

Sarcoma South UK Support Group

Minutes of support group meeting held at The Grove Hotel, 2 Grove Road Bournemouth on Wednesday 11 September 2013 at 2pm

Present: 9

1. **Apologies: 4** Apologies were received and members introduced themselves. There was some discussion of British Sarcoma Group guidelines for follow-up of patients with sarcoma. Several members were being treated at Stanmore, where they received excellent care.

2. Minutes of last meeting

The minutes of the last meeting were taken as read and accepted as a true record.

3. Tricia's radio interview

In September, T gave an interview to Hope Radio in which she spoke about sarcoma in depth. For those of us who missed the broadcast, S supplied CDs on which he recorded the interview. Further CDs will be available for additional members who also missed or would like a record of the broadcast.

4. Maya Wiles: Research Assistant Sarcoma UK

The group welcomed our speaker Maya Wiles from Sarcoma UK head office. She administers the research grant programme there. To date, Sarcoma UK has funded 12 research grants. Applications for grants are invited annually. They are reviewed by the Research Advisory Committee headed by Professor Judson and additional peer reviewers. Grants average around £30,000 per year for 2 years and are mainly awarded for basic, pre-clinical research, although some are awarded for clinical studies. Researchers whose study outcomes are successful, are then expected to apply to larger funders, such as Cancer Research UK, to take their studies forward. It is acknowledged that studies funded by Sarcoma UK will probably not influence clinical practice in the near future, but eventually should make a substantial difference. Examples of studies that have been funded include a Quality of Life study in advanced sarcoma patients and an Isolated Limb Perfusion study

Maya provided samples of new Sarcoma UK publications designed to raise awareness of the disease and to supply much needed patient information. She drew attention to the recent results of the National Cancer Experience Survey which is the third annual survey. 64% sarcoma patients saw their GP twice before being referred forward for investigations. The latest survey results show that there have been some improvements for sarcoma patients but there is room for improvement.

Maya said that the British Sarcoma Group Conference in 2014 will take place in Nottingham on Wednesday 26th to Friday 28th February in Nottingham. On Wednesday, 26 February, the day will be open to patients and carers as well as health professionals. Sarcoma UK are hoping that members of sarcoma support groups will attend. More details are to follow.

6. Treasurers Report

A copy had been circulated to all members of the group with the minutes of the last meeting.

7. Any Other Business

There was no further business. The meeting closed at 4.00pm.

Post meeting note:

The next meeting will be on Wednesday 13th November 2013, 2pm – 4pm but will take the form of a tour of the Cancer Research UK facility at Southampton Hospital. You need to register by contacting Hannah.Fox@cancer.org.uk Tel 07918 626 201

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TM 20/10/13