

OPT – Organised Prostate Testing

A Zoom meeting was organised for a Prostate Cancer Screening Project lead by Chris Booth. 21 delegates attended the meeting, both from the UK and Sweden, with a number from Manchester University, GFCT and Support Group PSA Organisers from up and down the country.

The EU has set up a Grant system for 10 million Euros to subsidise groups who are organising PSA tests and are prepared to offer their results data to a National Database for analysis. The hope is that a better idea of the effectiveness of PSA testing can be proven together with a better awareness of the cost effectiveness of this procedure.

A detailed presentation from Chris Booth, the National Co-ordinator for OPT in the UK, was given explaining how analysis together with a letter of authentication with the test results, would help to present a clearer case to the Health Department of the UK (The IWPCSG is signed up to this campaign.)

This was followed by a presentation from a Swedish representative who explained the similarities of the Swedish Health set up to the prostate cancer screening and the NHS. He emphasised the need for Organised

PSA testing and the difference from non-targeted testing. He also endorsed the need for effective PSA testing over a period not a one off and collecting and analysing the data collected.

Next up was Graham Fulford from the GFCT who gave a brief history of the GFCT from 2005 to date, and how the testing had transferred from handwritten to computerised systems. The work of Empresa and GFCT had enabled a vast database and an appointment driven service. The involvement of National Services, Police, Fire, Ambulance, Prison Service and National Men's groups, Masons, Lions, etc. A more refined advisory service, together with a risk/repeat algorithm.

He finished by expressing his concern that if bigger was better then quality and accuracy must not be forfeited, so quality control was essential.

A Local Government Data Researcher also homed in on PSA testing and infrastructure and GPs in so much chaos – re Covid and backlogs that cannot always rely on them. Director of Public Health is still opposed to PSA testing.

Another speaker mentioned that Palliative care was not always successful and ten times more expensive than early diagnosis. There was a need to update the costing system.

Another comment was about screening, using MRI rather than PSA, but the cost was restrictive.

There was more talk about the size of testing sessions, reminders to previously tested persons, and how to cope with funding these tests.

In conclusion the meeting was an exercise in explaining how data collected by PSA testing groups up and down the country could be used to justify a UK National Screening Campaign and how important data was to the statistical experts. It was hoped that this would motivate the groups at ground level knowing how their data would help this campaign. An interesting meeting if you were mathematically minded but challenging work if not!



Bill Turnbull

January 1956 – August 2022

Journalist and TV broadcaster Bill Turnbull passed away aged just 66 years.

He had been diagnosed with advanced Prostate Cancer in 2017 having ignored some aches and pains in his legs.

Bill publicly announced his situation in March 2018 and from that point on and at every opportunity he urged men to be tested.

We have seen the 'Turnbull' effect ourselves, as he has changed men's attitudes towards testing from resisting to embracing and we thank him for that.

Our thoughts are with his wife Sarah and children, Henry, Will and Flora.

Future Dates/Events

24th September

PSA test event at Ryde Academy, Pell Lane 8.10am – 2.30pm. Volunteers please contact the Organiser on 07568245124.

12th October

Asda Newport promotion/awareness stall in foyer 10.30am – 2.30pm.

16th October

Tractor Rally – start at the Griffin, Godshill 10am. Finish at Arretton Field 3pm, stall at finish line.

20th October

Members' meeting Newport County Cricket Pavilion 6.15pm. One to one counselling available.

21st October

Preparation for PSA test at Totland Bowls Club 7 – 9pm. Helpers welcome to set up evening.

22nd October

PSA test day at Totland Bowls Club 8.30am – 2.30pm. Volunteers for the day please contact the Organiser on 07568245125.

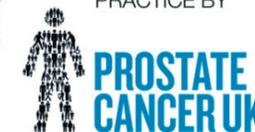
Newsletter

September/
October 2022



Registered Charity 1173916

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Newport PSA Test Event Report



For the first time the Support Group was able to organise and run a PSA test event in Newport. In the past, there has always been a problem with venues with suitable parking and finding a financial partner to help with the event.

Finally, an excellent venue was offered to the Group by the Newport Scouting Group which fulfilled all the criteria for a successful PSA test event. Once a date had been agreed, the trustees of the support group passed the proposal to finance the event 13 – 1 and a date was set up for 16th July.

250 places were made available for booking on the day which were quickly filled following several promotional events.

