



PROSPECT

Bristol and District Prostate
Cancer Support Group

Winter 2018-19

Newsletter

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PROSPECT is a local support group for prostate cancer patients, their carers and friends.

We provide help support and information and our newsletter is published four times a year. Any articles you think would interest our members please email to me, David Casley at: prospect.bristol@gmail.com



The committee of Prospect wish all of our members and friends a very happy, healthy and prosperous 2019.

THE LAST 10 YEARS

In 2008 10,000 men died in the UK from prostate cancer.

In 2008 the unreliable PSA test result was the first indicator of the disease.

In 2008 if you had radiotherapy for prostate cancer it's likely you would receive the hormone drug bicalutamide (Casodex) to help counteract the effects of the disease.

In 2018 11,000 men died in the UK from prostate cancer.

In 2018 the unreliable PSA test result is still the first indicator of the disease.

In 2018 if your prostate cancer had returned it's likely you will still be offered the hormone drug bicalutamide to help counteract the effects of the disease.

Is this progress?

JANUARY MEETING

Our BAWA meetings continue to be popular and we had over 40 attend on January 14 to hear Richard Martin, Professor Of Clinical Epidemiology at Bristol University, and Dr Emma Turner talk about the value of a one-off PSA test.

This was a fascinating talk and whilst most of us agreed multiple PSA test results give a more accurate diagnosis it was interesting to understand the thoughts behind this study.

Richard stayed on well into the evening after his talk chatting to members. Links have been placed on our website to the YouTube videos about the findings of his research.



Richard, talking to our chairman Malcolm Gamlin and his wife Caroline.

PROSPECT ON RADIO BRISTOL

If you were listening to Radio Bristol on 23 January just after the 8am news you would have heard our member Michael MacMahon praising the work of Prospect in supporting prostate cancer patients in the Radio Bristol area.

The radio topic was about the new approach to nerve sparing surgery being trialled at Southmead Hospital. Professor Raj Persad was talking about saving the erectile function nerves by undertaking pathology investigation during the surgery to establish how far the cancer has spread in the prostate gland. If there was a clear perimeter of tissue in the gland the nerves could be saved.

Michael was asked about his recent surgery experience and made the point of the importance of Prospect as a support group where men can discuss the subject of erectile dysfunction openly with others who have been through prostate cancer surgery or treatment.

This is a subject that comes up many times between individuals during our buffet discussion after the BAWA talks. It is a topic we

could perhaps discuss again at one of our informal BAWA meetings when we do not have a professional speaker. Check the website regularly for an update on our meetings content.

UPDATED WEBSITE

Please change your bookmark for the Prospect website to <https://> instead of <http://>

The https site is more secure and we will get one set of statistics for hits on the site instead of two!

The site is worth visiting often as Bernard regularly adds news items and updates. If you're seeking information on a certain subject, put it into the search box on the "front page".

It's interesting to note the statistics of who views our website. In the last quarter we have had visits from overseas as well as from the UK - quite a few from the EU and Russia. There were even visitors from Brazil, China and Japan. Then there were some from Australia, Switzerland, Malaysia and the Seychelles. In fact we had visits from 55 countries in all.

The ratio between visits and pages is impressive, we've been told. Just about every visit goes on to look at two pages - an indication that the website has been used to search for information rather than random views. As an example in December 4,151 pages were viewed during 2,534 visits to the site. The Google statistics are so detailed, they include that there was an average of 16 visits an hour during the month! Even on Christmas day 117 pages were viewed during 78 visits to the site.

CHRISTMAS LUNCH

Our Christmas Lunch at the Coach & Horses in Clifton proved as popular as ever. Numbers were limited to about twenty but after a couple of cancellations

and careful planning by Colin Trowbridge nineteen of us enjoyed the traditional hospitality of one of Bristol's few traditional pubs.



The necessary photo recording the event was forgotten in the chaos of the festivities but the above records the hangers-on before they finally departed.

HALL OF FAME



This photo of our membership secretary Robert Bennett was spotted on the wall of the entrance to the Clinical Research Centre at Southmead Hospital.

Clearly Robert impressed them when he took part in a recent research study.

75 YEAR OLD'S EXPERIENCE

Member John Hughes has written with Prostate Cancer UK's comments regarding his 75 year old friend who was refused an MRI scan due to his age.

