

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group Issue 19 October 2012

Editorial Comment

To ensure the Newsletter continues to be relevant, feedback is welcome from Members. You may do this by email to the Editor at ken.davik@yahoo.co.uk or, alternatively, write to the Chairman at his home address.

New Members

There were no additions since the August Membership list, so nothing to report this month.

October 2012 Group Meeting

The meeting was held on the 5th October when we had Allison Hunt a Research Nurse involved in Clinical Trials at the the Berkshire Cancer Centre, part of the RBH in Reading.

Allison explained she is in a team of eight which manages oncology and haematology trials concerned with a number of tumour sites. Interestingly PCa has three trials which are open to recruitment and one genetic study, but more of these later.

Clinical trials look at a variety of aspects: the risks and causes of cancer, screening for those at highest risk, treatments involving new drugs and the control of both symptoms and side effects. The aims of a trial can be summarised as:-

- is a procedure /treatment safe?
- does it have side effects?
- does it work better than the current “gold standard” treatment?
- does it make you feel better?

Allison went on to explain some of the benefits of participating in a trial as:

- you may be offered a treatment not normally offered
- from an altruistic viewpoint you may improve treatments in the future
- from a personal viewpoint it is likely you would have more check-ups during the trial period

It was emphasised that participation is voluntary and participants may opt out at any time, with no, well few, questions asked.

The phases of a trial were described, with Phase 2 being to decide if there was sufficient “promise” to go to a much larger trial (Phase3), plus which cancers the treatment was effective against, including any side

effects and their management and finally the dosage.

Phase 3 trials can involve thousands of people, many hospitals and also many countries. In this phase, the new treatment is compared with standard treatments and addresses both dosage and treatment application techniques, covering both drugs and Radiotherapy, as appropriate.

(the observant reader will note that the Editor did not have the wit to ask the coverage of Phase 1, if there is such a thing!)

Allison moved on to describe the first trial they are involved in called “Stampede”, which is a Randomised Control Trial (RCT) , a Phase 3 trial. In this trial they will be assessing newly available treatments which may be of benefit where PCa has become resistant to hormone therapy. Stampede will assess the use of such treatments as a first-line therapy in conjunction with Hormone therapy. It is anticipated that patients will be better able to tolerate this new treatment and there is also the possibility of greater and more long lasting effectiveness.

The next trial described was the Patch Trial. This trial aims to gather more safety and effectiveness data on the use of oestrogen patches; it is a two “arm” randomised trial where patients have either oestrogen patches **or** standard hormone therapy.

The rationale behind this trial is the concern about the long term side-effects of the prolonged use of hormones in the form of injections/implants, in particular cardiovascular and osteoporosis risks.

Oral oestrogen has been shown to be effective in reducing testosterone, but it is not routinely used due to the cardiovascular risk caused by the break-down of the drug in the liver. A skin patch with oestrogen results in the oestrogen being absorbed directly into the bloodstream thus avoiding the digestive system, whilst giving the same results.

The next trial Allison described is called “Radicals” and is an international, multi-centre, trial with two separate “randomisations”. It is a Phase 3 trial.

The first addresses early versus deferred radiotherapy following a radical prostatectomy. The second compares radiotherapy with no hormone therapy, radiotherapy with short-term hormone therapy and also radiotherapy with long-term hormone therapy.

The rational behind this trial relates to the

uncertainty of the optimum management following surgery. The main question to be answered is the timing of radiotherapy, with or without the inclusion of hormone therapy.

Before taking questions, Allison explained some of the aspects relating to the eligibility of a volunteer to participate.

The main thing to remember is you don't just turn up and say, "now what" and where is my cup of tea? There are rigorous inclusion/exclusion criteria published for each trial, which could well vary for each trial. In addition a Multi-Disciplinary Team reviews the eligibility of all "applicants" to participate in a trial.

There then following a good session of questions and answers with the main topics being clarification regarding the Patch trial and trial participation by RPCSG Members.

Members were invited to contact the Research team, particularly regarding participation; the telephone nos. are **0118 322 7960/8799**

For those who wish to seek further information Allison did suggest the following links:-

www.macmillan.org.uk

www.cancerresearch.uk.org

Awareness

The only point to mention here is that at the Earley Green Fair a Member did participate, particularly to learn the ropes with regard to how we handle the Awareness issue with total strangers; unfortunately our Cinderella left without giving our organiser, Ivan Peacock, his name. Well at the October meeting he revealed himself to be Alan Ebdon, who is still more than willing to join fellow Members on the next Awareness stand.

Fund-raising

You may recall being invited by Brian Buckner to attend a dance with a 60's theme with the group Trends, playing, proceeds to go to the Robbie fund. Well Brian has informed us that the event was highly successful with a total of £3000 being raised with Brian himself contributing some £124.

We continue to do well with Waitrose Community collections, Jane and Paul Sefcick have been instrumental in ensuring that the RPCG were one of the three chosen for customers, at a Newbury branch, to give their green tokens to, during September.

The good news is we will get a cheque for £375.00 so well done Jane and Paul.

In addition we are still in the hunt for about £1000 which Keith Jackson is persuing with John Lewis in Reading (their tokens are different we believe), the collection area is by the restaurant.

Forthcoming Events

2nd November - Erectile Dysfunction and Mechanical Aids. A Company who markets a vacuum device will be talking about their products and their usage; it will be interesting to hear what spin is put on the products compared with previous talks by Lorraine Grover who has spoken to us several times on ED and how it might be addressed.

Readers will recall that they have been given the opportunity to submit any questions they might have for the speaker, in advance and in confidence, to Chairman Steve.

7th December - The Christmas Social, there will be more details to **all** Members in a separate email.

Support

As you should be aware from issues of Pharos, there is a set of 'phone numbers on a credit card size laminated card, available for Members to take at the monthly meetings. These are for Members' use for seeking support.

For those who do not have the card, the names and numbers are: -

- ② Steve Allen 0118 9266 747
- ② Bill Forfar 0118 9619 655
- ② Ian Forrester 0118 9789 857
- ② Keith Jackson 0118 9842 999
- ② Paul Sefcick 01635 34778
- ② Graham Cook 0118 9691668

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