PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group Issue 15, May/June 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.

Voting for the frequency of Pharos resulted in a monthly publication being the favoured one, by a 7:3 ratio and appropriate distribution lists have now been prepared. Votes came in from far and wide ranging from Newbury though Spain to the furthest, from Sri Lanka.

All rules are made to be broken, as they say, you will note this issue is for May/June – ho hum!

Chairman's Thoughts

As planned, it has been some six months since I last wrote anything for Pharos. Over those months the Group has continued to grow in size. The constant regular numbers of people that come to each Friday meeting certainly must show we are doing something worthwhile and, I believe, doing something more than just providing a 'social club' where people can meet. Support, fellowship and information are the main reasons for our existence.

We are fortunate to have speakers from the RBH of very high calibre to keep us up to date with the latest information about our disease. Some of the speakers are concerned that they might just be repeating themselves, but from my experience they have always had something new to say. It also helps us give support to newer Members by reminding us of the various facets of our treatment(s)

Membership of the Group is free of charge and that will always been our policy. But running the Group is not without costs (such as hiring the hall, postage etc). We rely heavily not only on the income generated from the tea/coffee fund, but also on donations from outside, (See more about fund-raising later in the newsletter – Ed.)

I attended the AGM of the Prostate Cancer Support Federation a month ago. Much of this was, not surprisingly, concerned with PSA screening. I have written a little more about this separately, under "Awareness"

The year ahead for us looks very positive. We have a very active and hard working committee, a membership which continues to grow and we are now financially secure – what more could we want!!

But always remember, this is *your* Group. Feedback and suggestions are important. We can only do what you want if you tell us!!

Some thoughts from Graham Cook - our new Treasurer

My initial contact with the Group was just before Christmas 2011, so my first attendance was the Christmas Social. A very enjoyable evening, so I decided that I would like more of this social intercourse.

The opportunity to share experiences in a social environment is very satisfying, I found this aspect of the Group's activity to be invaluable. It is so comforting to realise that one is not alone as a sufferer from PCa. The monthly talks are very informative and it is invaluable to have learned presenters giving in-depth explanations of the types of illness and the variety of cures which are now available.

So far, for me, the highlight has been helping at the club stall at the Broad St Mall which was set up during PCA awareness week in March 2012. I really enjoyed soliciting (not that sort of soliciting!!) mature gentlemen, hoping to have the opportunity to persuade them to have a test for PCa at their local GP's surgery. It was interesting to note the wide variety of responses to my approaches, from a curt "…get lost! I don't want to know", to the guy who thought he was immune because over the past 47 years he had only missed 14 of Reading FC's home games, which suggested that he was immortal.

Shortly after I was elected to be your Honorary Treasurer and was to enjoy my first Committee Meeting since being elected.

More recently I was one of four Members who volunteered to give a presentation at the Open meeting. What a novelty to be allowed to speak for so long without interruptions from the audience, including my wife and fellow Committee Members.

New Members

Welcome to Bob and Janice Beech, John Galloway and Bill Sabani who all joined in April; Ian Gardner who joined in May and also Eric and Shirley Englefield who joined in June.

May 2012 Group Meeting

We all have an awareness of the work done by the Prostate Cancer Charity and this month we were delighted to hear from their Meg Burgess who is also a

new speaker for us. Meg is a Support and Information Nurse and as such has had significant experience in liaising with PCa "victims."

Meg opened her talk by saying she did not get out very often and was certainly not used to speaking to a microphone. She was clearly trying to relax the audience, because as her performance showed, both were eminently untrue!

The Prostate Cancer Charity is the UK's leading charity working with people affected by prostate cancer; funding research, providing support and information, and campaigning to improve the lives of men with prostate cancer. They provide a most comprehensive range of services dedicated to prostate cancer and provide vital support for everyone affected by it.

They do this by providing a UK-wide telephone and email Helpline staffed by specialist nurses and also a one-to-one peer support programme so men can talk to someone who has "been there". This is complemented by their source of free information, tailored to the needs of men with PCa and their families.

None of this is done in isolation, as they work closely with other Health Professionals and Policy Makers and also fund research into the causes, prevention and treatment of PCa.

