

# PHAROS

*A beacon of hope in the darkness*

*Newspaper of the Reading Prostate Cancer Support Group Issue 22 February 2013*

## **Valete # 1**

Pharos has been edited by the same person for nearly four years now, with twenty-two issues being produced and issued. So not only is it time to hang up my keyboard but also to stand-down from the Committee, which will be at the forthcoming AGM.

As is customary with farewells I should like to thank Members for their contributions to the newsletter but especially Irene for her patience and support during my period in office, in the many, many things I have done.

At the time of publication of this issue, a replacement has/has not come forward (delete as appropriate!) so don't be shy in coming forward. - Your Committee and the Group truly does need you.

## **Valete # 2**

As Members may know, Bill Forfar, the smiling face you see giving out the badges will also be standing down at the AGM. Bill has kindly provided a few words of both a personal and advertising nature.

### **“ Vacancy for Meeter and Greta**

I shall be leaving the Committee at the AGM since my three years tenure is up. I have enjoyed being Greta and keeping the Badges, Attendance and Membership records up to date. I think we have found a person to take on the Excel work of the above each month.

However, we need to find one or two BADGE-MEN or GRETAS who work together each month to MEET AND GREET Members at the door and hand out the badges.

This SUPPORT part of the group is especially important for newly diagnosed men and their partners who come to our meetings for the first or second time. Just a smile and handshake is often enough to relax them and start the conversation towards what is worrying them most. Then a chat with someone who has experience of their particular diagnosis/worry can work wonders in reassuring them and their partner.

If you think you could help once per month please phone or email me and I will explain in detail what is involved.

In essence the commitment would be –

1. Bring the Badge Board to the monthly meeting by 18:30

2. Greet members with their Badges (you'll soon be able to match face to Badge)
3. Meet any NEW man, ask him to write out his contact details and diagnosis information.
4. Find out who matches his diagnosis and initiate a reassuring chat between the two, or find a free Committee man to take over the chat.
5. Collect the Badges at the end of the meeting, tot up the attendees and tell our Excel record-keeper, and store the Badges.

Let's keep up the good work we have managed so far in the RPCSG in promoting awareness AND supporting those who have been diagnosed.

Best regards, Greta (aka Bill Forfar) “

## **Activities in the last month**

The meeting on the 4<sup>th</sup> January was less formal than normal than usual, with no speaker planned. Despite that some twenty-five Members attended, perhaps illustrating that Fellowship and Support is high in Members thoughts, rather than only listening to speakers?

Our regular Meeting on the 1st of February saw Dr Alan Tang visiting and speaking to us for the first time. Alan operates the ED (Erectile Dysfunction) clinic at the Royal Berks, apparently not only single handed but also from a single office/insulting room!

Alan began by showing us a list of some twenty “reasons” why a person might develop ED, these ranged through a lot of long words but did include:- loss of attraction, pelvic surgery, pelvic radiotherapy, diabetes, hormone deficiency, hypertension and certain drugs such as anti-depressants.

Addressing ED not only can help to restore “normal relations” but it can be a harbinger/warning/herald of cardiovascular disease, this being due to the fine arteries in the penis being blocked up to four years sooner than a larger but blocking main heart artery. The dimensions ranged from 1 to 2 mm diameter to 5 to 7 mm. in diameter

(Regular readers will recall we were warned about this “harbinger” before by Lorraine Grover, one of our speakers, who also runs a clinic.)

Alan then went through the the types of therapeutic treatments available, ranging from oral drugs with trade names such as Cialis, Viagra and

Levitra, through drugs which are injected into a very sensitive part of the male anatomy (Gosh, my eyes are starting to water at the mere thought of what I might soon be typing – Ed!)

A table of “warm-up times” was shown plus “effectiveness times” which not surprisingly varied not only from drug to drug but individual to individual, if they worked at all. Like many medications there can be side effects and the range and incidences of these varied from drug to drug.

