

## Sarcoma South UK Support Group

**Minutes of the sarcoma support group held on Wednesday 14<sup>th</sup> September 2016 at The Grove Hotel, 2, Grove Rd, Bournemouth BH 1 3AU (01202 552233) [www.thegrovebournemouth.co.uk](http://www.thegrovebournemouth.co.uk)**

1. **Attendees:** TM; SM1 and SM2; RK; JB and IB; AT, A and R; CC; CS.

**Apologies:** LB; SB; SH; MG; DE; LC; CS; SK

**Introductions** Everybody introduced themselves and gave an update on how they were doing. The group welcomed AT, his daughter and granddaughter to the group. IB had told AT about the group.

Issues discussed were the shock of diagnosis which was often late, the need to be seen at a specialist sarcoma centre, the shock of recurrence and also further spread of the disease and the struggle to try to obtain surgical treatment for lung metastases. Group felt it was important to be proactive in managing the care and that the medical secretaries are a good resource to help with information and communication.

The group welcomed CC who has head and neck cancer. He is interested in meeting other support groups and The Grove had told him about our group. CC runs The Swallows ([www.theswallows.org.uk](http://www.theswallows.org.uk)) a support group for head and neck cancer patients and he said that listening to our group head and neck cancer patients face the same challenges. He says that he works closely with the Clinigen group who he says are keen to be involved with sarcoma patients. The group advised him to make contact with Sarcoma UK to discuss with them.

2. **Minutes 13<sup>th</sup> July 2016** were taken as correct.
3. **Guest Speaker:** CS, Research Grant Officer, Sarcoma UK  
CS gave a very interesting presentation about Sarcoma UK and research. (A copy of the presentation attached with these minutes.) Sarcoma UK had recently held a “Basic Scientific Research Symposium” at which sarcoma researchers were asked to work on “What Causes Sarcoma” and how this can be taken forward with research. Sarcoma UK will publish a summary of the work that was done on the day. Sarcoma UK are planning to provide a “Clinical Trials Hub” manned by Sam Hackett, Claire

Kelleher and Helen Stradling. The group welcomed this initiative as it is still difficult to find up to date information about sarcoma clinical trials.

4. **Financial Report** had been sent out by email, not discussed at meeting.

5. **A.O.B.**

**Date for next meeting:** Wednesday 9<sup>th</sup> November 2016, 2 – 4pm.

The Grove Hotel Bournemouth 2, Grove Rd, Bournemouth BH 1 3AU (01202 552233) [www.thegrovebournemouth.co.uk](http://www.thegrovebournemouth.co.uk)

[www.sarcoma-support-south.org.uk](http://www.sarcoma-support-south.org.uk)  
(TM (5/11/16))