

Working to achieve a national screening programme

Karen Stalbow, Prostate Cancer UK (PCUK)

PCUK is committed to achieving the earlier diagnosis of prostate cancer. They will do this with a research budget of £7 million, funding new diagnostic tests, genetics research and imaging. This will take time. In the meantime, the aim is:

- To increase the awareness of risk factors among men and educate GPs to counsel men at risk about the pros and cons of the PSA test
- To harness recent changes to diagnostic and treatment pathways and get GPs to reconsider their views of the PSA test.

PCUK want to reduce the rate of late-stage diagnosis, but believe that further research is needed to find a more accurate test than the PSA test.

From Prostate Matters, The newsletter of The National Federation of Prostate Cancer Support Groups, August 201

The Graham Fulford Charitable Trust

Graham Fulford, Chairman

Graham spoke about the work continuing with PSA testing events, and about working with many Tackle member support groups. Over 122,000 tests have been done on over 88,000 men since 2004, with over 1,500 known cancers identified that otherwise may not have been discovered.

From Prostate Matters, The newsletter of The National Federation of Prostate Cancer Support Groups, August 2019

Sandown and Cowes Carnivals

On Saturday 27 July we attended Sandown Carnival. It was a well attended event, with hundreds there, on that balmy evening. Plenty of flyers and stickers were given out by Tony S, John and Lorraine, Sharon, Vic and myself, all sporting the new blue wigs! On Thursday 8 August we attended Cowes Carnival for the first time. A very wet, cold evening, yet still the crowds came out and hundreds of stickers and flyers were given out.

Well done to Elenid, Angela, Vic, Michael T and friends for supporting the event.

Future Events

22 August – 26 September 2019

Monday 26 August

St Helen's carnival 6 – 9pm.
Assembly point The Green, St Helen's.
Volunteers please.

Thursday 29 August Promotional stall, St Mary's Hospital 1 – 4pm

Thursday 29 August

Ryde main carnival 6 – 9 pm.
Assembly point by Boating Lake, Ryde.
Volunteers please.

Saturday/Sunday 31 August and 1 September

Wolverton Manor Show. 10am – 5pm or any morning or afternoon. Free entry for helpers. Contact Sharon for details.

Thursday 5 September Promotional stall, St Mary's Hospital. 1 – 4pm.

Monday 16 September Bookings for PSA test event open on website.

Thursday 19 September

Promotion of PSA test event in foyer of Tesco's Ryde. 9.30am – 3pm. Helpers please contact Alan Taylor.

Saturday 21 September

Macmillan tea and coffee fund-raising day, Wroxall Church Hall. Stall to be present 10am – 4pm, helpers needed – contact Alan Taylor.

Thursday 26 September

Members' meeting at the Cricket Club Pavilion, Blackwater – Speaker Ray Harrington, Vail Footprint Trust.

Update about the Portsmouth Daisy Bus

We are now looking at being able to run through to March 2020. However, I must stress that we can only ever be approximate! We have no idea what money will come in between now and then which may extend that time (we are of course fundraising all the time). At the same time, we do not know whether we will incur additional costs. For example, repairs, replacement hire, staff cover in the event of illness, and so on.

To illustrate this, our Southampton bus has undergone extensive repairs this year, leading to additional costs into the thousands. Similarly, someone crashed into our Portsmouth bus and, while it was being repaired, we had to hire another. So the income and expenditure are subject to unpredictability.

I hope this makes sense and helps. Of course, we would love it if your group considered supporting this service again. Thanks for your continued interest in the service, and willingness to help.

Cait Allen (Chief Executive Wessex Cancer Trust)

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Dr Boote's Retirement

After nearly 7 years as the Uro-oncologist for the Island Dr. David Boote has now retired. Sadly, this would not have happened if the government had not put "caps" on senior doctors' pensions and made it difficult for them to continue working as they have done in the past. However, it has happened and we all send our best wishes to him for the future as some lucky people now see him as a Locum Consultant.

This retirement has caused enormous issues for us as patients and families, for future patients, for St Mary's and for Portsmouth. Most of the issues arise due to poor forward planning. This we can lay quite firmly at the door of NHS England (Special Commissioning for Cancer), I.W. CCG and Portsmouth Hospitals in that order. The advertisement for the position has only recently been published, yet it was common knowledge several months ago that he was leaving.

Over the past 3 months Sharon and I have been lobbying all these groups (and our MP) to try to find out plans for the future of Uro-oncology on the island. We all know that St. Mary's has a policy of sending certain groups to Portsmouth or Southampton for treatment and this seemed to be the thin edge of the wedge for men with prostate cancer.

