

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group Issue 11, Winter 2012

Editorial Comment

Pharos is called a Newsletter, but since it is issued every three months some of the material is nearly three months old, some two months old etc.etc., scarcely a Newsletter, more a diary/journal. As I recall from business, “if you are not moving forward you are moving backwards”!

Pharos has been **produced** progressively for a number of issues for a while now, for example, the November 2011 meeting was written up within a week of the event and the December social similarly, you should be reading this within a week of the January 2012 meeting, because it has been issued earlier than normal.

So, as an experiment, the Spring quarter will have three, **monthly**, issues published soon after the February, March and April meetings. As a result there will not be separate events reminder emails, unless something unplanned happens all will be in Pharos, (he says hopefully).

Which leads conveniently to the next standard paragraph where you can either provide feedback now, or in the following months, as you wish.

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.

Just a point of clarification, when the term “Member” is used it refers to both the male and wife/partner unless stated otherwise.

Chairman's New Year Thoughts

Subject to the above-mentioned experiment, this is likely to be the last Pharos before our AGM in March, therefore I hope you will all forgive a few disconnected ramblings for your Chairman of (nearly) 1 year.

The Group has been in existence for over 4 years and has continued to grow in numbers. It was founded to provide ‘support and fellowship’ to those diagnosed with PCa and I think that our continuing success indicates we are still doing this. However, this is only achieved because of you, the Members, who are so

willing to be caring, open and honest in discussing your experiences with others, who need help and support.

The Chairman is often the first telephone contact that potential new members, often very anxious and worried, will have with the Group. It is tremendous to have the knowledge that we can call upon so many people who are willing to offer experience and support to complete strangers. I well remember how much I gained from speaking prior to my own operation with someone who had been through the same procedure. I find it encouraging that we are seeing an increasing number of new people coming before they have had their treatment.

I firmly believe that this ability to help and support others should remain our fundamental ‘*raison d'être*’.

Nothing happens on its own, however, and the Group owes great thanks to all of those who work in the background to keep things running smoothly. Whilst the Committee does do a considerable amount, emails do not get sent automatically, the chairs do not move on their own and cups of tea do not make themselves. The fact that I can write this in a newsletter only comes about because of the enthusiasm and considerable work done by our Editor.

Learning more about PCa is also another important function of the Group. The talks given to us by our speakers are always informative, relevant and frequently highly entertaining. To be honest, not every PCa support group is as fortunate as ourselves in having such support and close liaison with their local ‘medics’. We are also planning to have at least two speakers from outside the hospital in the near future.

We cannot escape from the practicalities of life, however, and the Group needs finance to pay for the basics of renting the hall, insurance and the like. From other issues of Pharos you will know we have been very lucky in the past year with donations from Waitrose and the Prostate Cancer Support Federation (PCSF) and more recently from the Wargrave Jazz Festival. Whilst the Group remains happily solvent at present, if anyone has ideas or connections that might be a potential source of future funding, then we’d love to hear from you.

As ever, the Group belongs to its Members and we need **your** input into how we can improve things. We are always open to new ideas and constructive criticism. So don’t sit in silence if you feel changes need to be made – but be prepared to be asked to help make those changes happen!

Finally, if it is not too late.....

May I wish everyone a very happy and healthy New Year.

New Members

Welcome to Chris Floyd, David and Pamela Priest and also Tony West all, of whom joined in November 2011; then Don and Ruth Palmer who joined in January 2012

Activities since October 2011

Our **November** meeting saw 72 Members, including 23 wives/partners, attend a talk by Steve Foley FRCS from the RBH, on Incontinence. In summary this was a very informative talk by a speaker who was interesting, informative and amusing. (As an aside it seems that many of the Surgeons who speak at our Meetings really wanted to be comedians, viz Peter Malone, Ed Shah and now Steve Foley, but thankfully for many our Members, they chose surgery.)

Steve F started his talk by explaining that initially his experience was based on female incontinence. The changes in male anatomy caused by removing the prostate is a little like the second birth, where many problems start for ladies and so as time went by his involvement in male incontinence grew.

Steve F explained the main categories of incontinence namely, Urge, Mixed, Overflow and Climatura.

With "Urge" there is an element of "zip jamming" when most inconvenient, this type is common as a result of surgery and good old fashioned ageing.

However "Mixed" tends result from stress such as coughing or a 400yd golf drive.

Not surprisingly "Overflow" is as a result of a full bladder which can be exacerbated by Urge and Mixed.

The clue is in the name, so not surprisingly, "Climatura" is associated with sexual intercourse!

There was discussion with the audience on frequency, Steve suggested that it was not abnormal to go eight times a day and once at night.

