

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group Issue 12, February 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.

This is the first of three “experimental” **monthly** issues, so in the April issue you will be asked which you prefer, monthly or quarterly.

How did it all begin ?

Looking at the May 2007 edition of *Talk About*, the RBH staff magazine, shows how the RPCSG started and why.

“ To mark PCa Awareness Week a group of nurses at the RBH set up an information stand at the main entrance. They were aiming to raise awareness of PCa and encourage anyone affected to come along to a dedicated Prostate Cancer Support Group, set up earlier in the year. Bev Skelton, the spokesperson, said that the need for such a group was identified from a patient feedback questionnaire in 2006. Shortly after the article there were about six members, including wives/partners, now there are 172 members including wives/partners.”

As Chairman Steve often says, “we must be doing something right”, or more likely, Awareness has increased.

New Members

Welcome to Kim and Gary Jarman and Norman Mills who all joined in February.

February 2012 Group Meeting

The February meeting saw 52 Members, including 15 wives/partners, attending to hear Graham Fulford speak to us on “Raising Prostate Health Awareness. In addition we had six or so members from the newly formed Oxford Prostate Cancer Support Group (OPCSG). Graham spoke for forty to fifty minutes, with great enthusiasm, mainly without having to resort to any visual aids.

The impetus to Graham's mission to raise awareness of PCa was the loss of a dear friend and a brother-in-law, both diagnosed too late. This resulted in Graham eventually forming the Graham Fulford Charitable Trust whose main objective is making people aware of PCa and its potentially successful treatment, if detected early enough. Graham carries out this work primarily in the Warwick area.

Graham and his associates have been instrumental in pioneering the RISKMAN initiative, which not only uses PSA test results but also, DRE testing, family history, ethnicity together with other factors to give a risk figure relating to the probability of an individual having PCa. It is expected that this approach will result in 30% more aggressive cancers being detected earlier than would otherwise be the case.

Graham then showed us a video of a piece of equipment from Mediwatch PLC which is easy to operate and fully portable, (small box of chocolates size), which from a pin-prick blood sample can give a PSA reading in ten minutes, usually in a surgery/medical centre. So instead of days waiting, you can discuss the results with your medical professional almost immediately. The machine is about £1500 with £10 per test strip, new one strip needed per test.

You may wish to look at the link below which I believe shows a similar, if not the same, video.

<http://www.mediwatch.com/PSAwatch.php>

Graham continued his talk with a lot of stats. and anecdotes which were rather difficult to record, but two points stand out.

Firstly, whilst there may not be a Government sponsored National PSA Screening Programme, it is Government policy that all men 50 years of age or older have the right to have a PSA test, if they request it, i.e your GP cannot refuse you. (We did not find out what to do if you were refused – Court of Human Rights is a guess!).

Secondly, the present PSA test is vilified because it is not “guaranteed to give an unambiguous result”. Those of you that have reached the magic six-0 may have had the pleasure of sending off three sample for analysis for bowel cancer, (topical with current TV broadcasts talking about poo recently). The notes you get with the testing kit say amongst other things, “this test will not say that you have bowel cancer, that you do not have bowel cancer, nor that you will or will not contract it in the future” – the implication is Bowel Cancer testing good PSA bad??.

All in all, a thought provoking talk.

Awareness

March is national PCa awareness month and we now have a “pitch” booked for Friday the 16th March 2012 – all day in the Broadstreet Mall.

Last year we had a lot of support from Members to man the stand and talk to members of the public

about PCa, testing and ongoing developments. Twenty or so Members spoke with nearly 200 members of the public so, hopefully, we made a difference.

We have had some response from Members who attended the February meeting, if you wish to volunteer please let the Editor know in the usual way. We do need more of your support, **“Your Group needs You”**

Fundraising

Here is an unedited-ish note from Member George Pritchard regarding fund-raising work he and friends have been involved in over the last few years.

“ On Wednesday 25th January 2012, I and a fellow prostate cancer patient presented a cheque for £1000 to the Robbie the Robot appeal, on behalf of the Tilehurst Square Dance Club, of which we are both members.

The Club, founded in 1989, has a long history of charitable donations. Each year a different charity close to Members’ hearts is selected and money is raised by weekly raffles and by our annual Charity Dance every November.

Last year we raised over £1000 for the Duchess of Kent Hospice where the late Trevor Silk spent some of his last days. This year we will be raising money for the Berkshire Cancer Centre.

Past recipients include Canine Partners for the Disabled and the Oesophageal Patients Association.

It is quite an achievement for a club of around 55 members to be raising these sums of money every year and we felt very proud to be asked to represent the club in presenting the cheque to Mr Ian Thomson of the Royal Berks Charity.

We are always looking for new members to share in what is a very enjoyable and relaxing leisure activity. If anyone in the Group is interested in learning more about the club and American Square Dancing, details can be found on our web site at

www.tilehurst.webplus.net “

Well done the Tilehurst Square Dancers!

Forthcoming Events

2nd March - Dr Fawaz Musa, a histopathologist at the RBH, is coming to talk to us again about how PCa is diagnosed and staged by ‘looking down the microscope’. His talk last year was very informative and well worth hearing again, even if you were there last year.

This will be preceded by our Annual General Meeting. This, as usual, should be short and sweet.

13th April – This will be the first of several Open Meetings this year. Many Members have found the

opportunity to share their experiences with others, including frank and open discussion, to be extremely valuable to all concerned.

4th May – We all have an awareness of the work done by the Prostate Cancer Charity and this month we will hear from Meg Burgess. Meg is a Support and Information Nurse and as such has had significant experience in liaising with PCa “victims”

Please note, unless arrangements change no separate events reminders will be sent, so if you wish to attend any or all of the above, make a note in your diary.

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: -

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

Liaison with other Support Groups

As you will have read, we had some Members of the OPCSG with us at the February meeting, it is proposed that copies of Pharos are sent to them on a regular basis so they are aware of “what we are up to”, so far so good. In most editions Members names and some ‘phone numbers are included for various reasons, rather than have a redacted version it is proposed that **everyone** receives the same version, with the current type of content.

If you object to this approach please let the Editor know. This policy will not be implemented until the March edition at which time “silent consensus” will apply. Thank you for your help.

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. Since the list was included in Pharos there have been two or three requests out of some 500 readers, so in future the list and its contents will only be in the file Bill Forfar brings to the regular meetings. Please ask one of us if you require a copy of anything.