

Sarcoma South UK Support Group

Minutes of support group meeting held at Sunrise of Bassett, 111 Burgess Rd, Southampton on Wednesday 13th March 2013

1 Present: 8

Apologies: 6

The group introduced themselves and gave an update on how they were doing. Discussed the problem of late diagnosis and missed opportunities to being diagnosed earlier; the importance of appropriate imaging/tests being done and the need for doctors to explore the cause of symptoms rather than make assumptions. Patients greatly appreciated doctors who not only were experts but also considered the whole person rather than solely the tumour. Sadly for patients and carers an excellent CNS at PGH has retired. The difficulties and frustrations of being a carer was discussed and how different people coped with situations and uncertainties. The group wished R well and hoped that he would be accepted for a new trial drug for GIST.

2. Minutes were agreed.

3. Matters Arising: None

4. British Sarcoma Group Conference: T attended the recent conference. It was the first time that one of the days was organised for patients, carers and professionals and workshops included “Making Patient Information Fit Patient Needs”; “Patient Involvement – What it is and what it does”; “Your Treatment is over, now what?”; “Basic Science – Unravelling the Origin of Sarcomas”; “Raising awareness: Medical Education”. In a few months presentations from the conference will be available on the website www.bsgconference.org.uk .

5. “Understanding Sarcoma: a new patients guide.” Copies of the new booklet for were given out which have been produced by Sarcoma UK with help from patients and carers. GIST UK have also produced a new booklet for GIST patients and these were given out for GIST patients.

6. Sarcoma Awareness Week: 17th June - 23 June 2013 T asked for everyone to think of ideas of what we could do to mark the event. Last year the group had a cream tea indoors at the Grove Hotel in Bournemouth but it may

not have increased awareness of sarcoma among the general public. If the group decided to use the Grove then it may be possible to have the tea in the garden. Ideas and suggestions to T, please. **(ALL)**

7. Treasurer's Report: S had kindly produced an updated Treasurer's Report which was distributed.

8. Any other business

- Suggestions for speakers for future meetings - oncologists
- Discussed issue of why it took so long to wait for scan results; it is an anxious time having to wait for results. Radiologists have specialist training to read and report scans.

Date and time of next meeting:

Wednesday 8 th May 2013, 2 to 4 pm at The Grove Hotel, 2 Grove Road, Bournemouth BH1 3AU, 01202 552233

(TM 30/04/13)