To give some idea of the size of this undertaking, in 2010-11 they answered over 6000 enquiries, resulting in their Specialist Nurses speaking to 522 men and women affected by PCa and over 3000 callers ordered some of their prize-winning publications, most notable their "PCa Tool-kit". As if this wasn't enough, they held 317 Awareness sessions across the UK reaching over 12000 people and also matched 130 individuals to a volunteer for peer support.

As you might expect in this day of readily available information, there is a website. Unlike the defunct RPCSG one, there were over half a million "hits" in 2011, giving access to information on everything they do, including press releases, FAQs and importantly an on-line community forum (www.prostatecancer.org.uk/forums). In 2011, via this website, 304, 904 publications were mailed out and 19,262 publications were downloaded.

Meg mentioned two of their BMA award winning publications namely the "PCa Tool-kit" and also the "Guide for Newly Diagnosed Men". (From personal experience I can say that not only are these extremely useful but the 48hr delivery service is terrific – Ed).

Members that attended the last two Christmas Socials will recall the Movember Members who valiantly grew moustaches to raise money for PCa. The Prostate Cancer Charity are a major beneficiary of the Movember Foundation, which is worldwide, with over a quarter of a million men raising over £19,000,000 in the 2011 campaign by growing moustaches in November.

In addition to the Movember Foundation there are other areas of financial support including M&S and events such as the London Marathon, which in 2012 was done in conjunction with Breast Cancer Care.

Looking to the future, since 1996 they have awarded over £12 million to innovative research aimed at improving the lives of men diagnosed with PCa. Whilst the impact of the Movember Foundation can be seen for the Prostate Cancer Charity since their funding will allow the Charity to commit £7 to £8 million to new research, every year, for the next three years – a dramatic increase.

Their research strategy identifies three main areas for PCa research which include: identifying men at the highest risk of developing clinically significant PCa, distinguishing aggressive PCa from indolent disease and finding new, targeted treatments, for aggressive PCa. The last area being particularly interesting since it relates to developing new types of drugs which are inactive until they come into contact with the tumour - clever stuff, particularly as it reduces side-effects.

At the end of Meg's presentation there were quite a few questions and answers, in particular one Member mentioned the reluctance, even refusal, of a GP to sanction a PSA test. The consensus approach seemed to be to go and see the GP armed with the leaflet on pros and cons of testing take him though it and say that you fully understand what it means. (by the way it is Government policy that you have the right to a test when you reach a certain age)

The Group then expressed their appreciation in the usual way.

June 2012 Group Meeting

Our speaker this month was Lt. Col. Ed Shah, from the RBH, who has spoken to us on two previous occasions. As always, he was very well prepared with the gizmo to plug into our "projector"

Ed started off with three photos entitled, "since last time". You may recall that when he spoke last year he had just collected his keys for his new home, so the first was a photo of his new thatched cottage. You may also recall that when he spoke previously he was soon to go on-duty to Afghanistan, so the second photo showed the gates of somewhere in that country. Finally, and perhaps the most important, was a picture of him and his bride on their wedding day.

Ed explained that he had been asked to talk about the relative merits/superiority of open prostatectomy surgery versus robotic prostatectomy surgery and so he had prepared material on that basis.

So what do we mean by Superior, is it cancer cure rates, continence rates, potency or ensuing complications?

Like so many things it depends who you ask and what you ask. For example Intuitive (the American company who make Robbie), not surprisingly say it is superior! In fact "Robot-assisted radical prostatectomies are now the most common surgical treatment for prostate cancer in the USA, supplanting open radical prostatectomies. Robot-assisted surgery also has better

perioperative outcomes than open surgery." But there is no mention of cancer cure rates and so on. In the USA the situation is heavily driven by both patient and market forces with Hospitals being able to charge enhanced fees, particularly when using the latest version of the Robot.

Large and meaningful studies from the best centres show there is no difference in cancer cure, continence, potency or ensuing complications. Having said that the RBH find robotic is superior for recovery to full activity, reduced hospital stay and also blood loss, but … it not only costs more but takes longer. Like most things it is not black and white... "the robot's ability to reach into small spaces comes with trade-offs. Ordinarily, doctors can feel how forcefully they are grabbing tissue, how well they are cutting, how their stitches are holding. With the robot, that is lost. The robot is slow; it typically takes three and a half hours for a prostate operation, according to Intuitive, twice as long as traditional surgery." So it is no better/ worse for major outcomes and its major disadvantage is cost.