The weather on the day was hot which meant that the volunteers working in the car park were particularly vulnerable but coped really well finding shade and being well provided by our volunteers from the refreshment kitchen.

The event quickly got into its stride helped by fans being brought in by the

organiser and frequent refreshments and the exceptional efforts put in by everyone on the day. The five Phlebotomists performed to their usual high standard and the exit group led by Roy made sure all patients were informed as to the cost of running such an event and the need for donations to help supplement it. The event concluded at 2.15 pm and the samples were taken by Couriers Paul and Jacqui to the ferry and on to QA Hospital. Our thanks to Paul for organising complementary tickets for the ferry trip.

The results of the testing day were 32 high abnormal score and a further 56 having a high-risk green result. By following through the results from QA to GFCT the patients received their results on the Tuesday after the event, just a three day wait. With only one issue on the day to sort out and numerous texts and messages congratulating the group on yet another successful event, everyone who took part can feel satisfied that the time they gave to the event was well worth it.

Welcome

As you will have noticed, we have not produced a Newsletter since May and so this is an update of the Group's involvement over the past 4 months. The plan is to have this issue ready to give out at our next PSA event at Ryde on Saturday 24th September. We hope this will encourage the reader to pass on the information they read here and possibly get involved with the Group in the future.

There have been several changes to the Group's hierarchy over the past few months and a change in how the Group is organising its programme.

The Group now has two distinct branches, Wellbeing and Awareness, and PSA testing with support. You will have heard about the Yoga and the planned Tai Chi and Aqua aerobics that the Wellbeing branch is offering. You will also have seen the promotional events that the group has attended in conjunction with publicising the four PSA testing events being run this year. You will also notice the importance the group still puts on Support and Awareness.

We hope you will be able to attend our monthly members' meetings on the 4th Thursday of the month at the County Cricket Pavilion, Blackwater, Newport at 6.15pm and if you would like to volunteer to help at our next PSA test, then the number at the bottom of the page is the easy contact, or maybe you would prefer to make a monthly contribution to the Support Group. Whichever way you choose, you can be sure of our gratitude and that of all those involved with the Support Group.

Awareness Promotion Events

Custom Car Show Arreton

The Annual Custom Car Show at Arreton was again a venue for our awareness and promotion stall on Sunday 20th July. Paul and Jacqui Davies attended with the A-Board to try it out as a crowd attention device. Unfortunately, the bright sun made it quite difficult to see the image on the screen clearly and the noise of the cars parading had a significant effect on the sound quality. But it was certainly worth a try.

As with all the age appropriate events that we attend, so many of the general public want to shake a group member's hand in thanks for the PSA event having "saved their lives" plus other comments about how useful the helpline is and having well informed volunteers in the group to help with problems faced throughout the pathway of the diagnosis and treatment.

So much feedback can be picked up from the public and members at these events, necessary for all interested parties.



Ventnor Park Day

The Group was invited back to Ventnor Park Day on Saturday 2nd July and again scored high points with the weather and huge turnout of people. Those present at the stall were Rita and Graham, Vic and Alan. As per the previous year, we had a commanding site at the exit to the park, so there

was a continuous flow of people all day with large numbers enquiring about the Ryde PSA event, so much so that we had exhausted the quantity of flyers by mid-afternoon and had to write details on the back of our general flyer. Another excellent day for the Group in both promotion and awareness, this is such a well-attended yearly event we have already made a tentative booking for next year.



Chale Show

This two-day event held on 6 – 7 August at Chale Showground is always well attended and so it was again this year. We were incredibly grateful to John and Lorraine for turning up having recently recovered from Covid and parading around the show grounds for a number of hours with our flag and bucket, encouraging men

to obtain a PSA test and to find our gazebo for more information. Roger, Geoff, Angela, and Alan attended during the two day show and were giving out Totland PSA flyers as the Ryde event in September had long since been filled. Alan was interviewed over the public address system and each time it led to an increase in people attending the Group stall.

As usual, there were plenty of positive

comments about the work the Group is doing in conjunction with PSA testing and numerous testimonials of how individuals had been helped both by the test and by the help line. It was noted that the need for a more up to date Newsletter was in demand by a number of the public and members, together with the mainland flyers. A terribly busy and tiring two days where more help was needed to cope with the huge interest in the Group's work.

Music Quiz

Claim your IWPCSG enamel badge and pen by answering the following:

- 40's – Which American Vocal group had a hit with Whispering Grass (don't tell the trees)?
- 50's – Adam Faith's 1959 Number one hit?
- 60's – Jimi Hendrix cover of a Bob Dylan Song?

