Notes of Prostate Cancer Support Group Meeting
Held on Thursday 7 November 2013

1. Welcome and Introduction

Ian (Chair) welcomed everyone to the fourth meeting of the Haywards Heath & District Prostate Cancer Support Group, noting that we had many people attending for the first time. He gave a brief outline of how the group was started in summer 2012 by Jenny and Phil Stanger, who, this week, moved house to live in The Wirral to be near to their family. We are, however, fortunate that Jenny's role on the committee has now been taken on by Arthur Millard. Ian explained that within the coming months we will be looking for someone to take over his role as Chair, and that of Jenny Lea (Secretary) although in all probability they will be able to cover the March 2014 meeting.

Ian advised that, very sadly, Mr Whittholme, one of our members died in June, but it was to be noted that his wife had expressed her thanks and sent her best wishes to the support group whom she felt are "doing a great service".

Dawn Hughes, the speaker for this meeting, was then introduced and thanked for giving us her time.

2. Guest Speaker - Dawn Hughes - Prostate Cancer Clinical Trials

(Questions taken as appropriate)

Dawn, is a Prostate Cancer (PC) Clinical Trials Nurse, based at Worthing Hospital, with 26 years nursing experience, including that of Theatre Sister (Surgery) in Urology theatres and Research Nurse for 4 years. Her work involves patients undergoing active treatment as well as others in follow up phases. She firstly explained that death rates from prostate cancer have fallen by 20% since the early 1990s (source: Cancer Research UK). The downward trend is largely as a result of new approaches to treating prostate cancer, such as earlier, more widespread use of hormone therapy, radical surgery and radiotherapy, as well as earlier diagnosis linked to use of PSA test. However, more work continues to be needed. Trials are important in helping find better treatments and by being involved in a trial you obtain information and evidence that may be helpful to you in the future as well as helping the NHS to give people the best possible standard of care.

Dawn explained that Research is at the forefront of everything they do, with protracted processes taking place through different phases to trial new medications and comparisons. Patients benefit from past research and continue to benefit from current research. Two main trials include:

The Radicals Trial, The study will look at patients who have had radical prostatectomy, and establish the best way of treating them, ie, Radiotherapy may be used after surgery at one of two different times. It may be used within a few months to reduce risk of recurrence, or later to treat recurrent disease. As we are not sure which way is best, we need a comparison. Dawn explained that radical prostatectomy is when the prostate is removed. This is only done if the PC is confined to the capsule. Patients are currently hospitalised for a couple of days, the operation now being much improved on what it used to be.

Men who take part in a trial are put into groups by a computer and each group is given one of the two study treatments. A fair comparison can be made with results to see if one treatment is better than the other. Patients have an equal chance of receiving either treatment. Allocating treatments this way means the comparison will be fair. During a trial, treatment progress is usually monitored more closely than if the patients were receiving the usual treatment. It is possible to withdraw from treatment at any time. The study is organised by the Medical Research Council and funded in UK by Cancer Research UK on behalf of the National Cancer Research Institute.

Stampede - this study trials patients further down the line, looking at the use of hormone therapy alone and hormone therapy with combination of drugs or treatment. The aim of this trial is to see which treatment is best for PC that has spread outside the prostate gland.

Radicals and **Stampede** are both national trials, and run in Worthing area, but recruiting throughout the world. Standard of treatment throughout different countries is the same. Prostate Cancer UK has a list of open trials. There is always the need to know there will be sufficient number of patients to enable a trial to be beneficial. Patients need to be fit and well enough to tolerate any treatment. No placebo is used. Prior to any commitment to a trial, patients are fully informed and they need to give their consent. Dawn is available

to patients by phone if necessary. If severe side effects are experienced, or it is shown that a drug is not beneficial, it will be stopped.

Dawn explained that PC is hormone (testosterone) driven and we need drugs to stop testosterone production. Abiraterone works on specific part of the testosterone cell. It is licensed for later use, but is being tried in earlier stages of PC. The patient's tolerance factor plays a large part. Note - If the PC has metastasised to other parts of body, or is in lymph nodes, the spread is treated as PC.

Dawn explained that there is no national screening for PC as there is no universal standard. If you have any worry, you should see the GP and ask for the PSA test. It was pointed out that a raised PSA is not conclusive evidence of PC. Raised PSA can also be caused by infection or enlarged prostate.

Dawn confirmed there is a urine test for PSA, available only privately; not on NHS - a few years away yet!

If undergoing your own research, Dawn stressed the importance of using only credible Internet sites eg. nhschoices to avoid being misinformed.

3. Intermittent Hormone Therapy - Terry

Terry outlined his personal situation undergoing hormone treatment for PC. He explained that a number of clinical trials have taken place over the last 15 years to see what the effect would be of interrupting the hormone treatment periodically, and Terry is undergoing intertmittent treatment with currently no evidence of spread.

One large-scale trial, led in the UK, by Professor Dearnaley of the Royal Marsden, has shown that periodically stopping hormone therapy can result in fewer side-effects without reducing survival chances. A trial in the USA has shown, however, that for men with early advanced cancer, i.e. where there has started to be spread, continuous hormone treatment extends life as compared with intermittent treatment.

In one form of intermittent therapy, hormone treatment is stopped once the PSA drops to a very low level. If, or more likely, when the PSA level begins to rise, the drugs are started again. Another form of intermittent therapy uses hormone therapy for fixed periods of time – for example, 6 months on followed by 6 months off.

The Royal Marsden, where Terry is a patient, has been developing its approach to intermittent treatment over the past couple of years. For this reason, Terry thought it might be useful to explain how things have changed in the way he is being treated.

* A brief Summary of Terry's history of Prostate Cancer is appended to notes

4. Any Other Business

Roger Bacon, Chairman PCaSO, Reg Charity, est. 1998.
Roger gave details of PCaSO and suggested attendees help themselves to any of the leaflets or booklets he had brought along to the meeting, noting the summer Newsletter had content on PSA testing.

Discussion took place on difficulties experienced by some men in persuading doctors to approve PSA testing. Roger stressed that doctors are obliged to give you a PSA test if you ask for one. Guidelines are sent from the Dept of Health regarding this and it states that men over 50 years are entitled to the test. PCaSO have been offering free testing using their own equipment. Roger also highlighted information on the Penny Brohn course 'Living Well with Cancer' focusing on nutitional based treatment.

Fees
Reminder £5 per family per year membership, renewable July 2014.

Next Meeting
It was confirmed that the Haywards Heath and Lindfield District Prostate Cancer Support Group will, for the forseeable future, continue to stand alone as we have volunteers on board to facilitate this. Ian emphasised

the need for members to actively spread the word about prostate cancer amongst family and friends. No particular preference was identified for afternoon or evening meetings, although it was acknowledged that we would need a larger meeting room if numbers are sustained.

Next Meeting **6 March 2014**

J Lea 07112013