

Sarcoma South UK Support Group

Minutes of support group meeting held at The Grove Hotel, 2 Grove Road Bournemouth on Wednesday 13th January 2016 at 2pm

Present: TM; SM1; SM2; SB; LB; RK; SK; PH; AS; CS; KD

1. Apologies: DE; SH; MG; IB; MO'N; TO'N; YP; TP.

Introductions: The group welcomed 2 new members, AS and CS. AS spoke about her diagnosis and the shock of it and her ongoing treatment plan. The group shared their experiences and feelings and how being diagnosed with sarcoma changes one's life and thinking. Adjustment is difficult.

Some members have been able to access complementary therapies and SK recommended The Coates Centre in Lymington which offer a wide range of therapies, activities and social events www.thecoatescentre.co.uk. The Penny Brohn centre near Bristol is similar but in addition offers residential courses www.pennybrohn.org.uk

Wessex Cancer Trust have opened a branch locally. (**NB Post meeting note:** called Bournemouth Cancer Support Centre, Fairview House, 17 Hinton Road, Bournemouth BH15 4QQ (01202 315824) Bournemouth.centre@wessexcancer.org.uk It is open Tuesday, Wednesday, Thursday 10-4 and offer befriending, counselling, reflexology, aromatherapy and information services.)

Other issues discussed were follow up, recurrences, long term toxicities from radiotherapy, need to see specialists in sarcoma and travel insurance.

The group also welcomed KD who was visiting from the London support group which she runs. KD is also a Trustee of Sarcoma UK. The group talked about the benefits and difficulties of running a support group. The Bournemouth group has the advantage of having a team of people being involved in running the group as this shares the work load and provides peer support. The group has also been able to have grants from Macmillan and Sarcoma UK.

2. Minutes 9th September 2015 taken as correct.

3. Financial Report update had been circulated. Thanks to SM1 for doing this for the group.

4. Dr Rachael Brastock, Macmillan Specialist Clinical Psychologist has been newly appointed for Dorset and is based at Joseph Weld Hospice in Dorchester and she will be visiting the group on July 13th 2016

5. Group Lunch Plan to book with Hotel Du Vin for a Sunday – Tricia to contact hotel and arrange.

6. Conferences and Events. TM and KD will be going to the British Sarcoma Group Conference in Manchester in February.

Tricia is a patient representative on the Sarcoma Advisory Group (SAG) in the London South East Sarcoma Network www.lsesn.nhs.uk Go to this website to read minutes of meetings, guidelines and pathways, referral forms, trial information and newsletters. Please let TM know of any patient issues that you would like raised at the SAG. (Issues can also be raised with the CNS and PALS.)

“Dorset Living Well Active” are offering places on “Freedom and Beyond Programme – Empowering Women” . Contact them on 01202 426588 support@livingwellactive.org

7. AOB The CNS s in Southampton are going to have the Southampton support group in the Macmillan Centre at Southampton General on the alternate months to the Bournemouth Group i.e. April, June, August, October but still on the second Wednesday of the month at 2pm.

Sarcoma UK will be launching their new Sarcoma Support Line in March. More information will be given once it is open.

8. Date for next meeting: Wednesday 9th March 2016, 2 – 4pm, The Grove hotel Bournemouth, 2 Grove Rd, Bournemouth BH 1 3AU (01202 552233)

(TM 7/3/2016)

www.sarcoma-support-south.org.uk