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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



SUMMER IS HERE

Welcome to the summer edition of our newsletter. Hopefully this will remind you that our group is still very active. After our spring and summer daytime events don't forget our next evening meeting at BAWA is on 24 September.

KINGSWESTON WALK

Our first walk of the year took place on a fine Saturday at the beginning of May.



Chris with our walking group

Chris Millett led an enthusiastic group around the Kingsweston estate located in north-west Bristol. There were fine views over Shirehampton and Avonmouth to the river Avon and estuary. After tiring everybody the group enjoyed a welcome lunch in the mansion house café.

CANCER RESEARCH UK

Thanks to Peter Williams and Steve Biddlecombe for this report:

Five Prospect members were among 15 visitors who enjoyed a tour of Cancer Research UK's laboratories at Southmead in May.

Ros Fry from Cancer Research UK Introduced us to the team at the laboratory.

A super presentation slideshow followed, explaining what the charity's vision is. "That within the next 20 years 75% of people with cancer will survive."

Cancer Research UK wants the survival rate in the UK to be the best in the world by helping to prevent cancer, diagnose it earlier, and develop new personalised treatments to make them more effective.

Amazingly smoking is still the biggest preventable cause of cancer.

Ros went on to explain how 80% of donated money was spent by the charity, the final 20% being attributed to admin and fundraising etc. It was very humbling to discover how the money is spent.

The fun part of the afternoon was to visit several of the labs.

We were split into various brightly-clad lab-coated teams, visiting some of the remarkably dedicated research students.



Peter modelling a peach gown and green gloves!

We were shown how to prepare culture dishes, and were tested against the clock to see who was the fastest.

Other labs offered us insights into their particular study. We saw slides and culture dishes, showing both prostate and breast cancer cells.

The event finished with a really interesting presentation on how to donate to cancer research.

Information was also given on pledging to leave a gift in your will.

Cancer Research UK spent nearly £2 million last year in the South West on some of the UK's best scientific and clinical research.

Prostate cancer is the most common cancer in men, with more than 47,000 cases diagnosed every year in the UK.

Dr Rebecca Gilbert has a Population Research Postdoctoral Fellowship from Cancer Research UK and is using computer algorithms and risk prediction tools to analyse data from clinical trials to find a more personal approach to the PSA test to avoid false positives and unnecessary biopsies.

Dr Gilbert is optimising the PSA blood test method by investigating the impact of genetics on PSA levels.

Cancer Research UK has an Inspire event at Taunton Racecourse on October 17 featuring a researcher from Exeter University who is investigating the use of light scattering as a non-invasive technique to assess cancerous tissues.

Prospect members are welcome to request a ticket or more details from Ros Fry, Community Legacy Manager – South West.
Tel: 01308 423805;
Mobile: 07920 297727.

ANNUAL DOCKS WALK

The weather was not kind to us again however this did not deter our enthusiasm to enjoy a coffee stop, dodge the showers and enjoy the hospitality of the refurbished Cottage Inn for lunch.

Somebody forgot to take the obligatory photograph!

Many thanks to Ken Head for organising this popular annual event in our calendar.

HENLEAZE BOWLING CLUB

Mike Batt kindly organised a taster session for our members at the Henleaze Bowling Club in July.



A team of enthusiastic bowlers.



A club house to tempt all.

Bowler Peter Grindon kindly writes this article.

NOT EXACTLY PLYMOUTH HOE

On the evening of 2 July we were introduced to the art of bowling at the Henleaze Bowling Club by Mike Batt and Sue Edwards.

An enjoyable time was had by all, of which Sir Francis Drake would have been proud. Alas I would not have been amongst the chosen team! I suspect I would

have been swabbing the decks or even walking the gang plank.

None the less we enjoyed ourselves and a thank you to Mike for arranging the evening.

PENNY BROHN LUNCH

There were over 30 at Connie Shiridzinomwa's talk at the Penny Brohn Cancer Care Centre in July.

