

## **Sarcoma South UK Support Group**

### **Minutes of support group meeting held at The Grove Hotel, 2 Grove Road Bournemouth on Wednesday 9<sup>th</sup> March 2016 at 2pm**

**Present:** TM; SM1; SM2; SB; LB; RK; PH; SH; MG.

- 1. Apologies:** DE; IB; Y and TP; SK; NS; C and CG; A and CS.

**Introductions:** Everybody introduced themselves and gave an update on their situation and what they were having to deal with. Discussion ensued about where to be seen, where to have treatment and follow up regimes.

Group discussed impact of recurrences and difficulty of making decisions about treatment with particular reference to chemotherapy treatment. It was hard to make a decision about starting chemotherapy when patient is asymptomatic and chemotherapy is going to affect quality of life. Trials were discussed – there are no trials available locally and it was felt it was unfair to a patient to be allocated to a placebo arm of a trial when there was a novel agent being tried.

- 2. Minutes 13<sup>th</sup> January** taken as correct.
- 3. Financial Report** Thanks to SM1 for doing the report.
- 4. Macmillan and University of Southampton: PRESENT: Patient Reported Experience Survey.** University had requested patient help in doing survey to do with the language that patients use describing their ill and treatments. This will help with the analysis of qualitative data collected on the annual National Cancer Patient Experience Survey. Link had been sent out to do the survey.
- 5. Group lunch at Hotel Du Vin** had been enjoyed (apart from the problems SM1 had encountered).
- 6. Conferences and Events.** TM attended the British Sarcoma Group Conference in Manchester in February. Sarcoma UK presented their National Sarcoma Patient Survey 2015. They had commissioned the survey and they had 64% response rate , 558 patients. Follow up regimes varied across centres. Worryingly 1% bone sarcomas and 3% soft tissue sarcoma patients said they were never followed up. (Attached to papers is

Sarcoma UK's presentation.) Tricia has copies of the conference programme which has summaries of presentations and posters.) Pre-operative radiotherapy and also radiofrequency ablation is being used more frequently. Immunotherapy drugs were discussed but trials are so open and only in large centres. One oncologist said she sees patients every day in her clinic and they are asking "When are these trials going to open with these new drugs?" TM attended the Sarcoma Advisory Group in February. RNOH and RMH are under increasing pressure with increase in referrals. Often clinics have patients who have been referred inappropriately eg patient with warts. Plan is to train and support local clinics to screen and image some patients. ( Brighton is a good model for this type of clinic. The plan is to target hospitals who have a high number of inappropriate referrals.) Group also wants to focus on governance to try to improve adherence to guidelines.

7. **Sarcoma UK Patient Experience Survey 2015** Copies were given out.
  
8. **A.O.B.** Sarcoma UK Support Line is up and running. Phone: 0808 801 0401  
Email: [supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk)
  - 16<sup>th</sup> March Lab Tour of Cancer Research Labs Southampton Hospital . They do regular tours (contact TM if you are interested in the future.)

**Date for next meeting:** Wednesday 11<sup>th</sup> May 2016, 2 – 4pm, The Grove hotel Bournemouth, 2 Grove Rd, Bournemouth BH 1 3AU (01202 552233)

(TM 9/5/2016)

[www.sarcoma-support-south.org.uk](http://www.sarcoma-support-south.org.uk)