Answers to: iwpcsg@gmail.com

Good Luck!



Havenstreet Steam Show

The Support Group' first appearance at the 4 day 47th Annual Steam Show was reduced to 2 days as the stall was wanted elsewhere during this period. So, arriving on the Saturday, the second day of the Show, we pitched our site around the main parade area and prepared ourselves for the event.

This location meant we were very close to all the steam traction engines throughout the two days that we were present at the Show, which made it difficult to talk to the public about prostate cancer and PSA testing. The vast majority of stalls were selling

items and so they were able to proceed easily with plenty of notices giving cost of articles for sale. If we were to return again for another show next year, then a more distant location would be better to avoid the noise and the smoke. The stall was supported over the two days by Vic, Rita, Angela, and Alan Taylor. As mentioned, we cleared up on Sunday, a day early, as we had been invited by some members to the Shalfleet Fete on Bank Holiday Monday. Plenty of interest was shown at the Show despite limitations with the location and cost of attendance.



Jaguar Autofest

Having quickly packed up from the Rotary event the day before, the Group awareness/promotional stall decamped to Sandown Airport for the Jaguar Auto on Sunday 31st July. This was another large event with a high number of Jaguar enthusiasts attending both from the Island and mainland. Vic has designed a flyer especially for mainland attendees and these were liberally handed out throughout the day by Vic, Angela, Alan, and Geoff. We were particularly impressed with Geoff's contribution

to the event, as he was quite prepared to pass on information about prostate cancer and the work that the Group is doing to help men on the Island.

Again, a number of people came forward to thank us for "saving their loved one's lives" including a lady who appeared out of the group as we were talking to a particular stubborn member of the public, she endorsed our work and thanked us for testing her husband, who had now made a full recovery. The public person was convinced we had set this up but eventually conceded and left with a commitment to get tested.



Rotary Picnic on the Green

The Group was invited to attend this Rotary event in Ryde on the Green by the Esplanade, by the Ryde Rotary Group. We were visited by the Mayor of Ryde. The Community Champion of Ryde Tesco Superstore was very keen for us to return to their store for an awareness and promotional day. Being so close to the beach path and with a number of shows put on during the day, Vic, Alan and Angela were busy all day, with a special interest in the PSA event coming up in Ryde in September. This meant that a large number of PSA test flyers were given out during the day.

St Mary's Awareness Day

The Group was invited to the Green by the Duck Pond at St Mary's Hospital on 20th July to inform the staff of St Mary's about prostate cancer and the PSA testing we offer.

Having just run the Newport PSA event the Saturday prior to this event, a number of staff who had attended were hopeful that we might have their results. Unfortunately, they were not available until the following Friday, but Roger, Vic and Alan were kept busy with general questions about prostate cancer, and Alan made sure that all the stall holders were visited and left with flyers for the next PSA event at Ryde.

Classic Car Show Chale

The Group was invited to this show by the organisers at a very windy and overcast day on Sunday 26th June at the Chale Show Ground. A large number of classic cars turned up, but the inclement weather meant that only a few spectators came and so Alan decided to visit all the stall holders and a number of show men to hand out flyers and pass on information about the work the group does. This left Roger to hold the fort at the gazebo which on a number of occasions threatened to take off into Freshwater Bay!

Awareness Promotion Events



Bembridge Street Fair

The long Platinum Jubilee Bank holiday weekend started for us on Thursday 2nd June with an early arrival at 8.15am to set up the gazebo and awareness stall ready for the day. Traditionally the Bembridge Street Fair is well attended, and this year did not disappoint. It was reported that there was a 1000-foot fall per hour throughout the day, so not surprising everyone who attended was busy with enquiries about our next PSA event and general information

about prostate cancer diagnosis and treatments. There was a surprisingly substantial number of men who had been treated who offered their congratulations for the work the Group is performing and individually for how they had been helped. Those attending from the Group included Vic and Roger, Rita and Graham, Paul and Jacqui, Roy, Angela and Alan. We would like to thank these trustees and members for their tireless work throughout the day.