This probably explains the additional seating that had to be organised for our lunch that exceeded our reserved allocation. It just shows the draw this event has for our members.

Connie's talk on her research into the body image problems prostate cancer patients experience was fascinating and the numerous questions after indicated our interest in this unusual subject.

A BIT FROM THE OLDIE

Bernard Smyth submits this interesting article from "The Oldie" magazine.

In the June edition, the "resident" medic tells of a debate in the British Medical Journal in which a breast cancer specialist argued that certain cancers are so slow growing and rarely cause death that they should no longer be called cancer because of patient anxiety.

On the other side of the debate, a histopathologist argued that cancer lesions are not simply malignant or benign so we shouldn't shy away from the word cancer.

Given the impression that they'd had unnecessary operations, patients would become confused and angry.

Prostate cancer is used by both sides of the argument - one saying that "ultra-low risk" versions have such high survival rates that, because it is initially

diagnosed by measuring the PSA, screening by means of this test has fallen from favour because doctors think the cancer is innocuous.

The other side argue that the operation is necessary because it is the only way to know that at the cancer is low-risk. They argue that 30pc of those with a biopsy diagnosis of "ultra-low risk" cancer in fact have higher risk cancers in other parts of the gland when it has been removed and examined histopathologically.

Therefore the argument that the ultra-low risk cancer should be re-categorised as non-cancer because none of the men die from it after a radical prostatectomy is not valid.

The histopathologist says if the public were educated that "benign" signifies very low risk rather than no risk, anxiety-inducing labels could be avoided.

"The Oldie" doctor says "there are dangers to overtreatment and under treatment and we are naturally inclined to over treat".

From a personal perspective, I think it would help if hospital staff explained a bit more about prostate cancer - that it can be low risk or high. Just telling someone they have cancer and leaving it at that is not good enough and inevitably leads to worry.

JOHN WINBOW'S STORY

Member John Winbow, 76, has been through the mill, but he keeps on smiling and turning up at Prospect meetings and coffee mornings.

He was diagnosed with prostate cancer just months before his retirement in 2007 from his job as superintendent at Wickwar quarry.

He had radiotherapy and hormone treatment until 2010.

In 2015 he had a flexible cystoscopy to investigate blood in his urine and difficulty urinating.

This identified that he had radiation cystitis and a stricture.



John Winbow

In 2016 he was listed for a TURP (transurethral resection of the prostate) at Southmead and dilation of a stricture. But in July that year he had a heart attack and a stent was fitted. The TURP had to be postponed because he was on anti-clotting medication.

In February 2017 he was admitted for three days as his urethra and bladder were blocked by blood clots and he had the clots washed out. He started using self-cauterisation in August of that year. Urethral dilation and tunnel resection to the prostate led to a catheter being fitted but that was removed after a week.

He was entirely incontinent so the catheter was refitted after 10 days.

He had to go into Southmead again in November that year for blood clots but was there only overnight.

In February last year he had uro-dynamics to check the possibility of an artificial urinary sphincter being fitted. This was recommended and the operation undertaken in January this year. His catheter was removed but he is still incontinent so the sphincter was activated in February.

John, who lives at Cromhall,

Wotton-under-Edge, says it was working very well and he has a good flow but after six weeks it became variable and very slow at times.

He saw a nurse specialist in May and by this time the sphincter was working well. But he has her contact details in case he has the same problems again.

For now his flow is OK and he's mostly dry, using only one pad a day. But unfortunately his cancer has returned, with two spots on his spine, so he's back on hormone treatment.

OPEN SURGERY

Peter Brown had open surgery to remove his prostate in 2009.

Most surgery carried out in Bristol to remove the prostate is now undertaken using the Da Vinci robot (robotically assisted laparoscopic surgery) however there may be reasons why open surgery is necessary and Peter writes the following: I was advised by a consultant urologist to have my PSA monitored annually after I suffered prostatitis, because my uncle died of prostate cancer in his late 60s. I was aged 50 at the time.

