

The Pharos

A beacon of hope in the darkness

Newsletter No. 3 January 2010

Editorial

This Reading Prostate Cancer Support Group (RPSCG) Newsletter continues to be produced in accordance with Members' feedback, the style and content being essentially the same as the first edition.

To ensure the Newsletter is 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.

“The Committee at Work”

Your Editor attended the January Committee Meeting and this served to enhance the Newsletter production process.

Competition

The competition to name the Newsletter was won by Allan Wise, a relative newcomer to the Group. In all there were some 17 entries. The voting by the judges, (the Communications Focus Group), was tight, but it was felt that the name with its implications captured the essence of the RPCSG. Allan insisted that the liquid prize be raffled and Pam, his wife, did the draw. Pam also took the opportunity to express her thanks to the Group for the support they had both received at the start of their challenging time. The raffle winner was Peter Reader, I trust he enjoyed the wine. The raffle raised £30.

The heading of the Newsletter is an interpretation of Allan's winning entry.

Chairman's Thoughts

Here we are in 2010 already and I send good wishes for a healthy year to all of you and your families.

In the last Newsletter, I said that I was willing to stand as Chairman until the next AGM, that is, until March 2010. Discussion in the Committee has shown that it would be impracticable to get one of the existing members to become Chairman for the next year, so I have indicated that I am content to remain in the role

during 2010 and early 2011, after which I would positively stand down.

I believe that an effective Committee is one which does not run in perpetuity and stagnates, but periodically and regularly draws in new personalities so that fresh ideas are debated and, if considered sound, are converted into action. Ideally each member should only serve for three years, and we should try and arrange matters so that each year we look to replace two members.

I wonder if there is anybody within the Group who would like to volunteer for service on the Committee? It is not an onerous task; the main commitment is to attend a meeting at the Royal Berkshire Hospital (RBH) once a month, on a weekday afternoon. The ever kind Support Nurses even provide tea! Please approach any of the Committee members at our next meeting on 5 February.

Finally, never forget that the word **Support** features in our Group title, and as I said at our first Open meeting last year, we are always looking for better ways of achieving this function. **Have you any ideas? Please let us know.**

New Members

Welcome to the following new members who have joined the Group since publication of the September Newsletter:

Pam and Allan Wise also Brian Ames joined in October; Ian Cliff also Gina and Jonathan Tagoe in November; with Janet and Ian Forrester joining in December.

Total male membership at the end of the year stood at 58, up from 35 since the beginning of the year, which is an encouraging rate of growth, from a support viewpoint.

Activities since September 2009

Our monthly meetings continued during the third quarter of the year with Nicola Dallas, a Senior Registrar at the Hospital, talking in October about radiotherapy treatment. This was an excellent presentation on a subject of relevance to many members, with great interest being shown.

In November Neil Derbyshire, a Radiologist also from the Hospital, spoke to us about MRI and other scanning techniques. This was his second visit to the Group and, by focusing on the increasing use of scanning in the identification and treatment of tumours, followed neatly from the previous month's presentation.

The last meeting of the year was the Christmas social. There was so much interest from Members in this event that we had to stop taking reservations for fear of exhausting the supply of tables, chairs and cutlery and exceeding the insurance limits on the Hall! On the night, following some cancellations, we ended up with a total of 45 attendees who enjoyed a very convivial evening.

The event was very well organised by our Chairman and his wife, Monica, with valuable support from June and Peter Giles and other members who helped with the housekeeping. In addition Chris Woodhams ran the quiz and your Editor ran the raffle. Although not intended to be a profit making event, a small surplus was achieved which has been added to Group funds and the £80 made on the raffle has been donated to Prostate UK. Thanks to all who made this evening so worthwhile.

Awareness

In order to increase awareness of prostate cancer the RBH is investigating the possibility of again holding an Awareness Stand on its premises during the March Awareness Month. In addition the Committee are considering a further Stand or Stands in Reading town centre also during the Awareness Month and/or on the June National Prostate Cancer Awareness Day. Help from Members is likely to be sought for these displays. More news to come.

Forthcoming Events

Unfortunately the weather intervened again, resulting in the cancellation of our January meeting. It is hoped that the proposed speaker, Amanda McLean the Chief Executive of Prostate UK, will be prepared to address us later in the year.

For the February meeting we will be addressed by Lorraine Grover who will talk on causes, consequences and possible solutions to erectile dysfunction. Lorraine is a Clinical Nurse Specialist in sexual wellbeing and a specialist

advisor to Macmillan Cancer Support. She has already addressed two other prostate cancer support groups on this subject.

In March, following a short AGM, our guest speaker will be Peter Malone, the senior prostate surgeon from the Royal Berks. We are very privileged to have Mr Malone speaking to us for the third time. His presence together with the support we receive from the Clinical Nurse Specialists and other staff at the Hospital indicates that our Group is perceived to be of value.