Dr Tang then showed some pictures entitled, “Recipe for Good Sex” when using appropriate drugs

1. Stimulation is needed, but from the picture it only seemed to be appropriate for Humphrey Bogart and Loren Bacall in a 30's clinch.
2. Food you have eaten can affect absorption – but no examples were given.
3. Awareness of post-dose timing is important
4. Finally, don't give up too easily, under medical advice – try another drug, we all react differently.

Now for the eye watering bit. Alan showed us a picture of a process of injecting a pellet of Alprostadil intraurethraly into the penis. The trade name for the process is MUSE (Medicated Urethral System for Erection). I must say I prefer the Greek mythology version of a Muse which is - one of nine goddesses. The drug stimulates blood flow in the penis, although things are shorter and softer than pre-ED. Some side effects have been observed, such as penile pain, pain in the legs and prolonged erections, which need to be addressed relatively quickly.

Alprostadil can also be injected transversely into the penis where it has similar effects and reactions. Sometimes these injections can lead to Priapism. (( Editorial research reveals that this is a prolonged and painful erection that can last from several hours up to a few days. Contrary to popular belief, this condition is not associated with sexual thoughts or sexual desire, even though the etymology of the word itself comes from the Greek male fertility god, Priapus.

In the normal erection process blood flows into the penis and, usually following an orgasm, drains out of the penis without discomfort. When priapism occurs the blood is unable to drain as it would normally. Because there is little room in the penis for blood to circulate, it becomes stagnant and begins to lose oxygen. Without oxygen, red blood cells become stiff, making proper penis drainage even more problematic. The occurrence is usually linked to dosage greater than that recommended being administered.))

Alan then went on to discuss Vacuum devices which have been more than covered in the November and December issues of Pharos, besides which, the “paper” written by a practising Member - “The Astonishing power of a Vacuum - Version 4 is available, on request..

Next we had the “multi-part inflatable prosthesis” complete with reservoir, cylinders and pump, the latter in the scrotum. I wonder if it is an electric pump and does it use lithium ion?

Alan then mentioned a couple of web sites which might be useful, the Sexual Advice Association <http://www.sda.uk.net> and a second one which is more of a text book entitled “Intimacy and Sexuality for Cancer Patients and their Partners” . It has an NHS logo, with the latest reference year being 2009. Below is the address.

<http://www.issc.nu/uploads/02-brandenburg.pdf>

Dr Tang then took and answered several questions and was thanked in the usual way with appreciative applause and a bottle of medicine, to be taken orally.

(As several Members commented to me “An excellent speaker, explained things in layman's' terms and we should have him speak regularly” - all of which I thoroughly endorse – Ed.)

### **Awareness**

As many readers will know, March is National PCa Awareness month and the Group is more active than normal at this time.

In particular, Keith Jackson is liaising with the Broad Street Mall management so we can, as usual, have an RPCSG stand there. Additionally he will be seeing if we can have a presence outside of M&S on the same day.

The date for your diaries is Friday the 15<sup>th</sup> March. Not only can you say hello as you pass by, but Keith would really, really, really appreciate it if you could volunteer to man/person either/both stands for a while during the day

Please contact Keith on 01189 842 999 if you wish to help. At the February Group meeting some Members volunteered but we still need more so come on “Help to make people Aware!

### **Fund-raising**

As reported in the December issue, money from the Social raffle will be donated to the newly formed Reading Bladder Cancer Group, this has been increased to £300 from RPCSG funds, which can well stand the donation.

### **Forthcoming Events**

1st March – The Group's AGM plus a speaker and topic (TBA) will take place at this meeting

### **Support**

As you should be aware from previous 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, currently

the names and numbers are: -

1. Steve Allen 01189 266 747
2. Bill Forfar 01189 619 655
3. Ian Forrester 01189 789 857
4. Keith Jackson 01189 842 999
5. Paul Sefcick 0163 34778
6. Graham Cook 01189 691 668

## Outside Reporting Team

### Report #1

As you may recall from a recent “event” flyer the Central Reading Lions Club recently organised a PSA screening session - here is a report from our Chairman whose evangelism shines through the blizzard.

