

## **Sarcoma South UK Support Group**

### **Minutes of support group meeting held at The Grove Hotel, 2 Grove Road Bournemouth on Wednesday 10<sup>th</sup> September 2014 at 2pm**

#### **Present:**

TM; SM1; RK; DH; YP; TP; JH; TH; IB

#### **1. Apologies**

CS, LS, CG, LC, SH, MG; LB, AF, SB, KW, SM2

#### **Introductions**

The group welcomed JH and TH. They told the group about JH's eventual diagnosis and the difficulties of being diagnosed, being seen locally and in London and having treatment locally. It was extremely complicated and stressful. The care was not "joined up" and they had not been told about the support group and only discovered the group by chance. The group were very glad that JH and TH had found the group and offered to help them in any way they could. The group made several suggestions which as individuals they had found useful in dealing with living with sarcoma. IB gave her contact details to JH for support.

#### **2. Minutes of last meeting**

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

#### **3. Support Group Website**

SM1 took the group through the new website he has created and developed for the group which everybody thought was excellent and the group thanked him for all his skill and hard work. He encouraged us to post to the blog and to use Twitter. SM1 is very good teacher and taught TM how to use Twitter. DH thought it would be good for SM1 to give us all instruction in the future on how to use Twitter.

**4. London and South East Sarcoma Network: Follow Up Guidelines for Bone and Soft Tissue Sarcoma** The guidelines had been circulated and a link to them is on our website. The guidelines were discussed. They have been drawn up by the Sarcoma Advisory Group of the London and South East Sarcoma Network which is the network that we in Wessex belong to.

#### **5. Peer Review: Royal Bournemouth Hospital: Sarcoma Locality Measures**

These were discussed in detail. IB explained that the report that is currently on the website has been superseded by a more recent report that has not been uploaded yet. Go to the website [www.mycancertreatment.nhs.uk](http://www.mycancertreatment.nhs.uk) to look up your cancer services and

read reports on standards and quality.

**6. Finances.** SB had produced the latest financial statement and this had been circulated. The Macmillan Grant had included funding for two to attend the British Sarcoma Group (BSG) Conference and also Sarcoma Voices, if Sarcoma UK arrange one for next year. If anybody is interested in attending please inform TM. DH said he would be interested in attending the BSG.

#### **7. AOB**

- RK informed the group about the Kindred Study for sarcoma patients. This study is looking into the familial links with sarcoma. Please contact AH at the Royal Marsden if you would like to participate.
- RK is going to contact Macmillan and order some more copies of their cookery booklet which has proved to be very useful and popular. She will bring them to our next meeting.

The meeting finished at 17.10 hrs

**The next meeting will be at Sunrise of Bassett, 111 Burgess Road, Southampton, SO16 7AG (02380 799449) on Wednesday 12<sup>th</sup> November 2014, 2pm – 4pm.**

**(TM 9/11/14)**