

BONE CANCER RESEARCH TRUST

MINUTES OF MEETING OF TRUSTEES held on Sunday 29th June 2008 at the Leicester Hilton Hotel following BCRT's second Conference held the previous day.

1. PRESENT

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

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

Supporters:- Marian Dealey

APOLOGIES

Trustees:- Rob Grimer, Patrick Hardman, Patricia Smith, Sally Hurst, Fiona Foley.

2. MINUTES OF MEETING OF TRUSTEES held on 3rd May 2008.

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 Annual Conference of Childhood Cancer Charities and Support Groups in Blackpool – Saturday 10th May. Ros and Mike Francis had attended with the BCRT Display Stand. As reported in Minutes 3.05.08 Section 9.6, Mike had been invited to speak on “Challenging Consultants”. He based it on the BCRT funded Belfry Consensus Meeting of professionals. This not only promoted great interest in the practice in different countries and the resulting success criteria but also helped to raise the profile of BCRT. Two MPs for the Blackpool area were present and asked to be kept in touch with BCRT's future work.

Good links were made with other charities and in particular the George Easton Memorial Trust with whom it was agreed links should be put on both websites.

3.2 The Bone and Sarcoma National Database. Mike Francis said he would be circulating the Minutes of the meeting he attended at which both Rob Grimer and Jeremy Whelan were also present. Mike highlighted BCRT's approach to funding research and in particular the grant given to Dr .Richard McNally, which could tie in with the work being undertaken by the West Midlands Cancer Intelligence Unit.

4. IMMEDIATE REFLECTIONS ON THE SECOND BCRT PATIENTS' AND SUPPORTERS' CONFERENCE held the previous day.

It was agreed that this had again been a very successful event attended by a good mix of former patients and patients on treatment and by families and supporters. Also by professionals present because of their own interest in BCRT and its aims as well as professionals who were speakers. Thanks were recorded to Kate Connor and David Fisher for all their hard work in the preparation for the Conference.

Thanks were also recorded to I D M Pharma for kindly part sponsoring the Conference.

The Programme. The following observations were made:-

- Did we try to include too many items? As last year, time allocations were over-run. Further thought to be given to continuing to present a wide range of topics or narrowing the content
- at the risk of attracting fewer people.
- **Diagnosis.** Bob Grant GP in Fife - “Improving the Time to Diagnosis”. A good starting topic, relevant to everyone in the room.
- **Research.** Speakers on the first piece of BCRT funded research to be completed – “An Epidemiological Study of Bone Tumours in Children and Young Adults” led by Richard McNally, Reader in Epidemiology, Newcastle University and Rachel Eyre, Research Assistant, Newcastle University. Information concerning incidence of bone tumours had been analysed using four of the regional registers and the presentation was split into a review of literature and the findings of the research. This was felt to have been a worthwhile piece of research which could now be extended.
- **Fertility.** Allan Pacey, Senior Lecturer in Andrology, University of Sheffield, spoke on Fertility. He provided much information on the help that can be given particularly around chemotherapy related fertility issues.
- **Fundraising.** BCRT’s Fundraiser David Fisher was able to introduce himself and outline all the progress that is being made. He gave information on the amazing fundraising events and personal challenges that are going on all over the country and in other countries too in support of BCRT and its aims.
- **Artificial Limbs.** An informative talk from Carl Elliott, Prosthetist, Seacroft Specialist Rehabilitation Centre, Seacroft Hospital, Leeds with much interest for everyone as well those actually involved.
- **Current Issues around Bone Cancer.** Ian Lewis, Consultant Paediatric and Adolescent Oncologist, St. James’s University Hospital, Leeds and Chairman of BCRT’s Scientific Advisory Panel brought delegates up to date on recent developments in research and in the progress towards new drugs.
- **Personal Experience Speakers.** Comments from delegates and those present showed that these were again a very well received, real and relevant part of BCRT conferences. This year these were alternated with the above speakers rather than being in two groups of three as last year. This was felt to be better as it spread out the emotional impact that they inevitably have on the listeners. These had included:- Andrew Belshaw and Liam Fox, both former patients who are keen to support current and future sufferers, Harriet Webb and Rachel Holloway who talked about the amazing range of fundraising events they are holding in support of a friend who is a current patient, Hannah Millington and Carol Starkey who both spoke last year whilst on treatment and talked about their new lives now in remission and Sally Hurst who also spoke last year about being pregnant in spite of chemotherapy and this year brought her beautiful daughter with her.
- **Discussion Groups.** It was felt that these had been better organised than last year with good facilitators who then fed back at the end of the day. It was agreed that the points made should be put on the website and in the next Newsletter.
- **Information Stands** on Fundraising, Benefits and the National Sarcoma Register and the Speakers all reported a few visitors but it seemed that most people used this afternoon slot for “unstructured discussion”, sharing experiences and exchanging contact details.
- **The Final Session – Boomwhackers.** As expected there had been varied reactions to this “music making” activity all together. More thought and time to be given to finding an appropriate motivational speaker next year.

Next Year’s Conference. It was felt that after two years in the same part of the country, it was time to consider other venues. All to think about this bearing in mind easy transport links, cost and where our support is around the country.