### ***Avalanche hits Reading!!***

On 24<sup>th</sup> January 2013 an avalanche hit Reading’s Royal Berkshire Hospital. No, not more of the snow from the previous week, but an avalanche of men attending the first ever PSA screening session in Reading. In just 4½ hours nearly 500 men (489 to be exact) attended to have their blood taken for PSA analysis.

The evening was organised by the Central Reading Lions Club. Arguably more used to being involved with fund-raising BBQs, firework evenings and the like, this was a very new venture for them.

The project was managed by one of their more prominent members, John Mack – a powerhouse of enthusiasm and vitality, and someone in whose vocabulary the words ‘no’, ‘impossible’ or ‘unlikely’ simply do not exist.

### ***Good organisation is essential***

The venue for the evening was the Royal Berkshire Hospital – home of a Urology Unit with a national reputation for the excellent management of prostate cancer and where all of the blood samples would be processed.

The hospital layout fortunately allowed for the use of a large waiting area for the initial reception, completion of forms etc. and there was additionally a League of Friends tea bar which did a brisk trade for the whole evening. The pathology dept was only 30 metres away, complete with a secondary waiting area and 4 purpose designed phlebotomy areas.

The event was timed from 5.30pm to 9.30pm. Using this time-scale allowed the free use of the large nearby staff car park – how often can you now park at a hospital for free!

On the evening, the Lions had a machine that worked with military precision – car park attendants, reception staff, patient data forms and even an ample supply of pens with which to fill in the forms. You name it, they had thought of it!

### ***Publicity is the key***

How on earth do you get 500 men to come? As one of the Lions said: “*Publicity is the key – if the*

*public do not know about it, then they don’t come.”*

5,000 flyers had been printed and distributed – many by the Lions Club Santa Claus as he visited the Reading area as part of the Lions pre-Christmas fund raising. Posters and flyers were sent to Golf Clubs, other Lions Clubs, local companies and displayed on community notice boards. 2 local radio stations and the local press gave good coverage.

John Mack said: “*We hadn’t a clue whether 20 or 200 would turn up. We never dreamed that so many would come.”*

However, the whole team rose to the challenge, particularly the phlebotomy team. Even Steve Allen was drafted in to help take bloods in the latter half of the evening (as well as being Chairman of the local prostate cancer support group, he is also a recently retired Consultant Anaesthetist at the Royal Berks Hospital.) Rarely did anyone wait longer than 30 minutes for their test.

### ***What about the cost?***

The Lions had underwritten all costs, but had sensibly obtained some financial funding from local companies. A robust financial contract had been agreed with the hospital. Apart from the strategic placement of collecting buckets for those who wished to make a donation, the tests were free.

### ***Keeping things medically supervised***

As with previous similar events, David Baxter-Smith (a Consultant Urologist and Trustee of the Federation?) was involved and agreed to over-see the reporting of results to patients with the standard red/orange/green letter system that has been used in the past. Also he will follow up all patients with abnormal test results to ensure they seek appropriate treatment locally.

To be honest, the local urology unit had shown support – but from a distance. They were not actively involved at any stage but, equally, were not hostile to the project – as has been the case in other parts of the country. One of the local Consultant Urologists dropped in to see how things were going on the evening. It was staggering to find later from David Baxter-Smith that, despite having done 300 or so such events, this was the very first time he had been able to meet with a urologist local to the area concerned.

### ***But why are such evenings needed?***

Many would say that it is little short of a scandal that there is no national PSA screening programme. Even worse, patients are still being advised against testing by ill-informed GPs – often in younger patients in their 50s. When will people realise that the earlier an aggressive PCa is found then the better it can be treated. As Steve Allen said: “*PSA screening done in an appropriate way is not scaremongering. It is just plain common sense*”

There is little doubt that the evening in Reading will pick up some patients with PCa that can then get earlier treatment. Equally, it will also reassure the

majority of men that they have nothing to worry about.

