

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group Issue 10, Autumn 2011

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.

With the passing of time Members' details do change, so to keep our records up-to-date for contacting you, could you please inform the Committee when things change. This might particularly apply when Members change their email address or go on-line. The easiest way could be for you to let the Editor know via email or let Bill Forfar know at a meeting.

This quarter Pharos is a few days late, I could write a good yarn but prefer to say – sorry.

Committee Vacancy or Your Committee needs You

After nearly four years of committed service our Treasurer, Peter Giles, is standing down as required by our Constitution at the AGM in March, when his replacement will be formally elected.

So why not consider putting yourself forward for this role? To help you decide, set out below are some relevant extracts from the Constitution, which you should already have:-

- To maintain suitable records of all monetary transactions of the Group,
- To operate a bank or building society account for the Group,
- To prepare annual accounts to 31st December each year and to arrange for the annual accounts to be examined and agreed by an independent examiner approved by the Committee.

In addition, as a full Member of the Committee, there are requirements to be an active participant in regular Committee Meetings, which are held at approximately six-weekly intervals. These meetings are held on a Thursday **afternoon** in the RBH Urology clinic and last for up to two hours.

Apart from these regular Meetings, mainly phone or E-mail takes care of intra-Committee liaison, so an appropriate level of PC literacy would be more than helpful for this and the role itself.

So... if you are interested, please make this known to our Chairman Steve Allen, by phone, Email

or at a Group Meeting.

New Committee Member's thoughts

Some thoughts from Paul Sefcick

“ Having given some thought to the request for a nine month input to Pharos, I am pleased to say I have valued the input from the Group at meetings as well as the talks and enjoy being a member of the Committee.

Some have suggested that the repetition of talks by the medical staff may be too much, but I feel that hearing talks more than once can reveal aspects not previously fully appreciated. Additionally, we should not lose sight of the fact that for newer members it will most probably be the first time.

For me, the most rewarding aspect of the work we do, is the interface with the public at the Butts Centre, the Awareness work, after which so many more were diagnosed, where they may not have bothered to seek information.”

Thank you Paul, Members are sure to agree with your Awareness observation in particular.

New Members

Welcome to David and Barbara Tribe, Brian and Freda Buckner, Brian and Gail Worrall, Graham Smith and Jane Sharp, all of who joined in September, then to Graham and Pamela Cook, who joined in October.

A pleasant surprise.

In September, out of the blue, the Group received a cheque for £300, putting our reasonably healthy financial position into a better state.

Tim Hodges, who runs the Jazz Night, which is part of the Wargarve Village Festival, an event held every two years, sent this to us.

Tim has been organising the Jazz Night since 1989 and this year tickets sold out within two hours **and** there were 40 people on the waiting list – clearly a very strong following!

All sorts of people take part and event organisers can elect where the money goes. In Tim's case the charity he chooses depends on what has happened to his friends. For example, last year it was Macmillan Cancer Care before that a Kidney

Transplant Charity.

Tim and a few of his friends have personal experience with PCa so he thought “ what better charity to select”.

If you wish to know more about the Festival try www.wargravevillagefestival.co.uk

Your Editor and Chairman have already written to Tim expressing your appreciation.

Activities since July 2011

Our **August** meeting saw 38 Members including 18 wives/partners attend the Summer Social, which was held at the Crown in Play Hatch. Unfortunately the Editor was unexpectedly unable to attend due to a “nerve” problem, (not lack of!), but in general the feedback has been good, both with regard to the venue and the buffet. Suffice to say we had an outside reporter present, so the best way to report the event is to see his comments!

“Sorry you could not come on Friday after all your work in arranging it. The assembled elders enjoyed themselves greatly, ate well, nay GORGED would be more appropriate, on the main course. Then, even though most of us were replete, we found a corner for some Scones with Cream or Profiteroles..... Aaaaahhh! Roll on next year at the same location. A well chosen venue”

So there you are!

Our **September** meeting saw 58 Members including 20 wives/partners attend the talk by Lorraine Grover on Erectile Dysfunction (ED), yet another simple topic to report on! Fortunately an electronic copy of her presentation was sent out on the 5th September, by Member request, but here goes.

As expected Lorraine did not disappoint us, not only was there more information than last year but plenty of samples of “things” were passed round to Members for examination.

Lorraine began by outlining the NICE requirements for PCa victims with ED problems, the World Health Organisation’s “rights to sexual health” and the importance of sex in the context of a good relationship(s).

Lorraine then spoke to a colourful ven-ish diagram relating to what happens in a normal erection process.

The lifestyle factors with respect to ED were also described together with its impact on lives. This was followed by options for the management of ED as well as various medications, their benefits and potential side effects.

We then went into the toe-curling part with descriptions and images of Intraurethral therapy, Intracavernosal therapy, vacuum devices, and finally prostheses. Then, thankfully, we moved on to psychosexual therapy.

At about this time Members passed “devices” various round the hall for examination and

familiarisation.

Finally lots of useful references were shown for further information and Lorraine finished to the expected level of appreciation.

