

Notes from meeting 9th September 2014

Attendance: Sian, David W, Rachel R, Colin, Janet, Roger Apologies: Rob, Angie

All agreed that the tea & cakes open afternoon at the Hamar had been well attended, approx 100 people which included both staff and patients, it had raised awareness of the facilities at the Hamar which has led to an increase in referral to its facilities, Rachel thanked the forum for provided the refreshments. Two issues were brought to the forums attention at the event-Patients receiving chemo had a paper document to allow them reduced price/free parking for a number of visits. Unfortunatly patients are required to physically take the paper documentation down to the yellow booth which they are reporting as difficult due to their physical health. Even more concerning was this also applied to patients who had blue badges, so whilst they could park close this was totally negated by having to walk to the yellow box. Action: check if Eileen A was a member of the PIEP and could raise through this group as it is a problem that is likely to affect more than cancer patients. If not, approach estates directly.

Action: Sian approach Eileen A

The second problem was for haematology patients who had been told they didn't yet have cancer, but would do some time in the future so were on a 'watch & wait' pathway. Three different patients reported to us feeling abandoned & unsupported. One very specifically stating the CNS did not have time for her as she was too busy with proper cancer patients. It was agreed in the first instance that Rachel would invite the haematology CNS to the next meeting to initially get further insight into the condition and associated pathway. It was also suggested a short survey of those on watch and wait to see if it is a problem or just coincidentally we have met unsatisfied patients. **Action: Rachel invite haematology cns**

David W updated the group-

Sun Awareness project, following a successful bid for funding from Lingen Davis David is setting up a small working group with a view to assessing the local view on sun awareness particularly around families and school children. David is looking for a patient representative and particularly looking for someone from Telford area. Following this first stage and after assessing the information received it is hoped to do a local campaign. **Action: All** David is also considering bidding for some money to help cancer patients who have been affected by depression.

Rachel advised

SaTH have put in a third bid for funding for a CNS for rarer cancers That they are still working with Macmillan on an information & support centre at Telford

A new interim Lead cancer nurse – Julia Macadam has been appointed The group pre chemo assessment is working extremely well and is very successful.

They hope to have implemented E Chemo prescribing by March 2015

End of Treatment summary, these are not provided for patients. David is going to ask for an update. Sian thought these are being used successfully elsewhere and will find out where and let David know.

Action: David and Sian