(Note Steve was ably supported by Ivan Peacock and Graham Cook – Ed.)

## Report # 2

Our Chairman believes something like “Pharos captures the essence of the Group” and is one of the records we should keep. So even though those on email will have already seen this, it is reproduced here because

- it gives the outgoing Editor another first namely two outside reporting team reports
- it is very well written by Peter, having been reviewed by his co-conspirators.
- those that receive information by post can benefit from a good read.

## Group Therapy

Members of the Reading PCa Support Group may recall receiving a message early in January, forwarded from Medicys Ltd: “...an independent research facilitator, conducting genuine research studies for a broad range of clients and in many different subject areas”. They were inviting people with either PCa or BPH (benign enlargement of the prostate) to attend group discussions in London, “to better understand the experience people have with incontinence pads or external catheter bags” (by which they meant sheath & bag systems). Travel expenses and a not insignificant honorarium were offered! As I certainly had experience under both headings, and was free on the date specified, I signed up. And I understand that Medicys are now inviting people to a further group discussion on the same subject, in Slough. The following will give you an idea of what to expect, without (I hope) crossing the boundary of confidentiality. If you do attend, though, please don’t make it *too* obvious that you know something of what’s in store.

Late in the afternoon, I made my way to Hammersmith and the basement of an antiquated but well-appointed office block. There, over tea and sandwiches, I met none other than Dennis Woodhams and Tony Sawyer from our Reading group! No-one else was involved, on this occasion. So the three of us were shown into what I guess was a typical focus-group meeting-room: table and chairs, and a one-way glass wall. We were told there were people on the other side (it wasn’t really explained who), watching and listening to us, and that we would also be filmed and recorded. Our “host” was a friendly young man called Paul, who seemed to be experienced in conducting discussions on various subjects between people who (normally anyway) didn’t know each other. He said he intended to keep us only for the allotted 90 minutes, and that the session was for the benefit of a “well-known manufacturer” of incontinence aids. I had rather

assumed that we would be asked specifically about how people such as us coped with the things.

Instead, the direct questions from Paul turned out to be mostly about a sequence of “designs” which he showed us: how did we respond to them, in general and in detail? A rather dull task, you might think. But in the process, he encouraged us all to pour out our feelings and experiences (accumulated over decades, in total) regarding incontinence. If the clients of Medicys didn’t know a great deal before about the (mis)adventures of the man in the street whose waterworks are leaking or are likely to, they surely do now! And even the designs themselves were interesting to assess and discuss.

At the start, Paul spent a surprising amount of time getting us to introduce ourselves and our backgrounds. He also said: Suppose we all found ourselves on a desert island – what particular skill might we each contribute? He, for example, could do the cooking. Dennis offered the ability to build a shelter. Tony said he ought to be able to turn his hand to a variety of tasks. I muttered something about problem-solving and repairing things. Later I wished that I’d thought to say I could probably also write a good message to go inside the bottle!

We revealed three contrasting histories and attitudes relating to our common problem. I acknowledged that I had been lucky in not only largely overcoming it (though I don’t know how), but also finding myself able to accept philosophically whatever happened to me, without (much) complaint. Dennis and Tony each had some displeasure to express, about both their condition and their struggles to manage it. But it was pointed out that the unwritten motto of the Reading support group is that Everyone is Different. And indeed this was the excuse we offered several times during the discussion, for sometimes coming to differing conclusions about the designs.

I can’t say anything about these, for reasons of confidentiality. But they gave us the opportunity to put over several ideas which, in some cases, we hadn’t really thought about before. We found ourselves agreeing that “incontinence” is a demeaning word with unattractive connotations – we preferred “bladder weakness”. And people can get very depressed if they suffer from it, particularly if it’s long-term, so any indication that it can be combated by a range of aids should be welcome (though not all of us regarded them as successfully overcoming our problem).