As we stand now 15th August, (subject to change?): some men will be offered appointments in Portsmouth others will be seen in St. Mary's by Dr Yeoh until 16th September, with the exception of 22nd Aug. (it is still uncertain who will cover that day). In mid-September the Island Uro-oncology Clinics will be taken over by a Locum Consultant until a full-time substantive replacement is appointed to replace Dr Boote at Queen Alexandra Hospital and the Island. Uro-oncologists are a rare breed so it will be difficult to replace him.

This is not the best of situations but is the only answer at the moment. At least we SHOULD have a regular named doctor. Continuity is crucial for cancer patients under-going treatment. We will keep an eye on this.

In all the letters written and phone calls made Sharon and I have been trying to ensure that the "powers that be" understand and fully take on board the fact that Islanders should get the same treatment and quality of service that mainlanders receive.

If you feel you are missing out – make a fuss—politely. If you don't ask you don't get.

Remember the I.W. Support Group is here to help you.

Roz Dennison 15/8/19

The Mermaid Bar at the Wishing Well

Photo shows Conrad Gauntlet CEO of the Isle of Wight Distillery presenting a cheque for £500 to our Trustee Roy Colledge on behalf of the IWPCSG.

The Isle of Wight Distillery is sponsoring the IWPCSG 2020 Calendar. They have taken the decision to sponsor us as they see us as a cause very close to their hearts and will be selling the calendars in the Mermaid Bar at the Wishing Well for £2 each. All proceeds are being donated to our Group.

(from announcement written by Georgie Bottrill, 2nd August 2019)



Chairman's Chat

So much going on it's difficult to know where to start.

First Act at the members' meeting was a resounding success, and a few days later the MAN Float was at Sandown Carnival for our first parade. The Chale Show quickly followed, for two days over the following weekend, then Cowes Carnival.

Calendars on sale for £2 went like hot cakes and now Roy has arranged for them to be numbered, and a draw will be made at our Christmas Dinner to find the lucky number which will win its owner an expensive bottle of Mermaid Gin.

Having worked through all the Trustees giving their experiences of prostate cancer, we have decided to introduce members. Tony Sallabanks, who looks after the collecting tins and with many other activities, is first up.

The Trustees are keen to promote lobbying of the powers that be on any issues that affect our membership. One in point is the retirement of Dr Boote. Well done Roz and Sharon.

Angela continues to work hard on the new online booking system we will be using for our 19th October PSA test, and Tony Wheatley is heading up a sub-committee looking at aims and roles of the Group, maintaining contact with housebound members and a succession plan for executive Trustees.

The Trustees are also discussing inviting members to make a regular monthly £2 donation towards the running costs of the Group. Your views are very welcome.

Finally we have two more carnivals coming, plus a Show at Wolverton, all needing your support and a Barn Dance in October. Hope to see you there.

Alan Taylor



A member's experience of trying to get Hydrogel treatment

Hi Alan, hope all is well with yourself. I thought I would pass on an update on my situation on the basis that it may be of interest to members.

I finally attended my referral appointment at QAH a couple of weeks ago. The woman I saw was excellent and immediately referred me on for the radiotherapy treatment, as expected.

So far so good, but there is a twist! I asked whether I could be put forward for the Hydrogel trials at Belfast or Bristol. She immediately brightened up and said she was pleased I was aware of this new treatment. It was her understanding that the trials had actually finished and had been successful, such that a number of hospitals were adopting this refinement, including Bristol.

QAH intend to do the same but, as yet, had not put together an implementation plan. She said that she was quite happy to approach Bristol in order to see if they would accept me for treatment and would get back to me within the week with a few options. This she duly did.

These were, to be referred to Bristol (or any other unit offering the Hydrogel that I wanted, typically London), to go private at around £30k, or to have the treatment at QAH which required me to contribute towards an outside urological surgeon (for the Hydrogel process) procedure with the radiotherapy done by the usual team with expert input.

The last option is the route I have chosen. The QAH team are putting together the information and package for me to review and accept or decline, with treatment likely in October.

John Wood 9/8/19

Quote – Unquote

Life is not measured by the number of breaths we take, but by the moments that take our breath away.

I found there was only one way to look thin, hang out with fat people.

The love of a family is life's greatest blessing.

I've learnt that it is not what I have in my life but who I have in my life that counts.



Members' Meeting July 2019 – First Act Chale Show

A group of adults with various disabilities joined together to form First Act based at Shanklin Theatre. They learn songs from shows presented at the Theatre and then showcase them to willing audiences around the Island. It was very moving and motivating to see this group overcoming their difficulties to achieve a level of confidence and expertise that enabled them to perform in front of an audience. The evening was enjoyed by 42 members, our biggest this year and at the end the Support Group made a small donation to the First Act leader to cover transport costs etc.

