

## **Sarcoma South UK Support Group**

### **Minutes of support group meeting held at The Grove Hotel, 2 Grove Road Bournemouth on Wednesday 8th January 2014 at 2pm**

**Present: 8**

#### **1. Apologies: 7**

R was unable to attend the meeting as she has been in hospital. Whilst an in patient she met a young bowel cancer patient who did not know about the “Semi colons” bowel cancer support group and R gave her their contact details. R was able to give her lots of information and support and wanted group to discuss what information a newly diagnosed patient needs to have. R thought that

“ Cancer doesn’t mean death. When you see your consultant, take someone with you who is capable of taking notes as you might not remember everything that is being said. Take all your questions with you and make sure you or your friend is given enough time to write down the answers. Ask for any literature. Ask how private treatment might differ from NHS. Ask that any letters, scans and pathology reports are copied and sent to you and then keep a file. If no private CNS ask to see NHS one. Write down any questions you have straight away so you don’t forget them. Look up your particular cancer on the internet but be aware that worst cases are often featured, which can be really scary. Look up and contact support group, national and local. We think that CNS should have this information.”

The group suggested that new patients need to be given a contact telephone number so that they can speak to member of staff if necessary; to have an opportunity to speak to fellow experienced patients; to write down questions before you go for appointment and say if you don’t understand the answers; to see the CNS as they have more time to spend with you; to ask about treatments and what options are available; to ask what tests will be done and how long it will all take; to keep the GP in the loop and don’t be afraid to ask for a second opinion. Sarcoma UK has produced a new booklet for newly diagnosed sarcoma patients.

Everyone gave an update on their situation and discussed issues around late effects of radiotherapy; pain management; follow up care; and upcoming surgery and treatments.

#### **2. Minutes:**

The minutes of the September meeting were taken as read and accepted as a true record.

#### **3. Matters Arising:**

British Sarcoma Group Conference will be held on 26<sup>th</sup> – 28<sup>th</sup> February in Nottingham.

Patients and carers can apply to go to the first day [www.bsgconference.org/uk](http://www.bsgconference.org/uk)

**4. Visit to Cancer Research UK laboratories** at the Somers Building at Southampton General Hospital on 13<sup>th</sup> November. Seven members of the group were able to attend and listened to a very interesting talk by the Director Professor Richard Johnson about cancer and the groundbreaking research that is undertaken at Southampton, including immunotherapy. The group were given a tour of the research facilities and met researchers and a research clinical nurse specialist. The event was very popular and oversubscribed and CRUK plan to repeat the tour, to request a place contact Hannah Fox on 07918 626 201 or [Hannah.Fox@cancer.org.uk](mailto:Hannah.Fox@cancer.org.uk)

**5. 2014 dates for support group:** dates for The Grove Bournemouth are 14<sup>th</sup> May and 10<sup>th</sup> September; dates for Sunshine of Bassett are 12<sup>th</sup> March; 9<sup>th</sup> July; 12<sup>th</sup> November.

#### **6. Any Other Business**

- CNS Southampton has returned from maternity leave and another has gone on maternity leave.
- Suggestions for future speakers included a pathologist, Oncologists and a Consultant Nurse who is knowledgeable about Post Traumatic Stress and cancer. Previously J had suggested asking a physiotherapist.
- The Celebrity Mastermind episode on 10<sup>th</sup> January will feature Para Olympian Gold Medallist.
- Sarcoma UK have arranged a conference/workshop “Sarcoma Voices” for sarcoma patients and carers in Birmingham on 22<sup>nd</sup> March 2014. Please contact Sarcoma UK to apply for places.  
Meeting closed at 1600hrs

**The next meeting will be at Sunrise of Bassett, 111 Burgess Road, Southampton, SO16 7AG (02380 799449) on Wednesday 12<sup>th</sup> March 2014, 2pm – 4pm.**

(TM 09/03/14)