Ed then moved on to address learning curves, where again, it depends. If a surgeon has extensive open or laproscopic experience it could be quite a simple learning curve, but with no laproscopic experience it has been suggested that after 100 "goes" a surgeon would be experienced with using a robot.

So what do published figures reveal when comparing the two types of surgery? It seems there is no significant evidence of improved continence or potency. As far a cure rates are concerned, evidence is again unclear since sometimes hormone treatment is stared very early and also improved PSA testing will reveal " failure" earlier than it might have been the case pre robot say ten years ago. It is all quite complicated, for example in the USA there are multiple theatres in use, in the same hospital, with the surgeon moving from theatre to theatre with other teams preparing for his arrival and finishing off when he leaves, these teams record their own results and there is intense personal pressure to be the most successful team.

So the approach at the RBH is:-

- be honest, frank and open
- keep up to date
- bring in latest improvements
- be meticulous (an operation will take as long as it takes)
- accept complications will happen, but work hard to keep to a minimum

Looking to the future, there are developments in the cardiovascular area where new software is being developed which synchronise the movement of the " knife" to the beating of the heart, so the surgeon sees a stationary heart on the screen.

All in all a really interesting talk, with many questions that Ed described as "that's a difficult one" but gave a good answer anyway.

Awareness

The following input was provided by Chairman Steve following his attendance at the Federation AGM in May of this year

PSA Screening

It is currently agreed that the conventional PSA test is not ideal as it does not always distinguish between raised levels due to cancer and those due to normal enlargement of the prostate gland. However, it is currently the best and easiest screening test that we have and is widely available. Also, compared with other screening tests, it is not that bad. For instance, the 'pick-up' rate for cancer is much less with the current test being used for screening bowel cancer (using smears of faeces sent through the post) or possibly even current breast cancer screening techniques. Doing the PSA test is not the problem – it is what is done with the results that matters. Current thoughts are to tailor screening to those at risk rather than perhaps offering blanket screening.

The Prostate Cancer Support Federation are actively supporting the 'Riskman' project. This uses a screening tool combining known risk factors (age, family history, ethnic group etc) with the findings of a rectal examination and a blood test that measures both 'total and 'free' PSA (see ** below) to estimate the likelihood of a prostate cancer being present. It does not normally include a prostate biopsy (and all of its possible complications) for the initial screening. There appears to be a very high rate of positive findings with very few false negatives. The aim of this approach is to reduce the number of unnecessary prostate biopsies being performed, without reducing the accuracy of diagnosis of prostate cancer. There are currently further trials being set up in a number of GP practices to assess how useful this approach will be.

(** PSA is found in two forms in the blood. 'Total' PSA is exactly that – the whole amount found in the blood. 'Free' PSA is that which is present freely in the blood and not attached to other molecules such as protein. The ratio of Total to Free PSA can be a useful indicator as to the source of the raise levels – i.e. whether the raised PSA is from cancer cells or not. For various reasons, this slightly more complex blood test is not the standard one used in most hospitals – although there is an increasing body of opinion that it should be.)

At what age should we do PCa screening?

Current advice in the UK is that a PSA test should be offered to any man over 50 yrs who requests one. However very few men know this – such is the poor publicity currently available.

There one opinion – albeit not a generally accepted one as yet – that the initial PSA screening age should be set as low as 40yrs. The argument is that at this age there is little or no 'background noise' of raised PSA due to normal enlargement of the prostate with age,

inflammation of the prostate etc. The argument is that even a minor rise in PSA at this age may suggest a patient who is at risk from developing PCa and indicates the need for closer monitoring. The earlier the PCa is found, then the more minor the treatment that may be required.

It is a very interesting concept, but yet to be proven with definitive scientific data.

The variable nature of Prostate Cancer

We all now understand that PCa is not one single disease but varies from being slow growing (the 'pussy cats') to being highly aggressive (the 'tigers'). Current research is throwing up many different factors:

- Within the same biopsy sample there may be up to 5 different genetic sub-types of prostate cancer cell
- It has yet to be definitively established which of these sub-types is likely to be an aggressive cancer
- Not every low-grade cancer cell will develop into an aggressive one
- Some aggressive cancer cells produce very little PSA and make the test more difficult to interpret
- Not all cancer cells are capable of producing a secondary tumour if they 'escape' outside the prostate gland (e.g. via the blood stream). Many of them will simply just die without any further effects. But it is not yet clear which cells can do what.