Since the talk, one Member, who last year wrote an account for us of his experiences with a vacuum-assist system has commented that “ the one Lorraine gave us to inspect is not unlike his (apparatus), though with one or two advantages and disadvantages. Either is obtainable on prescription. The important thing to remember is to allow time, (a week or two!), to practise using it.”

I am sure we all appreciate this information and feedback information from a fellow Member.

If any Member wishes to read about our Member’s experiences, please let the Editor know in the usual way, the archived article is “The Amazing power of a Vacuum”.

Our **October** meeting saw 52 Members including 15 wives/partners attend a talk by Dr Steve Allen on pain management, the main points are summarised below.

Everyone will have experienced pain of some sort. Acute pain is a warning sign of potential harm to the body – from injury, infection, inflammation etc. – and therefore has a useful purpose. Chronic pain, however, is rarely of any use once the original signals of pain have been sent to the brain.

The transmission of pain to the brain is a complex business. The pain impulse is modified at many stages along the nerve pathway to the brain. Psychological processes and previous experience of pain are very important on shaping how the individual ultimately experiences the pain. The concept of a high or low pain threshold is undoubtedly true, but also an over-simplification.

Treating acute pain early and effectively is important as it reduces stress on the body. Untreated pain may cause a rise in blood pressure that in turn can severely stress the heart.

There are many ways in which acute pain can be treated and a large number of routes that can be used – by tablets, injections, suppositories. Local anaesthetics are also commonly used after surgery.

A combination of several different drugs and routes often gives the best results – the so-called ‘multi-modal’ approach to pain relief.

No one should ever be scared of pain. Modern medicine has enormous resources that can be employed.

Awareness

No specifics this quarter, but early next year keep your eyes peeled for PCa Awareness week next March-ish.

Forthcoming Events

Firstly a thank you to those Members who responded to the request for ideas, on both topics and speakers, for 2012. Steve Allen is now considering both these and the draft set you have already seen. You will be brought up to date when further information is available.

Listed below are forthcoming events, where known.

- 4th November: -Mr Steve Foley a consultant at the RBH will bring us up-to-date on treatments for incontinence.
- 2nd December:- Christmas Social
- 5th January:- TBD

Support

As you should be aware from the last issue 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: -

- Steve Allen 0118 9266 747
- Bill Forfar 0118 9619 655
- Ian Forrester 0118 9789 857
- Peter Giles 0118 9861 163
- Keith Jackson 0118 9842 999
- Paul Sefcick 01635 34778

Report from our Outside Reporting Team

As in Summer Social, earlier.

Medical

I am told that there are numerous research initiatives regularly reported in the battle against PCa. Despite that, there was one in the summer, which is vaccine related and described by a research team at Leeds University as "a completely new approach."

This experimental treatment primes the immune system to recognise tumour cells and destroy them, usually the body does not see cancerous cells as a threat and so they are left to grow and spread.

Like many initiatives in medical treatments in general, this potential treatment is based on a growing understanding of genetics. In this case thousands of gene fragments associated with cancerous prostate cells are inserted into a virus, this is then injected into the patient. As the lead author of the study said "The immune system thinks it is being invaded by the virus which is expressing cancer-related antigens that should be eliminated" thus prompting the body's defence system.

The success of the vaccine technique has so far

only been demonstrated at an 80% success rate with mice suffering from PCa, but as a representative of the Prostate Cancer Charity said "The vaccine does not cause any damage to normal, healthy cells while helping to kill the prostate tumour."

The research team hope that within the next few years clinical trials will offer clearer evidence as to whether the new vaccine lives up to its promise. They also said they hoped the approach could be applied to other, **more deadly** cancers – hmmm, I guess it depends where you are standing!

Archiving

Since the Newsletter is the only common publication seen by all Members, one of the roles of the Editor is to maintain an Archive for all Members; the contents list is shown below.

The list contains some articles of a **personal** and sometimes **graphic** nature relating to Members' experiences. Changes since the last issue of Pharos are shown in **red**

Bill Forfar maintains a file, in hard copy form, of Members' experiences and this is available at each RPCSG meeting for Members to "browse" through.

If you wish to have a copy of **any** in the list please let the Editor know if you have Internet access and the Chairman if not.

As mentioned in the summer edition of Pharos, this published list has been "cleared" of timed out material.

(Please be aware that links sometimes "time-out", i.e. don't work, as I have found in the past.)

- Travel Insurance with a Bank - May 2010 (Describes a Member's experience in evaluating and setting up a new account type with a Bank which offers a range of benefits including travel Insurance)
- Before and after a Radical Prostatectomy by robot, Parts 1 to 4 - May 2010 (Written by Member provides a comprehensive outline of "Approaching the Operation part 1, In Hospital part 2, Back home part 3, Incontinence part 4 version 2, July 2010" and covers experiences and practical advice.)
- The astonishing potency of a vacuum! Version 3 – October 2010 (Describes a Member's practical experiences in using a "mechanical aid")
- You Are Not Alone (YANA) - 30 pages or so, a document written by an American diagnosed in 1996 and at publication, still writing, this is the latest update in 2010
- RPCSG Constitution June 2011
- Mr Peter Malone's presentation on the 1st July 2011, pictures only, no text
- Pharos, the Group's Newsletter - June 2009 to **October 2011**

