

The Pharos

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group

Issue 4, April 2010

Editorial

The Newsletter continues to be produced in accordance with Members' feedback; the style, content, depth and breadth of material being essentially the same.

To ensure the Newsletter continues to be relevant, feedback continues to be welcomed from Members. You may do this by email to the Editor at ken.davik@yahoo.co.uk or, alternatively, write to the Secretary at his usual postal address.

There was quite a lot of input to the newsletter, for which many thanks. Unfortunately incorporating all contributions would have made it more than twice the "normal" size. Before the next issue is produced the Committee will review size, scope and type of content of future issues. If you have thoughts on these aspects please make your views known as above, ideally before the 6th May

John Patrick

As you will know John passed away on 12th April both suddenly and unexpectedly, not from his prostate cancer but from other causes. John had been a founding member of the Group and its first Chairman. He had been a great asset to the Group throughout his membership, always willing to help in whatever way he could, rarely missing a meeting and a great supporter of other members providing information, fellowship and comfort where sought or appropriate. We all will sorely miss John.

His funeral took place on the 28th April and the size of the congregation spoke volumes for the regard in which he is held.

Chairman's Thoughts

Recently I took part in a survey originated by our local MP. He sought opinions about the state of the National Health Service over the last ten years or so. One question was: "Do you think that the NHS has improved over that period?"

I was surprised by the reply: over 80% of the respondents thought that it had only improved

marginally or not at all. Maybe the questions were asked of a non-representative sample, or maybe Reading is at the top end of the postcode lottery.

Speaking personally, I find that my local medical centre has improved its services steadily and I think the same is true for the cancer treatment and diabetic services with which I have had close contact with over the last three years.

What do you think? Answers please via a email to the Editor, letter to the Secretary, or better still on the Group web site! The Editor will produce a synopsis of the results of this "survey".

New Members

Welcome to the following new members who have joined the Group since the beginning of the year.

In January Jo and Peter Soul joined the Group and at the February meeting Anne and Peter MacDonald and Keith Thoreau became members. In March we had a record intake and were joined by Neelam and Ravi Aggarwal, Cleone and Frank Augur, David Bazley, Carol and William Brown, Alan Ebden, Wally Franklyn, Peter Hall, Ivan Peacock, Brian Smith and Barbara and Fred Taylor then in April Carole and Peter Bolton and Peter Dunn became members.

At the time of publication of this Newsletter total male membership now stands at 72.

Activities since January 2010

After aborting the scheduled January meeting because of weather conditions, the February meeting proceeded as planned with an address by Lorraine Grover on erectile dysfunction.

This was a very successful meeting at which Lorraine, a Clinical Nurse Specialist in sexual wellbeing, gave an excellent presentation full of helpful and practical advice on a serious subject lightened with touches of humour. Some members felt that Lorraine ranked among the best

of our guest speakers.

In March we had a record attendance of 68 who attended the short AGM, this was followed by another excellent presentation by Peter Malone, the Senior Prostate Surgeon at the Royal Berks.

Mr Malone addressed specific questions raised by members and then spoke more generally about the detection, treatment and particularly about the surgical options for prostate cancer. PSA tests were identified as being more meaningful **after** certain types of treatment.

The RBH hosted another visit to and demonstration of the daVinci machine for twelve or so Members, this was extremely interesting and appreciated. Our thanks again to the staff who organised it and participated in the demonstration.

The April meeting was the second of our 'Open' meetings at which a panel of members spoke of their own experiences on the cancer road. Special thanks in this connection to the Panel of Peter Reader (brachytherapy), Nigel Tailyour (robotic surgery), Monica Woodard (the Partner's perspective), Keith Jackson (radiotherapy and hormone treatment) and Steve Allen (open surgery and incontinence) all admirably chaired by Bill Forfar.

Awareness

The Hospital ran its Awareness Stand for a week during the Prostate Cancer Awareness month of March. Help to 'man' the Stand was provided by Members of the Group, for which many thanks. These volunteers distributed leaflets and information to the small but steady number of enquirers.