Genetic screening – is this the way forward?

60 different genetic markers associated with prostate cancer have now been identified. However, it is not yet known which are the most important. Genetic factors associated with prostate cancer are much more complicated than those associated with, for example, breast cancer.

Genetic screening can be done at a very early age and thus there will eventually be the possibility of identifying, almost at birth, those at risk of developing PCa - as may be possible with many other diseases. However, with such eventual technology will come huge social and ethical problems.

So where do we go from here?

Many cancers have a fairly simple basis and we can predict the course of the disease well. Prostate cancer is certainly not one of them. However, the encouraging feature is that so much research effort is being put into PCa – the most common cancer in males.

It is very much a case of 'watch this space'…….

Fund-raising

Members who attended the AGM can congratulate themselves on their wisdom, perceptiveness and far-sightedness in voting Graham Cook onto the Committee as Treasurer. At the May Committee meeting he announced he had persuaded Woodley and Earley Lions (of which he is a long-term Member) to donate £1000.00 to Group funds. So a very big **thank you** to both Graham and the Woodley and Earley branch of the Lions organisation.

The last I shall be reporting for Peter Soul's Beethoven initiative is that the latest figure is over £4000, including the Gift Aid element. To see the latest go to the Just Giving website and type in Peter Soul.

Waitrose have also again come up trumps - thanks to Paul Sefcick. The Group is one of the three beneficiaries of the June collection of 'green discs' in the Speen (Newbury) branch. You can always 're-direct' your green discs collected from other branches and divert them into the box at Newbury if you want us to! But don't forget that this is **only** for the month of June and the collection will have finished by next month's meeting.

We hope to have a similar collection in John Lewis in Broad Street Reading. They are doing a similar collection just for those people using the restaurant. Keith Jackson has put our name forward and we await a decision…..there is a rumour they will **not** be using the green tokens!!

Forthcoming Events

6th July 2012 – This meeting will have Karen Willmot, a research nurse from the RBH, supported by one of her colleagues, giving us their take on the research they are involved in, particularly with the University of Reading.

3rd August 2012 – We will have Helen O'Donnell also from the RBH speaking to us. Helen has experience in Radiotherapy, Chemotherapy and also Hormone treatments so whichever she focusses on should be interesting.

4th August 2012 – For over ten years Earley Town Council have supported the Earley "Green Fair". Many of the stalls are related to 'green' issues and the environment but there is also an opportunity for other organisations, such as ourselves, to be involved. The RPCSG has always been actively involved in promoting both the support that the Group can give to those affected by a diagnosis of prostate cancer and also encouraging awareness of this , the commonest cancer in men. We are planning to run a stall at this event and will be asking for you to help. It is from 10.00am to 3.00pm. Ivan Peacock has agreed to co-ordinate the event, so please pencil this into your diary and await further information.

9th and 10th August 2012 – At 3pm on both days you will be able to see Bev. Skelton's daughter, Katie, perform on TV in the British Synchronised swimming team, at the London Olympics. Bev. says "Katie is the little on at the front."

17th August 2012 – This is the planned date for the Summer Social. Those who have attended RPCSG socials seem to think they are both worthwhile and enjoyable; it is highly likely this one will be no exception. Venue, format etc. is being finalised so again mark your diary appropriately and then await more information.

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
- Graham Cook 0118 9691668

Something different

Life can exist in a variety of extremes, ranging from high pressure, through high temperatures to high levels of radiation and many other combinations. Most of these are single celled organisms, but they may have unique genetic structures and interesting survival strategies. Organisms of this type are classed as extremophiles – lovers of extreme conditions.

In the last fifty years or so there has been a rapid increase in the number of types identified. The toughest is one that has been listed in Guinness World Records, which can survive significantly higher levels of radiation than a human being. Ignoring why evolution developed the organism, it has a system for constantly repairing its DNA. Cancer starts a a cell mutation, so if we understood the above "repair mechanism" perhaps cancer could be stopped before it took hold – a thought!

Corrections

In the April edition it was stated that Richard Goldsmith appeared on Radio Berkshire, this was incorrect, it should have been Richard Goldingham – sorry Rich.

Not only was there that error, but I have been advised that in case Members wished to do any research into "shy bladder" the correct spelling for the medical term is "paruresis", although, for the avid researcher I did find that Google went straight to the correct area.