5. REFLECTIONS ON THE FIRST BONE CANCER AWARENESS WEEK – 21ST-28TH

JUNE 2008. It was agreed that this had done a great deal not only to raise awareness of bone cancer but also of BCRT. Thanks were expressed to David Fisher for the idea and to him and Kate Connor for all their hard work. Awareness had been raised in the following ways:-

- **In national and local press** with input from trustee Sally Hurst with her experience as a journalist and much work by David and Kate in making contacts all over the country. A wide range of newspaper cuttings had been displayed at the Conference. It was suggested that David might try to calculate how much publicity had been gained without cost including for example, the two page spread in The Guardian.
- **Through interviews** on the radio and on television in various parts of the country which had also included trustees Ian Lewis, Nick Bones and John Dealey. In particular, trustees expressed their gratitude to Emily Blunt and her family who did so much to raise awareness of bone cancer and BCRT at such a difficult time for them.
- **In Parliament** with much work carried out by former patient Nick Bojas to obtain an early day motion saying “ *That this House supports Bone Cancer Awareness Week from 21st to 28th June 2008, co-ordinated by the Bone Cancer Research Trust which promotes research into the causes and treatment of primary bone cancer; notes that primary bone cancers take longer to diagnose than any other type of cancer in young people; recognises the vital and urgent importance of raising the level of awareness of the symptoms of primary bone cancer amongst medical professionals, in particular GPs, and the general public; and congratulates the Bone Cancer Research Trust which is working to raise awareness of primary bone cancer which affects over 400 children and young people every year in the UK*”. This was signed by 82 MPs. It was suggested that another time, patients and supporters could be asked to contact their own MPs as well.
- **By mail shot** to everyone on the BCRT database with posters, press releases and case studies. Thanks were recorded to the many supporters who acted on this in a wide variety of ways.

Future Possibilities. It was suggested that David Fisher and John Dealey with his son Justin, should begin to explore possible input by BCRT within the Paralympic Games and to look ahead, perhaps with help from our patron Marc Woods, to the Olympic Games 2012.

6. FINANCIAL AND ADMINISTRATIVE BUSINESS

6.1 Current Financial Statement.

Prior to the meeting, trustees had received a statement to 24.06.08 including the main account and the seven dedicated accounts totalling £465,646.15. They also received a copy of the budget figures to the end of May 2008.

6.2 It was noted that BCRT had gained £13,000 through Justgiving sites during the last 2 months.

6.3 **Administrator’s Hours.** It was agreed that Kate should continue to work for three days a week. Gill to look at amending Kate’s contract.

6.4 **The Office.** It was agreed that Mike would investigate the possibility of a larger office, preferably in the same building.

7. SCIENTIFIC ADVISORY PANEL

7.1 The completion of the first piece of research funded by BCRT, led by Richard McNally - see section 4 Research, above. It had been agreed at the last meeting that Richard's second application had met the criteria for funding to research into the "Environmental contributions to the aetiology of bone tumours in young people: small area analyses". This would include looking at the possible influence of fluoride in certain areas of the country.

7.2 The possible extension of Richard's first research using regional registers. Ian felt that a continuation of this research would be very desirable. He thought there would probably be competition as to who would carry it forward and links had been made in this regard during the BCRT Conference with the attendance of Berni Lee from the West Midlands Cancer Intelligence Unit in Birmingham which is to become the lead cancer registry in the UK for bone and soft tissue sarcomas.

7.3 Update on the progress of the fourth round of research applications. Ian reported that the reviews were slowly coming in and that he and Rob would feed back to trustees for decisions at the next meet which will be in September.

8. PUBLICITY, FUNDRAISING AND MARKETING.

8.1 A report from the Head of Fundraising was received showing projected expenditure and income for all the running events BCRT is involved with this year, a summary of amounts received from supporter fundraising activity since the last meeting and notice of future events to be held. Other activities and promotional items were listed for trustees' information.

8.2 BCRT Stand at the Royal Parks Run. David Fisher said it would be necessary for him to go down to London the day before. John Dealey said that the Adam Dealey Foundation's name would also be on the t-shirts as many of the runners had been recruited in his name. Three names were put forward to act as cheerers holding banners.

8.3 BCRT Leaflets. Stocks were reported to be extremely low. It was agreed that minimum alterations should be made to the original (ie. change of the office address, change of some trustees etc) so that a small but economic print run could be done as soon as possible. A more substantial review of the leaflet to be carried out at a later date.

9. ANY OTHER BUSINESS

9.1. The 3rd / next Newsletter. The timing and content of the third BCRT Newsletter was discussed and the following possibilities were suggested for further consideration at the next meeting:-

- **Content.** Timing needs to be taken into account around what has been taking place so that there is a good balance available of articles on research, conference and other activities as well as fundraising. There needs to be equal recognition given to both large and small income raising events, to physical and challenging events as well as to other types of events that are held and to events held by different age groups of people.
- **"News in Brief" listings.** The presentation of listing all income received from events, in memoriam, from legacies etc to be considered so that recognition is given to everyone who contributes (ie similar to in the Candlelighters' Magazine).
- **Readership.** Further thought was given to where the Newsletter is read, when and by whom. An important example given was that it is read in clinic when people are bored, unhappy etc. It is colourful and brings good news and could well be picked up by people who have not yet heard of BCRT. These places need regular top-ups of copies or other leaflets because of the turn over of people.

- **Preparation.** Items could be prepared in advance and a working group set up (by email so that interested people from further afield could contribute to the planning) and so that there is not an overload of work for a few people just before the deadline.
- **The next edition.** A suggested timing of the next Newsletter was that it should go to the printers in mid October for circulation in November. The point was made that this would be too late for good publicity of the Christmas Cards and possibly for a few of next year's events but it was suggested that there could be single sheet leaflets on such subjects distributed sooner / in between the publication of the bigger glossier Newsletter itself. It was also said that it needs to be remembered that not everyone looks at the website so that what seems like old news to us still needs to be included in the Newsletter for those who haven't seen it and for recognition in print for those involved.
- **Costings** need to be checked.

10. ARRANGEMENTS were made for the next meeting.