The Group is also planning to run its own Awareness Stand on Saturday 19th June in the Broad Street Mall in Reading. This will be for one day only and will coincide with a Fathers' Day promotion being organised by the Mall for the same day. When we ran a similar Stand last September it was very successful and we hope for similar success this year. Volunteers will be sought to help during the day so please make a note in your diaries.

Forthcoming Events

The May meeting will be addressed by Fawaz Musa, a Consultant Histopathologist at the Royal Berks. Fawaz has been our guest speaker on a previous occasion when he spoke about the work of the Pathology Department and Members

found his presentation to be particularly interesting. It was felt that this talk was well worth repeating.

In June our speaker will be Steve Foley, a Consultant from the Urology Unit at the Hospital, who will speak on incontinence. Sadly this is a problem that often arises from the treatment of prostate cancer and therefore the presentation should be both relevant and helpful.

It is particularly pleasing that Amanda McLean, the Chief Executive of Prostate UK, who was originally to be our guest speaker at the aborted January meeting, will now be our guest speaker in July.

Amanda plans to speak on the work of this Charity which has been particularly helpful to us in providing, through the Prostate Cancer Federation, financial support enabling us to purchase the Group Banner Stands, the Projector Screen and to contribute towards the purchase of the Projector and PC. It is hoped that Members will support this meeting in order to demonstrate our thanks for this help.

Speakers for the meetings for the remainder of the year are being organised but Members may wish to note one date in their diaries. It is planned to run, in addition to the normal August Group meeting, a Summer Social on Thursday 12th August to be held at the Sonning Golf Club. More details to be provided closer to the date.

Focus Groups

The Communications Group

Membership of the Yahoo Group Site continues to grow slowly now standing at 22 but it is still not working as well as had been hoped. If you are a member of the Site you are encouraged to post messages of relevance to members – sharing treatment experiences or posting queries – and if not a member then to consider again the possibility of joining the Site.

Towards the end of March the Secretary wrote letters to the local press advertising the Group and received several enquiries about the Group's activities. It is believed that these letters had some part to play in the record attendance that occurred at the March meeting.

Housekeeping

We have received a suggestion from one of

our Members about the name badges we use for the meetings and how they could be improved these are:-

- a) Use a larger font so the names are readable without spectacles.
- b) Add some details of treatment undertaken to help members seek out those with similar experiences.

Bill Forfar will be seeking your comments, so please look at the charts that will be displayed at the next meeting with the larger font and also some examples of a shorthand code for the main treatments. Examples of the badges will be sent in a separate email.

You will only have treatment details on your badge **if** you have agreed that this should be the case, you have to **opt in!**

The Support Group

A number of newer Members have asked “How does this work?”

Our aim is to provide help and reassurance to all Members but particularly to new Members.

When a new person joins the group your Committee emails or telephones the new Member and offers to discuss their situation with them. We then offer to put them in touch with other Members who have been given the same or similar diagnosis and have treatment experience. In this way they have access to the experience of all current Members.

As was seen by those who attended the Open Forum last month, the experiences of Members and their partners drew many questions from the audience. Talking to newer Members, after the panel discussion, we were glad to hear that many of you liked this format. We see this as an extension to the support work of the RPCSG and remind you that it can only be successful if Members who have undergone treatment are willing to share the experience of their treatment(s).

We are also in close touch with the medical staff at RBH and are able to feed back the comments from these Open sessions, which are, of course non-attributable.

Please be reassured that only a few people hold the treatment details that you may provide to the Committee and your confidences are respected. However, if the new badge scheme is implemented, then all Members will know your treatment(s).

Medical

Report from the Prostate Cancer Support Federation Annual General Meeting, 24th April 2010 by Steve Allen

The RPCSG is a member of the Prostate Cancer Support Federation (PCSF) and I attended their AGM recently on behalf of the Group.

It is always a mixture of both the formality of any AGM and also some education. The formal bits were, as with any AGM, somewhat predictable.

