

PHAROS

A beacon of hope in the darkness

Newspaper of the Reading Prostate Cancer Support Group (RPCSG)

Issue 23: April 2013

EDITOR'S FOREWORD.

Welcome to issue 23 of the RPCSG newsletter. Since the previous issue, some interesting things have happened, including the AGM! At the AGM there were some changes in committee members, including the editor of this publication. I have taken on the role of newsletter from Ken Davison, and I would like to thank him for the effort he has put in during the last four years, and the high standard that he has set for me to follow!

Let me introduce myself as the editor – I am Steve Parkinson, retired from the computer industry three years ago. I am a relative newcomer to the group, the first meeting that I attended was the November 2012 meeting, which was only 8 days after receiving the news of my positive biopsy, and I had a robotic radical prostatectomy in early January 2013. I had no symptoms or family history and was diagnosed only by a rising PSA, so I am a committed enthusiast for PSA testing.

The email for newsletter correspondence is newseditorRPCSG@yahoo.com. Any comments, suggestions and articles for publication in this newsletter will be gratefully received.

THE MARCH MEETING (1st March 2013).

The AGM was held in line with a published agenda. The Chairman gave a very enlightening account of his personal experiences over the past 12 months, and expressed his appreciation of the whole group and its achievements.

Two members stepped down and were thanked by the Chairman for their tireless efforts during their terms, and presented with gifts as tokens of appreciation. These were Bill Forfar who is now replaced by David Priest as the greeter and badge holder. Ken Davison relinquished his post as newsletter editor, and subsequent to the meeting was replaced by yours truly, Steve Parkinson.

There followed a lively discussion of the fact that the BMJ (British Medical Journal) had recently published an article that was quite negative towards PSA testing. The Chairman showed a presentation that summarised the views and justifications that were printed by the BMJ, which were mainly that PSA testing causes anxiety and is not totally effective ('false positives', 'missed positives') and unnecessary biopsies. The BMJ has previously expressed similar opinions in some of its earlier editions. The majority of the Support Group was in favour of PSA testing as this is more likely to 'catch it early', and was disappointed by the article in the BMJ.

AWARENESS DAY (15th March 2013)

The Group held a prostate cancer awareness day in the Broad Street Mall (I still prefer to call it 'The Butts Centre' – old habits die hard). A stand was set up outside and facing TK Maxx, and was manned from 9 a.m. to 5 p.m. in shifts of two hours. The number of people that we managed to engage in conversation was 170, which was quite a rewarding quantity. This quantity is somewhat less than last year; the main reasons for this were the facts that the location outside TK Maxx was not as prominent as last year (at the bottom of the escalators) and also the presence of other groups and temporary shops on the same

day provided a little competition and distraction, and we had been requested 'not to interfere' with the shop stands.

We will endeavour to hold another awareness day next year, and hope to regain our position at the bottom of the escalators.

THE APRIL MEETING (6th April 2013)

The guest speakers at the April meeting were Nicky Dann and Kay Hargreaves, of the organisation known as CoCoC (Comprehensive Care for Older patients with Cancer). Their aim is to improve outcomes and support for newly diagnosed cancer patients older than 70 years – who make up more than 50% of all new diagnoses. Quality of life for the patient is the paramount concern. Communication is their key to success, by patient education and assessment and co-ordinating the different services available to match each patient's needs. The team has five members and at present they cover West Berkshire as far as Reading and Wokingham. The organisation is funded for the next three years by the Macmillan Trust. The team can be contacted at Cococ.team@RoyalBerkshire.nhs.uk

A thorough covering of the organisation and its methods was given by the presenters, questions from the floor were answered, and a bouquet of flowers was presented as a token of thanks to the presenters.

FUTURE EVENTS

It is planned to again have a presence at the Earley 'Green Fair' on 8th August 2013.

FUTURE MEETINGS

The plan for future meetings is as below – this is provisional and confirmation of each event will be sent out shortly before each meeting:

3 May 2013 : Dr. Fawaz Musa is a Histopathologist at the Royal Berkshire Hospital and will describe the work of the unit that examines and reports on biopsy specimens.

7 June 2013: Dr. Neil Derbyshire – Consultant Radiologist, with a specialty interest in cross sectional imaging.

5 July 2013: Geoff Harris from Prostate Cancer UK will tell us about the work of the charity.

2 August 2013 : An open meeting

CONGRATULATIONS AND CELEBRATIONS

Congratulations to our Treasurer Graham Cook, who has received a Citizens Award from the Mayor of Woodley, for long term involvement and tireless voluntary work within Woodley. Among Graham's worthy deeds are:

- PTA at Southlake Junior school
- Associate of 1st Woodley Scouts Troop
- Member of fund raising committees
- Served on the Town Centre Management Committee
- Founder member of Woodley and Earley Lions Club in 1980, serving as President and other posts, over 25 years.
- CRB Administrator at St James Church

In addition he is the treasurer of the RPCSG. Well done Graham – where do you find the time?

NEW MEMBERS.

We welcomed new members at the start of the April meeting – Mike & Ann Watkins, and Mike Howard. We wish them all well and let them know that they are welcome to contact any of the support members listed below, should they need any help, advice or support on anything of concern.

SUPPORT CONTACTS

For any member who would like some help or support from the Group, or simply would like to chat with someone – perhaps another member who is or has been in a similar situation – any of the members below can be contacted:

Steve Allen 01189 266 747
Ian Forrester 01189 789 857
Keith Jackson 01189 842 999
Paul Sefcick 0163 34778
Graham Cook 01189 691 668
Steve Parkinson 01189 785 268

RPCSG WEB SITE

Able led by member Laurie Fineman who has had some experience of this already, a web site for the group is being set up. It is early days yet, and I will keep you posted on progress in later issues of the newsletter.

INTERESTING ARTICLES

Thanks to the member who sent in a link to an article that appeared in The Guardian of 31st March 2013. This interesting article concerns the story of leading prostate surgeon Professor Roger Kirby, who himself contracted prostate cancer. The article can be seen at:

www.guardian.co.uk/society/2013/mar/31/surveying-prostate-cancer

Also I have spotted an interesting page on the BBC website concerning the impact of gene BRCA2 on prostate cancer. This article has also appeared in the BMJ and makes me hopeful that the field of genes will eventually be beneficially incorporated into the diagnosis and treatment of prostate cancer. The article can be seen at <http://www.bbc.co.uk/news/health-22065289> and there are further links in that site, to other related web pages.

ARCHIVED DOCUMENTS

The following documents are held by the Editor and can be obtained if you have internet access by requesting them from the Newsletter editor, or from the Chairman if you do not have internet access:

1. 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.)

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

PARKING

All members are requested to park only inside the marked bays, as some cars parked near to the entrance door were recently blocked in. Remember that there is further parking 'over the wall' – i.e. the next driveway nearer to the hospital, underneath a sign on the building wall stating 'Trust Education Centre and Library Car Park'.

FINAL NOTE

Please note that capital letters in email addresses are for readability only and can be typed in lower case when sending emails.

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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.