

## **Sarcoma South UK Support Group**

**Minutes of the sarcoma support group held on Wednesday 8<sup>th</sup> May 2013 at The Grove Hotel, 2,Grove Rd, Bournemouth BH 1 3AU (01202 552233) [www.thegrovebournemouth.co.uk](http://www.thegrovebournemouth.co.uk)**

**1.Present:** 6

**Apologies:** 11

The group welcomed the new members and introductions were made. Issues discussed included the shock of being diagnosed with a rare cancer and the patient journey leading up to the diagnosis including the use of language and expectations; who to tell and their responses; the stress and practicalities of having to deal with travelling to tertiary centres; thankfulness for expert care and surgery; follow up care and scans and dealing with results and uncertainties; emotional reactions for patients and carers when recurrences happen and searching for and importance of support.

**2. Minutes agreed.**

**3. Matters arising:** S and M have asked their oncologist come and talk to the group again and she agreed to talk at the 11<sup>th</sup> September 2013 meeting at The Grove.

**4. Sarcoma Awareness Week 17<sup>th</sup> – 23<sup>rd</sup> June 2013** Plan to have Afternoon Tea on Saturday 22<sup>nd</sup> June at The Grove. S suggested in order to raise awareness contact could be made to the local paper and radio.  
**NB Post meeting notes: The Grove have confirmed Saturday 22<sup>nd</sup> June for our Afternoon Tea; S has contacted a friend at Hope RadioFM who has agreed to broadcast an interview with one or two of us – please contact me asap if you can help.**

**5. Sarcoma UK DVD** Sarcoma UK with the help of relatives and patients have made a DVD about being diagnosed with sarcoma. Go to [www.sarcoma.org.uk](http://www.sarcoma.org.uk) to view or look for it on Community tv channel.

**6. Any other business**

- S and S are extremely grateful for all the care he received at Royal National Orthopaedic Hospital at Stanmore and kindly want to make a donation to this support group. T will pass their details onto Sh who is the Treasurer of the group. **NB Post meeting note: S and S have kindly donated £200 to our support group. Many thanks for this generous donation.**
- Rarer Cancers Foundation have a “Patient Empowerment Day” in London on June 3<sup>rd</sup> 2013. R and T have been to previous RCF conferences and they are excellent. For more information go to [www.rarercancers.org.uk](http://www.rarercancers.org.uk)

**Next meeting on Saturday 22<sup>nd</sup> June Sarcoma Awareness Afternoon Tea 2pm at The Grove Hotel, 2, Grove Rd, Bournemouth BH 1 3AU (01202 552233) [www.thegrovebournemouth.co.uk](http://www.thegrovebournemouth.co.uk)**

**Next support group meeting on Wednesday 10<sup>th</sup> July 2013, 2pm – 4pm at Sunrise of Bassett, 111 Burgess Rd, Southampton SO16 7AG, (02380 799449)**

(TM 23/05/13)