

Can you help with an Exciting New Research Project?

Graham Fulford Charity Trust, in conjunction with Manchester University, have just launched a 2 year project where 50,000 men are needed to participate.

The project will cover not only an analysis of results taken by GFCT but also men's attitudes to genetic testing and other factors which could help improve the diagnostic pathway for prostate health conditions for future generations.

To this end all men who have received an abnormal letter i.e. yellow or red between 2010 and 2020 will be contacted over the next few months to ask whether having previously

indicated they would be happy to help with research, are willing to take part.

The questionnaire while only taking 10 to 15 minutes to complete, has several key questions in the area of genetics which will enable the researcher to write a much more meaningful report at the end of the project. Please share this project with any of your friends who may have had test results, the more responses we can get the better and more chance of making a real difference. To participate please go to the following website and answer the questions: www.mypsatestests.org.uk/Research

Many thanks University of Manchester.

PSA Update

The date of our first PSA testing event is 24th April at the Cowes Mason's Hall Medina 35 from 9am – 2pm. There has been some concern amongst the Trustees about the date and its proximity to the lockdown and possible restrictions after 8th March,



PSA testing Pre-Covid

the Government's date for the end of lockdown.

Another important factor is the vaccine programme that is nationally running, and the Government's statement that every adult over the age of 50 will have been offered a vaccine by 30th April. Since the majority of men tested are over 50, as are the majority of volunteers, then 3 weeks after 30th April might be a better date to hold the event – 22nd May.

The Trustees agreed with the PSA organising committee that no decision should be made until after the 8th March announcement by the Government, and all promotion of the event put on hold until this date. We can only run the event if everyone feels safe, both patients and volunteers, and so a decision to move the date can then be made. The Masons who are part of the organising committee, are also prepared to wait until 8th March. They, like us, are being asked when the next event is by a number of their members as everyone realises that Covid may eventually be controlled by vaccines, but prostate cancer as yet has no such control, and early diagnosis remains vital.

Chairman's Chat

So how was your vaccine experience? Did you have the Pfizer or the Oxford? Did you have any after effects from the jab – sore arm, tired, dizzy, headache or absolutely nothing? Quite a number of people I've spoken to have avoided the Pfizer because of allergies and have attended the Riverside Newport centre for the Oxford. In our household Angela had a bad time with her jab and I had absolutely no side effects, not even a sore arm.

My exploration of the Island continues on my e-bike and if anyone wants to join me give me a call.

As always I've attended a couple of Zoom meetings with mainland groups with the emphasis on the Prostate Cancer UK March Zoom Conference for which there is a spare place if anyone is interested.

The PSA organising committee are awaiting the Government's lockdown decisions so that this year's programme can start.

Focus groups have been created that certain areas the Support Group works on, and the Social focus group is working hard on the 10th Anniversary event and a fundraising event proposed by Graham Dooley for August.

The AGM this year will be a Zoom event in April and we will need your votes either on the day or by email before the meeting. Ladies please support the ladies' meeting and Elenid's request for craft and edible goods for the fundraiser in August.

I've been asked to remind everyone that 2021 is a Census year, and the

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Voting at the Annual General Meeting

Chairman's Chat

Census day is 21st March either by internet or postal, more details later.

It's great seeing so many of you attending our Zoom meetings and this month we have a speaker who is a delegate of Tackle to encourage people to "keep moving".

And so finally a reminder to those who have not joined our £2 a month support the group donation. These donations go towards the running of the group and are as essential as the general donations go towards the running of PSA testing events.

Alan Taylor

We intend to run our AGM in April at 2pm as a Zoom meeting. For questions to be brought up in Any Other Business, these need to be sent in 7 days before the meeting if you are unable to attend. Questions will be taken on the day for attendees. Voting will occur on the day for the position of Trustee and Executive Trustees (Chair, Vice Chair, Treasurer, Secretary) but again nominees for these positions not in post must be sent in 14 days before the meeting with a seconder to stand for election. This will give us time to add their names to the postal vote form.

