

## Sarcoma South UK Support Group

**Minutes of the sarcoma support group held on Wednesday 9<sup>th</sup> November 2016 from 2.00 pm – 4.00 pm 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; RK; SM1 and SM2; SB1; SK; PH and CH; AT and A; SB2; JB and IB; JJ and RJ.

**Apologies:** SH and MG; NS; CG1 and CG2; LB.

**Introductions** Everybody introduced themselves and gave an update on how they were doing. The group welcomed SB2, JJ, RJ and CH to the group. Facebook and word of mouth had enabled new individuals to find the group. Thanks were expressed to the group for helping with issues discussed last time, e.g. a phone call to a medical secretary resulted in patient receiving an earlier appointment to attend for scan results.

Patients are still having great difficulty being diagnosed and being referred to specialist sarcoma centres. Delays have occurred with GP s not referring for scan which resulted in delays in being diagnosed and with patient being treated suboptimally at local hospital instead of being referred to a specialist centre. All these caused great stress and anxiety. The shock of being diagnosed was made worse by delays. Patients expressed relief to have eventually been seen at the specialist units. “Golf Ball “ study information sheets were given out so they could be passed on to their GP s in an effort to increase sarcoma awareness.

Patients spoke of the difficulties of coping with advanced disease and trying to obtain the best treatment to for metastases, and the feeling of having to fight the system; of the stress brought on by delays in starting treatment; of the side effects of chemotherapy; and of the stress of “scanxiety”.

SB2 who lives in Brighton has met another patient in her area and have discussed the idea of starting a group in their locality. Advice, information and support was given. Impressed the need to obtain adequate help e.g from Macmillan Involvement Co-ordinator for that area and also from Sarcoma UK. Group emphasised that people need to be well enough to embark on such an undertaking and that their individual health needs are paramount. Sarcoma UK have said that they are planning

to have a day which focuses on starting and running support group but no more information has come through yet about this. Group members offered to help SB2 anytime if needed.

2. **Minutes** 14<sup>th</sup> September 2016 accepted as correct
3. **Wessex Cancer Trust.** Several members are attending the WCT in Bournemouth and are full of praise for the staff and services. Members are having various treatments and therapies such as Reiki, facials and counselling. Group suggested other members look into WCT in their area as it is such a helpful resource. [www.wessexcancer.org.uk](http://www.wessexcancer.org.uk) Group members have found counselling to be useful highlighting that you need to find a counsellor that you can relate to.
4. **Financial Report Post meeting note:** RK noted an error in the columns which has been corrected
5. **A.O.B.**
  - Sarcoma Advisory Group (SAG) meeting in December. TM is a patient representative on the SAG for London and South East Sarcoma Network (LSESN) and asked if there were any issues which members would like to be brought up. Communication issues are an ongoing problem such as patients not receiving copy letters and not being fully informed about ongoing treatment. There was a problem with RMH and trying to make an appointment so chemotherapy could be started.
  - Members were encouraged to make travel expenses claims for the group attendance especially as some people are travelling long distances.

**Next meeting Wednesday 11<sup>th</sup> January 2017 from 2.00 – 4.00 pm at the Grove Hotel Bournemouth 2, Grove Rd, Bournemouth BH 1 3AU (01202 552233) [www.thegrovebournemouth.co.uk](http://www.thegrovebournemouth.co.uk)**

**TM (7/1/17)**

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