PCUK's reply is as follows:

Prostate Cancer UK is working with NHS England with the aim of expanding Multiparametric MRI scan provision to all men who

could benefit from it, without restrictive eligibility criteria. However, we are not yet at a stage where all hospitals have achieved this level of provision. Previous guidelines have stated that mpMRI and/or radical treatment should not be offered where the patient has less than 10 years' life expectancy. These days, at 75 the government's own figures would say that life expectancy would be over 10 years, but hospitals may not have updated their policies on this in some time. We feel that age cut-

offs are not best practice.

Clinicians must in all cases make a judgement on the overall health of the patient. If they are not sufficiently well to undergo radical treatment for prostate

cancer, they do not need to have an mpMRI so the scan would not be administered.

Hospitals also operate PSA criteria for mpMRI scans – we recommend referral for a scan for any man in the PSA range 3-30, but these bands are not universally applied and some hospitals will have a higher threshold. It is unlikely that just the symptom

of frequent urination would be enough for a referral for mpMRI.

All this is to say there are legitimate reasons why a urology department may decline to offer mpMRI in some cases. However, if your friend is concerned that he has been refused for a reason that is not legitimate, there are routes through which a complaint can be lodged. The hospital should have a Patient Advice and Liaison Service (PALS) who can be contacted to lodge a complaint.

Alternatively, Healthwatch is an independent organisation that champions health service users and your local Healthwatch should be able to help.

tackle talk

Roger Wotton, Chairman of Tackle Prostate Cancer, the campaign name of the National Federation of Prostate Cancer Support Groups, gives his latest update:

If I reflect on the past year, we continue to make headway with our three aims of the Federation - Supporting men and their families through the network of support groups across the country, raising awareness of the need for earlier diagnosis and campaigning on issues related to prostate cancer.

SUPPORT

As far as support groups are concerned there are now 92 groups in the Federation and I looked back over the past three years and counted up visits to fifty-three of these, so I still have some way to go to meet all those who are helping so much at a local level! On this point, if you would like to hear about what we are doing on behalf of patients I would be happy to plan a visit to your support group - just drop me an email.

At our latest Board meeting last week, we reflected on a healthy financial position, at least for 2019, but we need to raise our game in terms of generating funds for all that we want to do. In the New Year we plan to make an application to the National Lottery for funding support that will enable us to have a more secure future as we try and achieve our aim of having every man diagnosed being signposted to one of our local support groups.

Such applications are not simple and may take up to six months but we have engaged an experienced fundraiser who has worked in this field and has had success in previous Lottery applications.

Many of you will be familiar with our Cycle to the Moon - Save a Dad initiative. As a Board we reviewed the progress to date and lessons learnt from our launch earlier this year. We had some success in raising awareness and we are grateful for all those members who contributed to raising funds. Our intention is to relaunch the initiative in the Spring of 2019, and this time we will be putting more effort into seeking support from cycling clubs and sports teams. One new dimension is our plan to target motorcycling clubs where we believe there is a real opportunity to raise awareness, particularly in the classic motorbike scene. So, you may see "Motorcycle to the Moon" as a variant of the message!

AWARENESS

In terms of public awareness of prostate cancer, we see almost daily a report in the media about one new development or another, which in itself is encouraging, but it can be confusing making sense of what is really relevant to most of us and as opposed to what makes a good headline! For us it is about getting the powers-that-be to embrace developments that will lead to better diagnosis and treatment. We are just embarking on a public consultation with NICE on revised guidelines for prostate cancer and this should help take us forward. On this note, it is becoming clear that the topic of screening for prostate cancer is being discussed more widely. This is good news and it builds on our push for more informed PSA testing.

CAMPAIGNING

Perhaps our most significant push over the last few months has been on campaigning through various channels for a more informed debate about prostate cancer. Along with

Orchid Male Cancer, we are involved in setting up an All-Party Parliamentary Group (APPG) on male cancer. This will have its inaugural meeting in January and we hope serve to influence politicians on the important issues where we need their help to make progress.

Secondly, with Orchid and the men's health charity CHAPS, we are planning an event in the House of Commons in February where we hope to explore the case for prostate cancer screening. Key influencers are being invited to this event, sponsored by Lord Ribeiro and Sir Bernard Jenkin MP. I will keep you informed of the outcome of both these initiatives.