The Show was well attended by Stall volunteers, and by the end of this beautiful sunny weekend, almost 250 flyers for the Group, holiday makers and PSA testing had been given out and a number of new members had signed on. The new calendar was on sale for a Show price of £2 and was a great success with the help of Roy's salesmanship. Each calendar has a number on it and a draw will be held at our Christmas Dinner, the lucky winner will receive a prize of Mermaid gin, donated by the Isle of Wight Distillery. Our thanks to Elenid, John and Lorraine, Roy, Peter, Vic, Roger, Sharon, John S and Angela for supporting the Show stall.



Here we are giving details of Member's experiences in the treatment of Prostate Cancer so that other members of the Group can speak to them if they think that their own case has some relevance.

Tony Sallabanks (Member)

In 2015 was when I had a PSA test. The results were just over 11.5.

I was referred to St Mary's Hospital where I was given a (TRUS) guided biopsy (I found this both invasive, uncomfortable and it left me with scar tissue). My Gleason score was 7.5. 30% one side 40% the other. I was put on watch and wait.

Over a period of the next 9 months, I had a further two PSA blood tests. On the second PSA test my count had gone up. I was then given

an MRI which showed dark mass contained in my prostate gland. I was then sent to the QA Hospital for a transperineal biopsy, which is an operation and I was kept in overnight. The result was the cancer had grown over 75% inside my prostate.

I had already made up my mind I was going to have a robotic prostatectomy at the QA. I went in on 1st November 2016. Mr Soloman did the operation. After 3 and a half days I was sent home with my goody bag containing incontinence pads, 29 days supply of syringes which I injected into my stomach and lots of literature. I wore pads for about a week, none since. I put that down to luck and doing pelvic floor exercises.

A month later I went back to see Mr Soloman. The operation was 100% successful. My prostate was larger than he had expected. I was discharged under the care of my GP. I have PSA tests every 6 months and the count does not even register 000.001.

Tony Sallabanks

The GP's Perpective by Dr Ann Williams

Dr Williams began as a nurse then graduated to become a GP with a special interest in urology.

As there is no screening, what is there to go on?

- PCRMP (Risk management programme) 17 sections in total!
- Any man over 50 is entitled to a PSA test.
- We know Afro-Caribbean men are more susceptible.
- Family history.

She feels there needs to be a proper programme as GPs are generalists not specialists and need more time per consultation.

Statistics

- 1 in 7 men are asymptomatic and a PSA screening will result in an elevated reading.
- 1 in 6 men with a "normal" PSA reading will have prostate cancer.
- 1 in 50 will have an aggressive cancer.
- 75 out of 100 with an elevated PSA will have a false positive.
- 1 in 3 men will have prostate cancer.

Pros and Cons of a PSA test

- Pros:** May detect cancer before symptoms appear.
May detect early cancer when cure is possible.
- Cons:** Not diagnostic of prostate cancer.
Not tumour specific.
False positives.

The PSA test is, however, a predictor. When the result is received, the GP should counsel the patient prior to referral.

Risk assessment conclusion

- Men need to be properly informed.
- Is screening the correct word?
- Conflicting views – the onus is put upon the GP, when there is lots of advice available from a variety of sources.
- The GP's role is to support the patient and family.
- A 10-minute consultation is not enough for a GP to be effective.

From Prostate Matters, The newsletter of The National Federation of Prostate Cancer Support Groups, August 2019

NHS Predict Prostate tool

A new online prognostic tool has been developed for men newly diagnosed with non-metastatic prostate cancer.

Known as PredictProstate, it is available on the NHS website at: <https://prostate.predict.nhs.uk>. It is recommended for use in consultation with your doctor.

To use it, you enter relevant information about yourself and your prostate cancer, such as your PSA, the clinical T stage of your cancer, your Gleason score and whether biopsy information is available. The tool will then show you how different initial management strategies affect the percentage of men that survive ten and fifteen years after diagnosis – along with the potential harms of each treatment type.

Given the known dangers of both over- and under-treatment, it is critical to make informed decisions at this stage about radical or conservative treatment. The PredictProstate tool has been developed to help you to do this.

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The The Street Wise Patients' Guide to Surviving Cancer by Karol Sikora – Former Head of Cancer at the World Health Organisation

(from a newspaper report provided by Roz)

He warns NHS patients that "the system is not actually there to help you alone but to maximise the quality of cancer treatment overall, and to make sure the organisation and the people within it make a living, and to ensure that the burden on society as a whole is not too great."

Prof Sikora recommends patients carry out detailed research in their particular cancer obtaining copies of their scans and pathological reports and look up guidelines on how they should be treated. Then draw up a treatment schedule. Next find out which hospital provides the best treatment and ask to be referred there. He reminded everyone if you feel you are missing out make a fuss – politely. If you don't ask you don't get.