The statistical incidence of Incontinence is quite variable depending on how the question is asked, whether it is face to face and also treatment availability for the person answering the question. In time-scale terms it can often take up to two years before significant improvement occurs, if at all, particularly after surgery.

Steve F explained that surgery, particular as it "attacks" the cobweb of nerves around the prostate, increases the risk of incontinence; this is exacerbated if surgery is followed by radiation treatment.

The talk then moved on to treatments which include, "Bulking Agents", "Slings" and Artificial Sphincters. Bulking Agents, which are akin to squirting goo into the lips of the mouth, makes up for loss of tissue due to surgery. It is easy to do, expensive but less efficacious.

(A bit like Lilly the Pink for those of the Editor's generation.).

Slings are quite common and have been used in various forms since 1914. In principle the sling reinforces the pelvic floor, making up for the loss of tissue caused by the removal of the prostate. The body tissue grows into a synthetic mesh thus reinforcing the pelvic floor. Long term success rate of up to 70% is achieved with marked reduction in incontinence and only minor complications.

A few Members have the Artificial Sphincter fitted, it is very mechanical, with an inflatable ring around the urethra, a reservoir of fluid to inflate the ring and hence stop the flow and finally an "actuator" in the scrotum; with the other bits in the pelvic area – good grief!

The good news is that long term results are good, the downside is that, being mechanical, bits do break, with 50% failing over up to seven years either mechanically or medically; but repair is relatively easy. Steve F did mention that he is shortly to go on a training "course" for this technique/surgery and hopefully it will be available next year at the RBH.

All in all an excellent talk and, as noted on the night, do remember we have Members who have had some of these treatments, in some cases more than one.

Our **December** meeting was our Christmas Social, which resulted in over 50 Members, including wives/partners, attending and enjoying both the food and the company.

The Committee arrived at the hall at 4-ish to set up and decorate the ten tables for Members and also the three tables laden with food and other goodies. Things went well and by 6-ish the Committee were "coasting" to such an extent they were able to crack open a couple of bottles for refreshment and sustenance.

One thing was particularly special and that was the "Menu du Jour" especially written and produced by Chairman Steve. During the evening a rumour started to circulate that it contained numerous errors, after investigation it was revealed that it had been written in francais-allenes, which some will be aware is a little known dialect from a French wine growing region. For those that wish to verify this, the menu can be seen at the end of the newsletter.

Committee donated Raffle prizes were won by ten Members, two even won two and one was placed back into the raffle; the Editor mislaid his tickets and when he got home discovered he would have won also, but naturally would have declined to take the prize – oh the pressure of Media work!

The table with Committee member Bill Forfar and Janet won the quiz, so you know who to sit with next year!! The quiz was lead with enthusiasm by our Chairman and Quiz-Meister – Steve Allen.

Events like this would not be the success they normally are without the hard work of the "ladies of the Committee" who made everything so welcoming and, in

particular, to Sylvia Allen who did the mega-shop beforehand. - Thank you ladies.

Finally, thanks to the generosity of attendees in buying 152 raffle tickets, a donation for £152.00 has been sent to the Robbie the Robot appeal as mentioned at the Social

The **January** meeting saw 48 Members, including 13 wives/partners, attend a talk by Bev Skelton on the role of the Urology nurses in the care of patients with PCa and other issues.

This talk was initiated as a result of feedback from Members, who you will recall were asked what topics should be included for 2012 - "it's good to listen"!

Bev opened her talk with a list of the nurses: the Clinical Nurse Specialists (CNS) are – Janet Forgenie, Sammi Kaur-Gill and Tessa Martin. Bev being our Urology-Oncology Nurse (UON). Bev introduced Tessa Martin who is Mary Hill's replacement, Tessa said hello and joined in the presentation and questions and answers as appropriate.

In scope Urology covers Prostate, Bladder, Testicular, Kidney and Penile problems, whilst in geographic terms it covers the whole of the Thames Valley including : Oxford, East Berks. Milton Keynes, Swindon, Basingstoke and University College Hospital London. In all, a considerable scope, a high percentage of the English population and provides the ability to draw on considerable skills, knowledge and experience.

In 2001 the Urology-Oncology post was set up, by Peter Malone, with the initial team comprising Bev and Liz Riddle. Later as a result of the benefits of such a role, the Clinical Nurse Specialist role was initiated and developed, with degree standard qualifications now being required.

The UON work closely with the CNS team and has a significant role in coordinating the bladder treatment clinic, the new bladder cancer service and also chemotherapy treatments in the Wards. Additional coordination work involves the penile clinic and last but by no means least, support to patients, their families and Ward staff.

