

## Sarcoma South UK Support Group

### Minutes of support group meeting held at The Grove Hotel, 2 Grove Road Bournemouth on Wednesday 14<sup>th</sup> January 2015 at 2pm

#### Present:

TM; SM1; SM2; SH; MG; CG; RK; YP; TP;

#### 1. Apologies

SB; NS; IB; MM1; MM2; DH

**Introductions** Everyone was welcomed especially CG who had travelled from Basingstoke. Everyone introduced themselves and gave an update on how they were doing and what problems they were having to deal with. The issue of late diagnosis, late effects of radiotherapy including nerve damage; “scanxiety”; and importance of support were discussed. A few of the group belong to Sarcoma UK’s on line support group Sarcoma Group Spaces -go to [www.sarcoma.org.uk](http://www.sarcoma.org.uk) – to register.

Recent announcement about 3 sarcoma drugs are being withdrawn from Cancer Drugs Fund : pazopanib; Caelyx and regorafenib (GIST drug). Patients who are already on these drugs will not have them withdrawn. Suggested we contact Sarcoma UK to see how they are addressing the issue and what we could do if anything. (**NB Post meeting note:** Lindsey Bennister CEO said that they are working closely with NHS England and leading sarcoma clinicians on the issue. Prof Judson (Royal Marsden) spoke at the British Sarcoma Group conference:

#### Cancer Drugs Fund

- Originally set up to fund drugs deemed non cost-effective by NICE
- During “re-organisation” of the NHS by the 2012 Health and Social Care Act regional cancer drug lists, e.g. London Cancer New Drugs Group (LCNDG) were lost and approved drugs were/were not taken into the CDF
- December 2014 – decision made, announced 13.1.15 that regorafenib, pazopanib and some indications for Caelyx would be taken off CDF

#### Key Problems

- CDF decision to trim the list politically driven
- Process based on very limited and strange criteria – e.g. unmet medical need only if there are NO other drugs for a disease.
- Inadequate consultation, no meaningful stakeholder involvement, unlike original regional panels, restricted appeals process
- Not transparent

#### Specific Issues Raised

- None of these drugs were appraised by NICE
- Decisions - other than for Regorafenib- reverse those made by bodies such as LCNDG
- Discrimination against patients with rare disease, cost savings minimal
- Irrational conflation of GIST and colorectal cancer for Regorafenib.
- Unreasonableness of ignoring unmet need of e.g. patients with GIST resistant both to imatinib and sunitinib

What next?

- Variety of appeals have been made – by physicians, cooperative groups, manufacturers on grounds of:
  - Lack of fairness
  - Discrimination
  - Rationality (lack of)
  - Reasonableness (unreasonableness))

**2. Minutes 12<sup>th</sup> November** taken as correct.

**3. Hotel Du Vin Lunch 18<sup>th</sup> January** 19 people plan to attend.

**4. Southampton Support Group** TM is asking if there is anyone in the group who is willing to take over the running of the meetings in Southampton. Please contact TM if you are interested. The room is booked at Sunrise for 2015. The Bournemouth group will continue as usual.

**5. British Sarcoma Group Conference 25<sup>th</sup> – 27<sup>th</sup> February** in Nottingham.

**6. Finances.** Plan to have a reprint of our leaflets but will wait until later in the year due to uncertainty of Southampton group. Encouragement to claim travel expenses.

**7. AOB**

- Launch of the Dorset Cancer Patients Group, recruitment open day at The Grove 7<sup>th</sup> February and training day 14<sup>th</sup> March. Flyer to be attached to Minutes.

**The next meeting will be at Sunrise of Bassett, 111 Burgess Road, Southampton, SO16 7AG (02380 799449) on Wednesday 11<sup>th</sup> March 2015, 2pm – 4pm.**

**(TM 28/02/15)**