Because of the timing of the AGM at 2pm, we realise that some members will be unable to attend due to work

commitments and so a postal, or email vote will be on offer. A voting form with all the names of the Trustees and Executive Trustees willing to stand again will be sent out together with any new nominees 13 days before the AGM by email and post, giving members time to return their form, by email or post prior to the AGM. These votes will be added to those counted on the day so that the result can be finalised at the meeting.

Should you have any queries about voting, all members are invited to vote and at our last count this was 297, please do not hesitate to call on 075682 451 24 or email at iwpcsg@gmail.com



that was of interest was for a group to have a member or Trustees responsible for Marketing and Publicity and to advertise in local Parish magazines.

This month's FOPS (Friends of Prostate Sufferers) meeting was again well attended with over 40 present to listen to the responses to questions from the three Consultants, Pelvic floor nurse and Pharmacist. As usual newly diagnosed persons were given first try and various questions on treatment, surveillance, types of MpMRI scans, pelvic floor exercise, effects of alcohol and caffeine on treatment and post treatment. Exercise was also mentioned, especially cycling and how modern special seats and suspension had eliminated pressure and jolting. Of course too much cycling and other exercise may irritate the perineal area if repeated daily and would have an effect on a PSA result.

The need to have some "Joy" in your life was essential in all the treatment and therapies and to talk to other people who are having or have had the problem essential for mental health.

As ever, UCL was always offered to patients from other parts of the country as the best place to attend for MRI scan interpretation and robotic operations, as they have 4 robots on site. All our members would be very welcome at their meeting and Angela can send the necessary Zoom code and ID, 1st Wednesday of the month is when they meet, at 7pm.

My third Zoom meeting was at Prosper PCSG and their speaker was Prof Norman Maitland, retired head of Hormone Therapy and Prostate Cancer Research for the EU for the last 30 years. This was a no-holds barred explanation

of what Hormone Treatment did, how it worked in the body, and why it has needed such a long period of research and where it is going in the future. Ironically he has had to retire because of enlarged prostate problems. His views on Hormone Treatment Holidays were very interesting and I'm hoping to get him to virtually come to talk to us later in the year.

Our members' Zoom meeting was attended by just over 30, some from the mainland, who wanted to listen and then question the Tackle speaker about her organisation's commitment to PSA testing which initially appeared to be on the fence, but by the end of the meeting, seemed to be a bit more positive.

Zoom Meetings

The February Prostate Cancer UK Zoom meeting was run by Wilf Baker, Chair of Lincolnshire and Humber support group, whose theme was about how Awareness was transmitted by support groups.

Ideas put out included (some of which may sound familiar) Supermarket stall, Garden Centre stall, have a good website, regular Newsletter, use of social media, Facebook, Twitter, representation on local forums and committees, local radio, involved in hospital video broadcasting, distribution of leaflets, booklets etc at public events – shows, carnivals etc. It was pleasing to see that the IWPCSG had covered almost all these options and that most groups were interested in how much awareness could be achieved by organising and running PSA testing events. The Chairman has been invited to talk at the Burton support group members' meeting on 1st March, about organising and running a PSA event both before and during Covid.

The PC UK Zoom meeting concluded with breakout groups, so that attendees could exchange ideas in greater detail before returning back to the group for a roundup of any ideas. One idea

Quote – Unquote

If you don't like where you are
MOVE – you are not a tree.

A river cuts through a rock not
because of its power, but its
persistence.

Choose to be optimistic, it feels
better.

A little progress each day adds up
to big results.

If opportunity does not knock,
build a door.

Givers have to learn to set limits
because takers don't have any.

Doubt kills more dreams than
failure ever will.

A year from now you'll wish you
had started today.

Monthly Contribution to the Support Group

As we have all heard in the press and on TV, charities' finances have been particularly hit by the Covid pandemic, since the stopping of face-to-face contact has meant most forms of fundraising has had to be curtailed.

