

Sarcoma South UK Support Group

A meeting of the sarcoma support group was held on Wednesday 8th July 2015 from 2.00 pm – 4.00 pm at Sunrise of Bassett, 111 Burgess Rd, Southampton SO16 7AG, (02380 983 566)

Minutes

1. **Present:** DH; VL; CG1; CG2; SM1; SM2; SB; RK

Apologies: TM; YP; TP; SH; MG;

2. **VL** (Sarcoma Nurse Specialist at Southampton hospital) has generously agreed to take over the running of the Southampton section of the support group. It will become a separate group making its own arrangements to suit their members. The currently advertised meeting date of 11th November will be kept but other dates will be organised and coordinated with the Bournemouth group. Members will be encouraged to attend whichever meeting is suitable. There could also be joint social events.
3. **Southampton hospital sarcoma service.** VL gave a talk on her work and the system at Southampton hospital. She shares a post with LS so there is an equivalent of one full-time sarcoma CNS. There are now two sarcoma consultants Peter Simmonds and Dr Keay with clinics on Thursday (for patients currently receiving treatment) and Friday (follow-up).

The monthly Friday clinic takes place with various specialists, the CNS and patient sitting around a table to discuss their care.

The CNSs encourage patients to contact them by phone, text, email etc, they visit wards to see patients, advise them on financial questions, introduce them to the Macmillan centre, take blood during clinics, organise scans, amongst many other duties.

They attend the MDT meetings which, when necessary, are coordinated with the London specialist centres and with Oxford.

There are around 70-80 new patients a year many referred from the 'lumps and bumps' clinic and there are currently 11 patients receiving chemo.

A few patients are referred to London, particularly RNOH Stanmore, but follow-up can be done at Southampton.

Consideration is being given to improving long-term care for patients who are discharged after 10 years of follow-up.

4. **AOB**

The group received a generous donation from CG1 & CG2.

SB will be contacting Sarcoma UK to see if they would organise a better system for paying their annual grant.

The new bank account has been opened with SM1 taking over as treasurer.

Next meeting on Wednesday 9th September 2015, 2pm – 4pm at The Gove Hotel, 2,Grove Rd, Bournemouth BH 1 3AU (01202 552233)
www.thegrovebournemouth.co.uk