
- It was noted that the section on the website had not yet been changed to include the Report on the Conference that had been prepared. It was asked that delegates and supporters should be able to see some feedback on their contributions made to the event through the discussion groups, Question Time and evaluations. **Action / Decision to be made at next meeting**

10.2 Conference 2010.

- Following much discussion and negotiation, it had been decided to hold this at Sopwell House, St. Albans for a second time. Due to availability problems, it had been necessary to book Saturday 9th October 2009. However, it had been agreed that in future, the BCRT Conference would always be held at the end of June / early July as this is a time when it should be easier to book good professional speakers.
- As a result it had been decided that planning should start early so that professionals might not already be booked up as October is the season for medical conferences.

10.3 Autumn Newsletter 2009 – BCRT's fifth newsletter.

Lauren Heslop had been working very hard on the preparation of the Newsletter but inevitably a few writers had proved illusive and adjustments had had to be made to the initial plan. It was expected that the almost final draft would be sent to Trustees two or three weeks before the printing date for comment and checking. It was planned that the preparation for posting would be carried out during the week beginning 26th October.

10.4 The Website.

- Alan Johnston pointed out that there was currently some confusion about the system for passing items to him to be put onto the website. It was said that the Information and Media Committee is the point of contact. **Confirmation to be made.**
- It was also known that the office staff would like to be able to put information on events straight on themselves and the question had been asked as to what the arrangements would be for John Newby with information that he will be preparing. **Discussion / decisions?**
- Alan explained that it was not possible for just certain sections of the website to be accessed by others and that this whole area needed proper discussion and decision. **ACTION for next meeting.**
- It was reiterated that it is so important to keep the website up to date so that visitors to the site have confidence in it. It is also matters that people who have held events can see themselves and the results of their efforts as soon as possible afterwards.
- Advertising supporters' sales on the website. The following contacts had been made by supporters asking for BCRT to advertise fundraising activities for BCRT that they were offering:- A BCRT supporter who has a cottage that is available for patients and their

families would like BCRT website users to be able to read about it there; The Anthony Pilcher Bone Cancer Trust is now selling a book written about Anthony; maybe Hannah Millington's Calendar could be advertised. It was felt that this should be done – Alan to work out how to do it and where to present it. **ACTION - Alan to advise.**

11. CAMPAIGNING COMMITTEE

11.1 National Cancer Intelligence Network (NCIN), Sarcoma Site-Specific Clinical Reference Group.

Mike gave notice that he would be attending this meeting in Birmingham on Thursday 15th October.

11.2 BCRT in Ireland. All present hoped that the BCRT Trustees in Ireland would be able to attend the next meeting to report on the progress they have been making in working towards a clearer BCRT presence in Ireland.

12. MANAGEMENT COMMITTEE

12.1 Report on recent IT difficulties in the office.

- Alan Johnston explained that five different problems had occurred at different times and each had been sorted out.
- The problems with Maggy's computer had been solved by the suppliers sending a replacement.
- Alan was aware that the facilities on the third computer in the main office were not as comprehensive as the others so hoped to be able to give this attention at some point.
- Alan explained that when he is at work he does not have access to the BCRT server. He said that he and David had been obtaining quotes for maintenance of the server etc. They had one that seemed good and another which was much more expensive. They would be continuing to look into this. **ACTION - Alan, David**

12.2 CRB Checks for BCRT employees. It was noted that although the appropriate paperwork had been received, nothing further had been done. Mike reported that the Wilf Ward Charity had agreed for BCRT to use them. **Some action required**

13. STRATEGIC PLANNING COMMITTEE

- Trustees were aware that this committee had not met since February. It had been hoped that John Dealey had found some professional advice through Unite to help with formulating the Business Plan so the meeting had been put on hold until this was arranged. However it had fallen through.
- It was felt that the work on the Business Plan should be moved on.
- It was decided that David Fisher would email Ian Lewis for some possible dates at the end of October / beginning of November.
- It was noted that any information taken from the committees' Terms of Reference and Objectives for insertion in the draft Business Plan, would be in draft only as they had not yet been passed by the full board of Trustees.

14. THE DATE OF THE NEXT MEETING WAS CONFIRMED.