Newsletter November 2020

AWARDED GOOD PRACTICE BY

Experimental blood test can confirm Prostate Cancer

and its clinical significance

The study

Scientists at Nottingham Trent University and Loughborough University, and Professor Masood Khan at University Hospitals Leicester NHS Trust have been developing a new test for prostate cancer which can also identify its potential risk level in order to avoid misdiagnosis and over treatment.

A new way

The scientific teams have found that prostate cancer can be identified by changes in the immune system in the blood, specifically in the white cells which protect the body against infection and disease.

Building on earlier work, they have devised a simple blood test which, combined with computer tools, can confirm the presence or absence of prostate cancer and also the stage of the disease - low, intermediate or high risk. It is expected that this new approach could reduce invasive biopsies by about

70% and help identify patients needing urgent treatment or closer monitoring. The test is also more accurate than current methods and can confirm the stage of the disease with 99% accuracy.

The new test would be used following a PSA test and would benefit men who are showing no symptoms but have a slightly elevated PSA level by enabling clinicians to put appropriate strategies in place.

The future of the test

The test is still at the experimental stage. The team now needs to validate the approach in a prospective Clinical Trial in a larger number of men, to demonstrate its effectiveness and get approval for it to be used to make important clinical decisions. The team is currently trying to obtain the funding which is needed to undertake such a trial.

Article originally commissioned by Rob Banner (Trustee, Tackle) for PROSTaid newsletter

IWPCSG Festive Zoom Members' Meeting

Open to all members, family and friends

11th December at 2pm

A light-hearted look at the many interviews performed by our guest speaker

JOHN HANNAM

To join us, with your glass of tipple and mince pies, just use the Zoom link or open Zoom and join the meeting using the ID and Password on the email which will be sent to you a week before the event by Angela Taylor.

Christmas Cards and Sprigs of Holly purchase

I expect you all know by now that we have designed and produced (thank you Vic) our own Christmas card with our Support Group details on the back so that we can all support our group by sending these cards to family and friends in the Christmas season. They cost £3 for a pack of 10 and can be purchased from

Elenid in Newport - phone 07854219961; (also sprigs of Holly available for a donation)

Pam at Ryde - phone 07811824313; Alan at Shanklin - phone 07874073675; Roger at Cowes - phone 07811824313 to arrange a convenient pick-up from their address.

Chairman's Chat

So there I was, lying in the tunnel of the MRI machine at St Mary's Hospital, with nothing to do for 40 minutes, and so I thought I would try to sort out this month's Chairman's

With Lockdown firmly in place, Tony Sallabanks and I had raced around to get our banners up before the starting date, and tidy up any that were a bit windswept.

PCUK have been in touch to get ideas on how we encourage men to get PSA tested, and Tackle booked a phone call exchange on their future and ours under the new care of Sarah Gray.

After a request from our Macmillan nurse, we have purchased male incontinence products for them to issue to men recently treated for prostate cancer.

The MuchLoved Peter Hunt donation site has been extraordinarily successful.

The ladies had their regular meeting and Pam Blayney for the Social Committee confirmed our Christmas speaker.

I must remind you all to purchase our Christmas cards to send to your family and friends and we all hope and pray that this lockdown will have had the required effect on the Coronavirus to allow us all to celebrate Christmas at home with our families and friends.

Alan Taylor

Quick Quiz

So here again is your monthly chance to win one of our new membership ceramic clip-on badges, just answer the simple quiz and sent it on an email with your name to iwpcsg@gmail.com or call 07568245124.

How many days is the latest lockdown going to officially last from when it started?



Sarah Gray Interview

On Tuesday 17th November I had an enlightening exchange with Sarah Gray, Tackle new National Support and Development Manager. She wanted to know how we worked, why we belonged to Tackle and what did we gain from the Charity, and explained how she saw the future of Tackle within their objectives of Support, Campaign and Awareness.

I explained the SAFE objectives of our support group – Support, Awareness, Fundraising and Education, of members and the general public.

She was delighted that our membership had increased and was particularly full of praise for our website and our use of social media. She was interested in the story of the group and hoped we could record some of our members' prostate cancer experiences, since she advised that when Tackle campaigned for more support for prostate cancer patients, personal accounts had a very strong influence on all levels. She agreed on the importance of PSA testing and the need for individual support after initial diagnosis and then after treatment.

She acknowledged that some groups were very proactive while others were hanging on by their fingernails and wanted to know about our succession policy.

She has plans to create task and finish groups up and down the country each concentrating on specific problems and then sharing the solution with all the support groups with regular get togethers. This networking would enable groups with developed skills in certain areas to be able to share

these with other groups. She saw this as increasing the value of Tackle to every man who is living with prostate cancer. She agreed that the public also needed educating re prostate cancer and that local support groups need better publicity so that they could be more accessible to everyone. Difficult issues such as fundraising, committee protocol, starting new support groups and expanding groups were issues she also wanted to work on.

