

## **Sarcoma South UK Support Group**

### **Minutes of support group meeting held at The Grove Hotel, 2 Grove Road Bournemouth on Wednesday 11<sup>th</sup> November 2015 at 2pm**

**Present:** TM; SM1; SM2; SB; LB; RK; SH; IB; SK; PH; MO'N; TO'N; DE

#### **1. Apologies:** YP; TP; KT

**Introductions:** Everybody introduced themselves and gave an update on how they were doing and what problems they were having to deal with. The group was delighted to welcome 5 new members and the majority of the time was focused on them telling their stories, how they were diagnosed (often delayed) and treated and how this had impacted on them and aspects of their lives. A great deal was disclosed and shared. Group members supported each other. The issue of support was discussed and how psychologically valuable it is to talk with others in same position when the individual is ready and able to do so. SK and PH had met at a recent GIST UK patient conference in Southampton. DE highlighted the value of social media. He is writing an inspirational and moving blog about his life with sarcoma <http://www.darrenevans.weebly.com> SM and TM follow the blog and recommend it.

The group was also very pleased to welcome Sam Hackett who was visiting the group. Sam has just been appointed Sarcoma Specialist Nurse at Sarcoma UK and part of her role will be helping in setting up support groups. Sam has been a specialist nurse at the Royal Marsden for the last 12 years. Several of the group expressed warm gratitude for the excellent care she had given them. Sarcoma UK are planning to have a conference for patients, similar to those of GIST UK, in the future.

Clinical Nurse Specialists were really appreciated and valued by the group.

**2. Minutes 9<sup>th</sup> September 2015** taken as correct.

**3. Financial Report** update had been circulated. Thanks to SM1.

**4. Dr Rachael Brastock**, Macmillan Specialist Clinical Psychologist has been newly appointed for Dorset and is based at Joseph Weld Hospice in Dorchester. Rachel is exploring the psychological needs of Dorset cancer patients and is keen to attend this support group to discuss this issue. Once she has settled into her job she will identify a date to attend the group.

#### **5. Conferences and Events.**

- TM attended Macmillan Voices Conference in October in London as a speaker on a workshop panel. The session was to help people set up and run support groups and was well received. Macmillan Cancer Voices

Conference is held annually in October for patients and carers. Macmillan start advertising the conference in the summer and applicants can register on line later in the year. Priority is given to people who have never attended before. The conference is uplifting , informative and supportive.

- Bournemouth University have an award winning Carer and Service User Partnership team which wants to recruit more patients and carers. The team have been in place for 10 years and they involve patients/carers in the recruitment and training of nursing and allied health profession students. This is an opportunity to raise sarcoma awareness and also talk about our sarcoma experience which members of the group have found to be therapeutic. Please contact Angela Warren the coordinator on 01202 962022 or [awarren@bournemouth.ac.uk](mailto:awarren@bournemouth.ac.uk) Angela is very supportive and they provide training for patients who would like to be involved. Expenses and small payments are made for time.

#### 6. AOB

- Group would like to organise a lunch for January. TM will make enquiries with Hotel Du Vin **NB Post Meeting Note: Will discuss this further at January meeting**
- SM2 has been involved with a patient partnership initiative at the Royal National Orthopaedic Hospital at Stanmore which is endeavouring to find out patient views about various aspects of care at the hospital.

**7. Date for next meeting:** Wednesday 13<sup>th</sup> January 2016, 2 – 4pm, The Grove hotel Bournemouth, 2 Grove Rd, Bournemouth BH 1 3AU (01202 552233)

**2016 dates for Bournemouth group: March 9<sup>th</sup>; May 11<sup>th</sup>; July 13<sup>th</sup>; September 14<sup>th</sup>; November 9<sup>th</sup> - all 2 -4 pm at The Grove hotel.**

**(TM 8/1/2016)**

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