A few years later, a blip in my PSA reading (increase in one year from 2.4 to 3.5) made me ask for a private referral, and I was diagnosed with prostate cancer in February 2009.

I had a radical prostatectomy using open surgery at Gartnavel Hospital Glasgow a few weeks later. Histology showed margins to be clear, Gleason score 7 (3+4).

Recovery from the open surgery however took several months.

Subsequent ongoing 6 monthly PSA checks have thankfully all been <0.1.

I would be happy to speak with anyone who has been recommended for open surgery. (Email Prospect for Peter's details.)

PROSTATE CANCER UK

Earlier in the year Mike Tremlin took part in a Prostate Cancer UK March For Men. Mike regularly fund-raises for PCUK and the following photo shows his enthusiastic supporters.



Mike is centre bottom row.

tackle talk

Roger Wotton, chairman of Tackle Prostate Cancer, gives his regular update. However as space is limited his report is summarised. The full text with photos can be seen at <https://tackleprostate.us12.list-manage.com/track/click?u=1d2d0b12657855f58481cffa4&id=2847d920d9&e=4ddd4b9c34>

AGM/CONFERENCE

This year we had a very good selection of speakers examining the issue of whether it is time for a screening programme for prostate cancer. Evidence presented pointed to that now being the case but how to proceed is still being debated. It is a complex issue and there are still differing views, even amongst clinicians. Nevertheless, our campaign continues.

CYCLE/BIKE TO THE MOON

Our major initiative continues, building on our efforts of last year. We have reached out to

gyms and 250 have expressed an interest. This year we have extended the project to include Bike to the Moon and we have reached out to motorcycling clubs and 100 have expressed an interest. We have established a relationship with the famous “Ace Café” in London, with the Classic Motorcycle Club and with the “Purple Helmets” motorcycle display team. The plan is to be present at motorcycle races at Donnington Park early in August and at Mallory Park over the weekend of 31 August and 1 September.

TACKLE MAN VAN

For some time, we have been developing the concept of a Tackle “Man Van” to be used to offer prostate cancer testing and “Wellman” check-ups to be used by our support groups across the country. We are pleased to report the vehicle has now arrived and we are piloting the services in the West Midlands.

SAVE A DAD

We are continuing to push for prostate cancer awareness to be included on the National Curriculum in secondary schools. We are still in discussion with a number of schools in the NW who are keen to spread the word and influence the next generation. We are producing a leaflet specifically aimed at encouraging conversations between teenagers and their dads about prostate cancer.

STRENGTHENING OUR BOARD OF TRUSTEES

I am pleased to report we have appointed Alphonso Archer as a new Trustee. Alphonso is well known to most of our existing Trustees. After 30 years working in IT, he made the decision

around four years ago to pursue his passion for music after being diagnosed with prostate cancer.

WALKING FOOTBALL

Alphonso has a close connection with a walking football team in Wiltshire and we are looking to collaborate this coming season to raise awareness and funds. This could develop into a very useful way of encouraging men with prostate cancer to get regular exercise, stay healthy and have a better quality of life.

NATIONAL LOTTERY APPLICATION

Our application for funding a resource to help us expand our support network is still being considered by the National Lottery Foundation. We now await the outcome of their review, which takes place against all other charity applications for funding in 2019. Watch this space!

NEXT MEETING

Coffee morning at the Macmillan Wellbeing Centre on the Southmead Hospital site on Thursday 5 September and Thursday 3 October.

Our next members’ meeting will be on Tuesday 24 September.

This is one of our very popular informal meetings where members chat about their medical experiences.

The meeting will start at 7.00pm at BAWA, Southmead Road, Bristol, BS34 7RG and of course includes the famous BAWA buffet.

On Friday 4 October we have our autumn walk and pub lunch.

Check our website

www.prostatecancerbristol.org.uk closer to the dates for further details.

Contact us by email at

prospect.bristol@gmail.com

or telephone our “Tackle” helpline 0800 035 5302.