Lastly on the campaigning front, a letter is about to go off to Dame Sally Davies, Chief Medical Officer at the Department of Health, asking for the inclusion of teaching 15-year-old school children about the prostate as part of the 'personal, social, health and economic' (PSHE) curriculum. This letter will be co-signed by Prostate Cancer UK, Orchid Male Cancer and the British Association of Urological Surgeons (BAUS). We hope this will kick-start our planned "Save a Dad" initiative.

LOOKING FORWARD

I see 2019 as being another year where we continue to make good progress, supported by our local hard-working members and Trustees. As an aside, we have just been awarded 'Best patient-led support charity in the UK' by the GHP Social Care Awards!

Looking to our conference next year, it will be held on June 13th in Edgbaston (same venue as last year). The theme will be 'Screening for prostate cancer - continuing the debate'. I hope to see as many support groups represented as possible. More details to come on this.

WHY P.C. IS GOOD FOR YOU

Prostate cancer survivors live longer than men without the disease if symptoms are caught early, figures show.

Experts said the statistics suggested that a diagnosis could act as a "wake up call", with such patients more likely to keep a close eye on their own health and attempt to improve their lifestyles.

The figures from the Office for National Statistics are the first estimates that show how survival from a range of cancers varies, depending on when it is diagnosed.

When prostate cancer was spotted early, at stage 1, men had five year survival rates 0.5% higher than men of the same age in the general population.

NEW TREATMENT

The first UK patient has received radiotherapy using a machine which could one day cure some cancers in a single treatment.

The Royal Marsden Hospital and Institute of Cancer Research (ICR) in London is only the third centre in the world to use the technology.

The MR Linac machine, described as a "dream come true" for radiologists, is unique in generating magnetic resonance images (MRI) while also delivering X-ray radiation beams. Barry Dolling, 66, who was diagnosed with early prostate cancer in April, said he "jumped at the chance" to be the first in the country to try the technology.

He will receive four weeks of radiotherapy as part of a small clinical trial of patients with localised prostate cancer at the Royal Marsden.

Many cancer tumours shift position during radiotherapy or between scanning and treatment. Breathing, bladder filling or bowel changes can all affect the location of cancer, raising the risk of radiotherapy being off-target.

However the MR Linac machine allows clinicians to constantly monitor the location of the tumour while delivering the treatment.



Professor Uwe Oelfke

Professor Uwe Oelfke, head of the joint department of physics at the ICR and Royal Marsden, who leads the project, said: "For us, it is a dream come true, because for the first time we can actually see what we are treating. We can see the tumour when it's moving, we can see the organs that are raised, we can see daily changes like shrinking of tumours or swelling of tissues. You can react to everything that's happening."

Clinicians using the machine take an MRI scan of the patient, before designing a plan for radiotherapy for that day, reacting to any changes in the anatomy. This can also be adjusted in real-time as treatment is delivered.

The UK trial will initially examine prostate cancer, but it is hoped the machine will improve radiotherapy for a wide range of cancers, including hard-to-treat lung and pancreatic cancers.

Dr Alison Tree, consultant clinical oncologist at the Royal Marsden and lead investigator of the trial, said: "Prostate cancer responds most effectively to large doses of radiation delivered over a short period of time. It is possible that this ground breaking precision will one day make it

possible to cure prostate cancer in a single treatment."

She added: "That is science fiction at the moment unfortunately, but that's our dream really."

You can see Professor Uwe Oelfke's presentation on this treatment at <https://www.youtube.com/watch?v=3qz7JeDfYl4>

WOMEN WISER THAN MEN

(Who didn't know that?)

Men know less about the prostate than women because they fail to take their health seriously, a cancer study has found

The survey looked at 2,500 Europeans. It found men had poor knowledge of key symptoms and did not take seriously early signs of potentially life-threatening conditions, such as prostate and bladder cancer.

Prof Hein Van Poppel, of the European Association of Urology, said "Persuading men to take their health seriously presents a serious challenge."

92,000 men die of prostate cancer in Europe every year.

NEXT MEETINGS

Thursday 7 March and 4 April. Coffee mornings at the Macmillan Wellbeing Centre on the Southmead Hospital site at 10am.

BAWA informal meeting on Friday 8 March and our AGM on Wednesday 10 April. These meetings starts at 7.00pm at BAWA, Southmead Road, Bristol BS34 7RG and include their famous buffet. Friends and family always welcome.

Check our website www.prostatecancerbristol.org.uk closer to the date for details of any speakers.

Contact us by email at prospect.bristol@gmail.com or telephone our "Tackle" helpline on 0800 035 5302.