

Sarcoma South UK Support Group

A meeting of the sarcoma support group was held on Wednesday 9th July 2014 from 2.00 pm – 4.00 pm at Sunrise of Bassett, 111 Burgess Rd, Southampton SO16 7AG, (02380 983 566)

Minutes

1. **Present:** SM1; SM2; RK; MM; RM; YP; TP; DH; KW; TM

Apologies: SH; MG; NS

The group welcomed new member KW who described the long path to correct diagnosis and treatment, extremely severe complications and side effects. Group members introduced themselves and issues that were discussed included: delay to diagnosis; the need to have confidence in doctors and continuity of care; the need for interested and compassionate GP and right to ask to see another GP if necessary; nutritional supplements; telling family members and their reactions; the need for 10 year follow up and imaging; reactions and attitude of work colleagues; returning to work. DH has been appointed to be a lay member of the new West Hampshire Clinical Commissioning Group.

2. **Minutes** 14th May 2014 agreed
3. **Sarcoma Awareness Tea Party** was held at The Grove on 28th June. 14 people attended and many had travelled long distances. It was felt to be successful. The group had made a surprise presentation to TM to thank you her for work with the group. TM was completely taken aback by the gift and very grateful.
4. **Support Group Website** www.sarcoma-support-south.org.uk
SM1 has designed and produced a new web site for the group. People were encouraged to go to the site to view it. It is very comprehensive with information and photos about the group, patient and carers stories, information about sarcoma and links to various sites. The group thanked SM1 for all his hard work and skill. SM1 is going to be keeping the site up to date. He has included a blog and encouraged group members to post to the blog.
5. **New support group leaflets and posters** were distributed among the group so that they could be taken to various hospitals and GPs.

6. **Macmillan Grant:** Macmillan have granted the group £2684 which will be used to help the group to continue its activities. The money is to be spent on a laptop, projector, software, travel costs, posters, leaflets, paper, print ink, social events, refreshments, conference attendance. SM1 has already bought a laptop for the group.
7. **“On the Ball” Sarcoma awareness campaign** Sarcoma UK’s On The Ball packs were given out so they could be given to GPs
8. **AOB**

The group has received a £140 donation from TLW Dance for which the group is very grateful.

RK gave out information leaflets about cancer that she had picked up from Royal Marsden.

YP suggested that KW sends her story to Sarcoma UK’s Connect Magazine so that others can read about it.

Next meeting on Wednesday 10th September 2014, 2pm – 4pm at The Gove Hotel, 2,Grove Rd, Bournemouth BH 1 3AU (01202 552233)
www.thegrovebournemouth.co.uk

(TM 02/09/14)