One reason for the demoralizing effect of incontinence, sorry, BW, is that it can be the subject of unkind comments. Tony told us of an unamusing remark made to him once by a colleague: “That old chap’s wearing dark trousers, he must have leakage trouble.” I nearly waved a leg in the air at that point, to demonstrate my courage in having attended in a pair of light-coloured bags!

We agreed that another of the downsides of BW was the odour, whether imagined, or detected by you but (hopefully) not others, or noticed by others but not

you. Pads may absorb a goodly quantity of liquid, but they can't contain all the smell. As for sheaths, pipes & bags, they may be tolerable when working well and you're not too much in spate, but if the bag fills up, or (worse) the plumbing falls apart, then suddenly you desperately need to know where the nearest Gents is. Or, with luck, you've already located it, just from habit. At this point, Tony repeated a comment that I'd made as we met, before the session started – and Paul needed to have it explained to him: “Never pass a loo or a sandwich!”

We took the opportunity of mentioning the Radar key (available from [www.radar-shop.org.uk](http://www.radar-shop.org.uk)) which gives you access to locked disabled toilets, and the Just Can't Wait card (from <http://www.bladderandbowelfoundation.org>) which you can wave at shop assistants and other guardians of private loos to engender their sympathy. We also added greatly, I think, to Paul's knowledge of penile clamps, bladder slings, various urological operations, the effects of intrusive internal scar tissue, and later-middle-aged life generally. Even so, I'm curious about how significant and useful a fraction of the total BW picture we supplied to the manufacturer, because after all we represented only a sub-group of sufferers, some of whom are female of course (though all lady readers of this account might reasonably be feeling that we men were protesting a little too much about our condition...).

In the end the session over-ran by more than half an hour, but we didn't at all feel that this was time wasted, especially as, when Paul disappeared to check with the unseen people behind the glass and returned, he said that they were not only still there(!) but also greatly appreciative of the information and insights delivered. And so we three departed for the Underground and Paddington – pausing only to turn left into the Gents on our way out.

*Peter Soul.*

## Medical

It would appear that the latest issue of the BMA journal has reignited the debate regarding to PSA test or not to test. In particular there is a list of bullet points which GPs can use to explain to their patients why it is not appropriate for them to have a PSA test. Dr Allen has been asked to produce a set of related counterpoints so that Members and their friends/relatives are aware of the “facts”

It is not clear when this will be available, but it should be no later than when we man our RPCSG stand at the Mall on the 15<sup>th</sup> March.

## Prostate Cancer Support Federation

The autumn issue of the Federation newsletter is now available – “**prostate matters**” - it is Issue 18, this link will take you straight to it [http://www.prostatecancerfederation.org.uk/ProstateMatters\\_latest.pdf](http://www.prostatecancerfederation.org.uk/ProstateMatters_latest.pdf) – hopefully!

Please note, hard-copy of the newsletter can be picked up at monthly meetings.

Interestingly, on the last page there are some arguments regarding the **value of PSA testing**.

## Disclaimer

The newsletter does not offer medical advice. Nothing contained on the newsletter is intended to constitute professional advice for medical diagnosis or treatment or to advocate or recommend the purchase of any product or use of any service or guarantee the credentials or appropriateness of any health care provider. Members are strongly advised to consult with an appropriate professional for specific advice tailored to their situation.

## 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.

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.

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

1. 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)
2. 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.)
3. The astonishing potency of a vacuum! Version 4 – (Describes a Member's practical experiences in using a “mechanical aid”)
4. 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
5. RPCSG Constitution June 2011
6. Mr Peter Malone's presentation on the 1st July 2011, pictures only, no text
7. Pharos, the Group's Newsletters - June 2009 to current.