This year’s meeting was held at the Penny Brohn Cancer Centre, Bristol. The treatment approach of this Centre is holistic and **complimentary** to standard therapies – they do not wish to be seen as using **alternative** therapies.

Their emphasis on relaxation, self reflection, exercise, diet and overall personal management of the cancer by the individual patient is one that I am familiar with – such an approach is commonly used in my own field of chronic pain medicine.

They have both residential and day courses run in a new purpose built complex that has 30 beds and good resources. It is beautifully built with a lot of natural wood and stone, the whole building exudes calm and serenity.

They are entirely run by a charity – no fees are charged for their courses, although donations of what the individual can afford are encouraged.

Further details from:

[-www.pennbrohncancercare.org](http://www.pennbrohncancercare.org)

Part of the morning was given over to looking at diet and prostate cancer. I must confess to a slightly cynical attitude to this, as the data and science base available is not very strong. The standard research tool of a ‘double-blind randomised cross-over trial’ is virtually impossible to achieve in such an area.

I was, however, impressed by the two speakers who gave a very balanced viewpoint. In summary, the basics of dietary advice for most medical conditions are the same: low fat, reduction in red meat intake, plenty of fruit and vegetables, increased nuts and seeds, low dairy.

It is suggested that a ‘plant-based’ diet may be of benefit in promoting a lower incidence of and a longer survival in prostate cancer (PCa). However, there is no strong evidence that PCa is seen less in vegetarians or vegans. Lycopenes – found particularly in tomatoes, particularly

processed ones, – may have a protective effect, as may vitamin E and selenium. Trans-fats – fats damaged by processing and found in chips, crisps, processed meat and other foods – should be avoided. And, as ever, alcohol is only recommended in limited amounts.

There are some on-going larger studies into diet and cancer in general, as well as PCa in particular. We will await the results.

The Centre has some healthy eating guidelines on their website and are due to publish some guidelines on food supplements later this year. There is also the *Prostate Cancer Cookbook* (published by the charity Prostate Cancer Care) which can be bought via Amazon.

The afternoon education session again took up the debate about PSA and routine screening for PCa. Ideally for any disease there should be early diagnosis allowing rapid and effective treatment with the potential outcome of a high cure rate.

The current PSA test is not sensitive enough to provide this in PCa (although it is an exceptionally good way of following progress after surgery).

The PCSF is supporting a research initiative looking at developing and validating a risk-based tool that uses, in addition to PSA measurements, assessments of urinary symptoms, digital rectal examination, ethnicity etc. This very simple collection of information can then predict the likelihood of PCa and its potential severity. A very important component of this is a more sophisticated assessment of PSA – measuring both ‘total’ and ‘free’ PSA. However the majority of centres do not do this at present.

They are striving to raise £100k in this next year to kick-start a 2-year research project

that will cost £2m in total.

Another topic raised with some concern was the advertising of pharmaceutical products that can be bought directly in chemists to treat urinary frequency.

The drug, tamsulosin (Flomax®) was highlighted. It is increasingly being advertised in the men’s toilets – especially in motorway service stations. Whilst the drug itself is medically safe, otherwise it could not be sold to the public without a prescription, the PCSF felt that the message given out by this advertising was entirely wrong.

Any man with increasing urinary symptoms – particularly men over 50 years with frequency, reduced flow and getting up a lot at night – should not be self-medicating but seeking appropriate medical advice, and almost certainly a PSA test.

There was concern that self-medication could potentially result in a missed diagnosis of prostate cancer.

There is no doubt that the PCSF is a vibrant organisation - they continually work alongside such organisations as Prostate Cancer Care to increase awareness of PCa and provide good support to local groups. We have already benefited from grants of nearly £500. We should continue to be members and support it.

I went to the meeting somewhat out of a sense of duty, but to be honest, I came back with increased knowledge and an enthusiasm to increase the awareness of a problem that we all share.

Statistically, 150 men per day are diagnosed with PCa. One man per hour dies from it. We must all strive to increase awareness and improve outcomes.