Bev then showed an illustration covering the CNS role, it was quite "busy" and contained much "Management speak", but, in essence, the CNS will have advanced clinical/diagnostic skills, an in depth knowledge of the tumour area, excellent decision making capabilities, the ability to assess patients' holistic needs, empathy for the patient and their family plus good interpersonal and persuasive skills; in short- be good at their job. So you can tick these off when you meet one.

Bev's last illustration captured it all, "Our main responsibility is to support **You!**"

In response, as a patient not an Editor, I would say "**You all** do it brilliantly" This sentiment was felt by the majority of the audience.

In his "vote of thanks" Chairman Steve said that he can remember the era before specialist nurses and it is

so, so much better now; he went on to say that we are incredibly fortunate to have them. Not unexpectedly thunderous and deserved applause ensued.

I nearly forgot - in the question and answer phase it was mentioned that Lt Colonel Ed Shah and Peter Malone both operated during their Christmas "break", so that schedules did not become more difficult. Not what you hear in the frequent doom and gloom newscasts, nor the fact that they would have needed a considerable number of support staff of many types to be available with them.

Awareness

Just a reminder to keep your eyes open for things to do for PCa Awareness month which is March, more details when they are available.

Forthcoming Events

3rd February - We will have Graeme Fulford a visiting speaker from Warwick. Graeme is a patient with PCa and has taken on a very active role in promoting screening for PCa. He works closely with David Baxter-Smith, a consultant urologist in the same area of the country. They have been innovative and instrumental in setting up mobile screening sessions for PSA testing and counselling. They have also developed the 'RiskMan' tool for PCa assessment.

Graeme is a new speaker to us and, we are told, highly evangelical about awareness, so this should be a very stimulating evening.

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 hopefully, sweet.

13th April – This will be the first of several Open Meetings for 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 (PCC) and this month we will hear from Meg Burgess. Meg is one of their Support and Information Nurses and as such has had significant experience in liaising with PCa "victims".

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
- Peter Giles 01189861163
- Keith Jackson 0118 9842 999
- Paul Sefcick 01635 34778

Football and PCa

Towards the end of last year RPCSG Members and many other Groups/individuals voted for the PCC to be the Football League's Official Charity partner for 2012-2013. The PCC had previously been short-listed down to six and this **final** voting stage, where RPCSG Members could participate, clinched it for the PCC – so well done everyone. It will now be interesting to see how the initiative develops and how Groups such as ours and individual Members are involved. Already the Oxfordshire Group are thinking of initiatives and Chairman Steve is liaising with them.

But please put forward any ideas you may have in the usual way.

Medical

If you were diagnosed before August-ish 2008 you may well have volunteered to participate in a study entitled Men After Prostate Surgery (MAPS). One of the main aspects to address was incontinence, the interim report recently published concluded that personal coaching in Pelvic Floor Exercises were only slightly more effective than "reading a pamphlet" and then doing the exercises.

Robbie the Robot Appeal- Sit-rep

One of our Members has enquired about the

financial 'health' of Robbie. Having been in contact with the Royal Berkshire Charity, who oversee all charity donations to the RBH departments, the current status is that a further £975,000 needs to be raised, over 3 instalments, to ensure the permanent viability of this cutting-edge treatment technology at the RBH. These instalments are due in 2012, 2013 and a final one later, the values are £305,000, £305,000 and a final instalment of £365,000, so easy to type!

An increasing number of patients are being treated via Robbie and major open radical prostatectomies are rarely being performed at the RBH now.

At present there are 28 da Vinci machines in the UK, which compares unfavourably with Italy at 45 and the USA with 1048!

At the expense of repeating what you have heard on many previous occasions, we, in Reading, are exceptionally fortunate to have a Urology Department of the highest calibre right on our doorstep. Many others are not so lucky.

Further information can be found on the RBH website.

www.royalberkshire.nhs.uk/pdf/RB_Robbie.pdf.

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 three or four requests out of some 500 "readings," so in future the list and its contents will only be in the file Bill Forfar brings to the regular Meetings. Please ask either Bill or the Editor if you require a copy of anything, ideally electronically.

Menu in francais-allenes for the Christmas Social 2011



PLAT PRINCIPAL

Saumon à la Sylvie
Dinde du Ken
Jambon au Wilhelm
Poulet Pignons du Forestier
Des quiches végétariennes à Irene

Salade de tomate
Salade verte
Salade de trois haricot à la Jane

Pain et beurre



LES DÉSSERTS

Tiramisou Pierre
Forêt noire gateaux de Janët
Tarte aux fromage et limon de Paul
Désert des pommes à la Sheila
Bavarois fraise au Étienne
Plat des pommes.
Clementines, bananes, raisins

Sélection des fromages