PSA Awareness Vectis Radio Interview (10th August)

Terry Ramplin who each year lights up his garden with a fantastic Christmas light show on Staplers Road, Newport, had donated half of his takings, some £2,250 to our plan to organise a PSA testing event in Newport had been invited to be interviewed on Vectis Radio. He phoned Alan Taylor, the PSA test Organiser, to attend the interview with him, to fill in the details about PSA testing and the Support Group's history on how they had taken up the challenge of running these events. The interviewer had a relative who had suffered from prostate cancer and so was extremely interested in how the Group had started PSA testing and details and statistics about prostate cancer. Terry explained how his event had raised a considerable amount of

money over the years for a number of different charities he had been able to help and that since he knew it was time for him to be tested this year, that a test event in Newport being proposed by IWPCSG was an ideal opportunity to make a donation to the Group. Vectis was also interested in our future plans for test sites around the Island and left an open invitation for another interview later in the year, when we could give further information on how our test results had gone in 2022 and our plan for 2023 and how they could contribute towards promoting these events. Our thanks to Vectis Radio and Terry Ramplin for all their support for the work we are doing organising PSA tests on the Island.

ASDA Promotion Day

For the first time the Group was invited to place their stall in Asda's foyer on a Saturday when traffic is at its highest. We must thank the Stores Community Champion, Claire Jones, for organising the date with Asda. Certainly, Rita, Vic, Roger and Alan were worked off their feet with so many enquiries and commitment to the next PSA test in Newport that by the end of the day the event at Newport was full and an opening date for the following Ryde event had to be planned. Rita who was attending her first Supermarket event, worked extremely hard and was not overawed by the large numbers encountered.

Shalfleet Fete 29th August

Having been invited to Shalfleet Fete on August Bank Holiday Monday for the first time, we were unsure what to expect, certainly not over eight hundred people attending! As usual there was a lot of interest in our PSA testing event, especially as it was being held just down the road at Totland Bowls Club. Rita, Graham, Vic, Angela, and Alan were kept busy with all the enquiries and interest in the Group's activities and wanting to be added to the testing booking list via our website. Great weather and a well organised Fete, together with a good site location makes this a Fete to attend on a regular basis for West Wight information and awareness.

Other Awareness Events

The Group stall attended a Cancer Awareness event at Newport Scout Hall, an open event to the general public, to pass on information about Cancer in general. Alan and Angela represented the Support Group. The group's stall was also at Ryde Tesco for an awareness/promotion day. Despite a very windy day, a large number of people enquired about the work of the Group and the PSA testing facilities. Alan and Angela represented the Support Group.



Tesco Freshwater

With the help of Pam Everson, the Group's awareness/PSA promotion stall was invited into the new Tesco Superstore on Saturday 10th September for a 5-hour session. With a tech event being held just around the corner at Totland, there was

a lot of interest in signing up for the 22nd October PSA test event. Roger, Vic Tony S and Alan attended together with Pam Everson, who appeared to know every other person that walked past us and so we very quickly filled the quota for the PSA test. Our thanks to the Tesco Freshwater Manager and Pam Everson

for allowing us to have our stall in their foyer and for their offer of tea/coffee and biscuits for the Totland event for the volunteers on the day. Our thanks also to Pam Everson for co-ordinating the event. When writing this, I do not have a total of the collection for the day, but it was generous.



IW Pompey Supporters Group

The IWPCSG was recently invited to the Yelfs Hotel in Ryde to attend a meeting and give a presentation about PSA tests to the Group. We were also advised that the Pompey Support Group would be make a donation to the IWPCSG.

Roy, Geoff, and Alan attended representing the Group. Alan gave a presentation on how PSA testing worked and the history of the Group's work over the last 4 years and the results of these tests. One of the

members then responded that he had been tested and found positive but had been extremely nervous about the treatment. But having spoken to the Group's support contact, had gone forward with treatment, and was now recovered from the operation and showing a low PSA. There was then a handing over of a £1000 cheque to the Group to help with the Ryde PSA test in September and pictures taken for the County Press. One of their members, Dave Russel, who is a TV programme producer, then interviewed Alan on camera and asked if he could also attend the Ryde event, and with permission take film of a typical PSA event with the hope of making a short programme of how the IWPCSG was helping the local community via PSA testing. A photo and report duly appeared in the 9th September County Press.

Wolverton Show

This two-day event was in short a resounding success. We were promoting the Totland PSA test event In October (22nd) alongside our normal awareness initiative. At the start we still had seventy-five appointments available and by 2.00pm on the Sunday all of these had been taken and we started on a reserve list which now numbers over twenty! Thanks to all our volunteers and to the High Sheriff for stopping by and praising our work.