For funds to run our group, we are also feeling the pinch, since most of our donations are ring-fenced for PSA testing events, rather than for group funds.

So we would like to remind you that if you could spare £2 a month as a regular donation towards the running costs of our group, which I can list to anyone who is interested, then a bank form is available to fill in so that the group can benefit with a regular monthly income. At present, 18 members are involved in the scheme, but with 297 members, this is hardly breaking the surface.

If you need any further information on how to donate, or how the group would use this donation, please call 075 682 451 24 or email iwpcsg@gmail.com. Thank you in anticipation.

Future Events

25 February Thursday 2pm

Members' meeting on Zoom. Speaker Tony Collier. Tackle delegate to talk about the importance of some level of exercise during treatment as well as after. Aptly titled "Keep Moving".

2 March Tuesday 7 – 8pm

Social focus group meeting on Zoom.

20 March Saturday 2pm

Ladies' meeting. Details will be sent to all members by email.

16 – 17 March 10am – 12.30pm each day

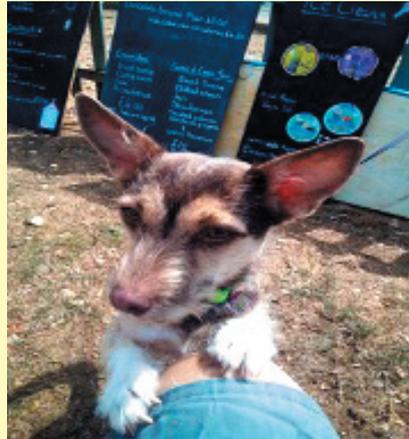
Working Together Network Event. One spare place for any member who wishes to join the Chairman and Vice Chairman at the event. Outline programme available for anyone interested.

25 March Thursday 2pm

Members' meeting on Zoom. Speakers Daffydd Charles and Caroline Prance talking about "Managing Wellbeing". They are both members of Oxford PCSG and Daffydd gives a brief history of his prostate cancer journey as introduction to managing wellbeing.

Lifestyle therapy for prostate cancer: Simplified with a dog!

by Graham Dooley



I have never been a lightweight and come from large stock. At 18 I was playing Rugby weighing in a 18 stone and I am still over that weight now. I have worked hard and played hard so I suppose something had to give. I used to keep very active but since the year the cancer was diagnosed although receiving lots of advice from the well-being clinic I just could not motivate myself at 70 to go back to the Gym or swim with lots of others up and down in separate lanes. I enjoy walking but had a set back with the sticks. One of our members who I consider a friend took me walking but unfortunately his cancer caused him to self isolate.

During my 26 years in France I had an active lifestyle and always had a dog. I was a keen hunter and really enjoyed watching my dog working, until my last dog died suddenly, A beautiful Hungarian Vizsla, and a friend. I swore I would never have another dog. Of course I never

expected to be confined to quarters for almost a year with lock-downs etc. I decided to find a rescue dog and spent a year on FB searching for a small dog on the Island. Around April 2019 a lady got in touch with me who had Staffy. A cute dog but when other dogs were around very strong and difficult to control. Two months later she got in touch with me again and said her dogs had to go as she was moving into a flat. She said it was not a strong dog although it had Staffordshire, chihuahua, Yorks and Jack Russell in her. It was love at first sight and that little dog has walked me back to feeling good again.

With a dog you have to get out whether you like it or not and I spend most days walking her round and up and down puck-pool and throwing the ball along the beach. Great exercise, bending, stretching and walking. You don't need a Gym for that? I can now walk without my sticks, bend over and I am generally feeling the benefits. What I am really enjoying is taking my camera and taking wonderful images of this beautiful Island. Living on my own for most of the time (my partner lives in Portsmouth) this little dog called Kyla has really changed my lifestyle. She is my personal trainer.

I hope to get the RSPCA and other local organisations on board and offer members some assistance when choosing an animal.

For me, as one gets a little older, small is beautiful!