If there are particular prostate cancer topics, likely to be of general interest, that you would like Mr Malone to address in his talk, please advise the RPCSG Secretary – say by the 19th February 2010.

The April meeting will be another 'Open' meeting at which there will be opportunity for members and their partners to share experiences of the journey along the prostate cancer road. The first meeting of this type, held last August, was very successful and it was felt that it would be worthwhile repeating the exercise.

In addition to the above Group Events, the Fund Raisers for the Da Vinci surgical robot are running a Quiz Evening at the Jazz Café at the Madejski Stadium in Reading on Tuesday 2 March. It is hoped that the Group will be able to put together one or two tables (8 persons per table) for this event to support the project. More information has been circulated to Members.

With respect to the Da Vinci robot viewing, the RBH has agreed that a further viewing be arranged for Tuesday evening 2nd February. Preference will be given, on a first come first served basis, to those who were originally listed for the cancelled viewing last September. It is hoped that further viewings can be arranged later in the year for those that are disappointed on this occasion and also for members who have joined the Group since September.

Focus Groups

The Secretary has recently circulated information about the Focus Groups to those members who have joined the RPCSG since Focus Groups were established. It is hoped that more members will be willing to become involved in this way and use their working life experience in the Group.

The Communication Group

The principal activities of this group over the past few months have been the production of this Newsletter and the development of the Yahoo Group Internet Site. With respect to the latter initiative, membership of the Site is slowly growing, having recently reached 20, but it is still not functioning as had originally been envisaged. It is planned that this group will exchange views in coming weeks to discuss the how the Site might be developed to encourage greater use as well as looking at other ways of improving communications both within the Group and with the 'outside world'. **Naturally Members' views are most welcome.**

Housekeeping

All is running smoothly.

The Support Group

Peter Giles assisted by Bill Forfar is co-ordinating this activity, but more help would be appreciated. This would be preferably from Members with treatments other than RP. If you are interested in helping please contact Peter or Bill at a regular Meeting, or by phone on **01189861163** or **01189619655**, respectively. Likewise if you need support please contact Peter or Bill and it will be arranged.

The team has been busy in the last four months with, for example, three contacts being made in December via the RPCSG leaflet which is made available by the specialist Nurses at the RBH Urology Clinic. Each of these Contacts has been provided with information and two are having treatment in January.

The Fund Raising Group

The Group is considering many ideas and when filtered some may be pursued. In parallel, Steve Allen has written to three pharmaceutical companies, with commercial interest in this area, so we await the outcome of these initiatives.

Medical

The Federation Newsletter, "Prostate Matters", usually includes articles of interest, only some of which are understood by some of us, myself included. Member Steve Allen has kindly provided a commentary on the more interesting points.

"So, what about pomegranate juice, then?"

The surgical and medical treatments for Prostate Cancer (PCa) are now well established. Strong evidence-based data have produced agreed treatment pathways. However, many additional therapies – medical, dietary or complimentary – also exist. Many have yet to be formally assessed, some are based on no more than personal anecdotes.

The recent issue of *'Prostate Matters'* gives considerable space to the role of vitamin D in potentially reducing the incidence and progression of PCa. The article, however, was somewhat confusing as it sometimes referred to vitamin D and at other times vitamin D3 - the latter apparently being the most important. Also it was not entirely clear whether there was agreement on the specific daily dose needed. This has, interestingly, come at a time when there is increasing concern about vitamin D deficiency generally in younger people in the U.K.

Another recent research article has suggested that moderate coffee drinking may reduce the incidence of PCa, but it was not clear for how long this is needed to be effective. We are also told to reduce our consumption of red meat, dairy products and alcohol but increase intake of cauliflower and broccoli. The list is seemingly endless.

It would now appear that drinking pomegranate juice may also help – albeit from a very small study.

I have an in-bred scientific scepticism of any new treatment – medical or otherwise. Potentially harmful therapies (as most medical ones inherently are) need careful assessment to balance risks and benefits. Vitamin supplements in moderation are normally safe, but taken in massive and uncontrolled dosages can still be potentially harmful. But if a patient with a potentially terminal illness fully understands the risks involved is it wrong for them to embark on treatment that has yet to be fully assessed? I don't think so. If someone wants to drink pomegranate juice, why worry? It may do no good at all – but is likely to do no harm except perhaps to raise false hopes of a 'cure' when none exists.

Many major advances in medicine were found entirely by chance, by serendipity - for example: X-rays, penicillin, anaesthesia and, more recently, Viagra. Perhaps the humble pomegranate may eventually rank alongside them? I do not

have a clue.

However, until the pundits have worked things out more, I'll continue to take my regular daily multi-vitamin supplement regardless. But

perhaps I should now drink it down with pomegranate juice – after all, I rather like the taste!

SteveAllen”