

Sarcoma South UK Support Group

Minutes of support group meeting held at The Grove Hotel, 2 Grove Road Bournemouth on Wednesday 13 May 2015 at 2pm

Present:

SM1; SM2; CG1; CG2; KT; AT; SB; YP; TP; JB; RK; NS; LB

1. Apologies: TM, IB; CS; LS; SH; MG; MM; RM; LC; SK; JH; TH

2. New member and Lindsey Bennister, CEO Sarcoma UK were welcomed.

3. Announcements:

- a. Awareness week Tea Party Saturday 20th June at The Grove
- b. The meeting on 8th July may be the last one in Southampton unless someone can be found to take it over. Future to be discussed at the meeting.
- c. RNOH Stanmore will be featured on The One Show tonight at 7pm

4. Group discussion with everyone giving an update on their situation and advice and support offered to the new member.

5. Lindsey Bennister gave a talk on the work Sarcoma UK does. This included:

- a. Later this year, setting up a new phone contact staffed by a nurse with a clinical background in sarcoma to offer advice to newly diagnosed patients, those unsure who to talk to or who want a second opinion. They will be able to refer them to a specialist centre. Currently get around 8-10 calls a day.
- b. They have increased the number of information booklets and will be publishing two more in a month's time. Volunteers are needed for an information review panel for the booklets.
- c. £350,000 will be allocated to research projects this year.
- d. A research day is being held in Manchester on 13th June. 5 researchers will be talking about their projects and patron Richard Whitehead will be there. Money is available from the Macmillan grant to pay for travel expenses.
- e. On The Ball campaign will be re-launched in Awareness week.
- f. Sarcoma UK will be sponsoring an online training module for GPs with free access.

- g. Sarcoma UK is the representative of rarer cancer charities on committees looking into funding cancer drugs.

The next meeting will be at Sunrise of Bassett, 111 Burgess Road, Southampton, SO16 7AG (02380 799449) on Wednesday 8th July 2015, 2pm – 4pm.