Quick Quiz

A chance for you to get your hands on one of our ceramic IWPCSG clip-on badges, which you can win free by sending your answer to our quiz by email to iwpcsg@gmail.com or call/text 0756 8245 124.

The National Census runs every 10 years, when was the 1st Census run – was it 1801, 1811, 1821, 1831?

Good luck!

Comments about the Group's work

Dear Mr Taylor

The Brethren of Osborne Lodge 2169 are most impressed with the effort and work your organisation does to both support those with prostate cancer, and to promote prostate cancer awareness/screening on the Island.



Census 2021

Having attended the Voluntary Sector Forum Zoom meeting for the first time, I was asked to remind all our members about the forthcoming Census. It will be held on 21st March and by taking part you'll help make sure your community is counted in decisions on services and fundraising. It is the only survey that provides a good picture of the whole population. This is because it covers everyone at the same time. It asks the same questions everywhere and thus makes it easy to compare different parts of the country. It helps with trying to plan housing, education, health and transport services for the

future. So Census day is Sunday 21st March and we will all get an official letter telling us what we will need to do. There will be two options, online data collection, or postal data collections, this will be the first time that there will not be a door to door collection of Census data. It will be another 10 years before another Census is run so to enable the correct data to be collected for the coming decade of planning and implementation, it is important we all take part. Interestingly the results of this year's Census is expected to be known by the end of April while previously it has taken up to 6 months to analyse the data.

Website/facebook/Social Media

A social media focus group met this month to discuss the future needs of our website. Norman Harris, who single-handedly has created and run the website, proposed that an IW based company, IW Websites, of Ryde, should be approached to take over the updating, design and make our website easier to maintain, and would also be able to reduce the hosting costs for future years, thus enabling the group to reclaim the initial expenditure. The group thank Norman for all his tireless effort and hours of work he has put in over the years creating and maintaining this website which even recently was praised by the Tackle representative Sarah Gray, as being of such a good quality. If you go looking at the support groups around the country the vast majority do not have this resource, and we know from the number of enquiries that have resulted from the website just how essential this site has been. Tony Wheatley and Graham Dooley will now be the admins of the site, but Norman will still remain part of the focus group. The present site will remain in place until the new site has been created, when a smooth transition will be initiated.

If you have had time to look at our

Facebook page, you will have noticed a donation button which has been introduced to help our funds.

I have also been asked to put another quick reminder on how to log on and join our Zoom members' meetings once you have found the link, code and password on your email message.

Social Events

Pam and her focus group met this month and discussed further plans for our group's social events this year. It has been decided that the 10th Anniversary should be run in October on one of our members' meetings at the County Cricket Club provided Covid restrictions allow, with various extras to a normal meeting including musical entertainment.

The fundraising event would now be run separately at the August Bank Holiday weekend with a stall for the group and refreshments also run by the ladies of the support group. The event will be a two-day affair to be held in Ryde, where a venue has been offered. Volunteers will be needed to help run this event and further details will be posted near the event.

Plans for a support group lunch were also aired and the Waverley Inn in Carisbrooke will be approached with a date of Wednesday 22nd September, more details later. Our thanks to the group for their efforts during this difficult time.

Trustee Thoughts

The group has been contacted by a couple of firms who are interested in us advertising their product to our membership and if anyone was to purchase it the support group would receive a % of the sales.

At the moment, there are a number of ideas for the fundraising event in August and the 10th Anniversary event in October.

The AGM will have to be a Zoom meeting this year and so members voting rights must be observed either by post, email or on the day. A speaker has been booked for the AGM who will follow after the business of the meeting.

The 2022 Calendar was discussed

with an idea for the 12 wonders of the Island, together with motivating words to be incorporated with each month's picture. Irene Dolby is the contact for any ideas (tel. 07568245124).

It has been decided that an Island-based company will be employed to update, re-design and make our website easier to maintain. The company has agreed to give us a 50% discount, and give us reduced hosting costs in the future.

Finally the Trustees await the Government's decision on post-lockdown measures so that our PSA testing programme can be implemented.