Sarah mentioned her plans to send out two surveys, one in the forthcoming months so she could understand more about how we work and how we can all work together. This was going to be a 3 year rolling programme, and Sarah was convinced that the more men who are able to access peer support through groups, the greater the collective sound of that voice to enable better services, treatment, care and support.

Sarah finished by saying how pleased she was at speaking to us and how unexpectedly surprised she had been having now spoken with the IWPCSG. She looked forward to speaking at our January members' meeting, where she will hope to gain more from our group from the questions we ask her.



Awareness Campaign

Once the proposal for a November lockdown was announced, it was vital that all the planned banners needed to be in place beforehand. Sign Shop was able to quickly produce the necessary banners with a slight variation on the design, and this has enabled us to give 3 banners to Wightlink to put up at their 3 ferry ports, with a perforated one for Ryde Pier Head and two normal ones at Fishbourne and Yarmouth ferry terminals. Our thanks to Dave Brookes, Wightlink (Solent.Co), for overseeing the placing and fitting of these banners.

Jewson's new IW General Manager, Jon Hayward, was very interested in continuing our association after the retirement of Ron Dawson, and he has agreed to allow us to place banners at all 5 of their outlets around the Island. This is a huge boost to our awareness programme as many of the builders and construction workers who regularly go to Jewson for their work needs are within our target age group. Our thanks to Jon for all his help and cooperation.

Our banners at Norris Grocery car park in Niton is also up, thanks to Wayne Norris for allowing us to put the banner up and to Tony Sallabanks for putting the banner up.

If anyone spots a banner looking a bit sorry for itself, or needing some TLC, please don't hesitate to contact us.



Ladies' Meeting 14th November on Zoom

Again a very enjoyable time spent together, albeit online. We talked about Christmas preparations, including our special members' meeting on 11th December with John Hannam, a friend of Pam's (really looking forward to this as he will be talking about some of his many interviews with interesting and famous people); DWP winter fuel payments; the support group's Christmas cards; online shopping for food and presents and lastly cards and calendars sent from other charities which have not been requested, but in the hope that recipients will pay for them.

Elenid updated us on the works being done on her kitchen, and Pam asked for details of the plumber who has proved reliable, as it can be difficult to find tradesmen who will take on smaller jobs. Marilyn has her new kitchen completed and is very pleased with it.

One advantage of being online with Zoom is that I could move the camera round to show everyone the many boxes of incontinence pads piled up, which the support group has bought, to donate to the Macmillan Nurses at St Mary's. We can hardly get into our front room at present, with the PSA test supplies and equipment against one wall, banners, leaflets and filing cabinet as well.

We all commented on venturing out during this lockdown period, Sandown

seemed to be very quiet with nothing much being open, Ventnor front was a very nice place with the sun shining yesterday and coffee being served outside a café, with no parking charges! We thought that as there were no parking charges at the front in Ryde, this must be due to one silver lining of lockdown ...

We had some fun using the Chat to send messages to each other while on Zoom, Reactions to show icons on our own picture of clapping, party, heart, and View speaker/gallery to switch between seeing only the person speaking, or all of us on the screen.

Elenid told everyone about Age UK planning to have volunteers to help people with using a computer online – especially for older people who have had no experience and useful for making an appointment for a PSA test on our booking site.

We agreed to have our next meeting on 16th January at 2 pm either on Zoom or at a café in Newport or Freshwater depending on the situation with Covid19.

Angela Taylor



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Macmillan Nurse (Incontinence pads)

After a conversation with Joanna at St Mary's Hospital, this resulted in a request from her for some incontinence products for men who had received treatment and needed pads until they had seen the incontinence nurse for an assessment and be given a prescription for their needs.

The Trustees quickly responded to this request, confirming that an order be placed for £500 worth of products to the specification asked for and that they be delivered at the earliest opportunity. Having spoken to the company that supplies these products, and explaining who would be using them, they agreed to give us a discount which we used to purchase more products and so ended up with 120 mini packs, and 28 maxi packs which were delivered to the Macmillan Nurses and gratefully received byJoanna on Wednesday 18th November.

Joanna informed us that Kathy is no longer working at the hospital, but had been re-assigned to a local doctor's surgery, so some of the members may be seeing her soon.

We intend to send a press release to our local newspaper with photo of the delivery of the incontinence products.

Brief guide to joining a Zoom Meeting

This may be helpful for anyone joining a Zoom meeting for the first time:

Using a laptop or personal computer:

- Open the email with the invitation to the Zoom meeting.
- Click on the Zoom link which is in blue, under Join Zoom Meeting (the link, ID and Passcode shown below are incomplete for security reasons)

Join Zoom Meeting

https://zoom.us/j/92548717342?pwd=Vbopxxxxx

- You should see a new window open, with a question "open Zoom meetings?"
- Point to, and click on, Open Zoom meetings
- If you don't have Zoom installed, click on that option
- Confirm access to your camera, speaker, and video otherwise you will

not be able to hear, speak to or see others in the meeting.

■ Instead of using the link, you can open your Zoom App, select Join a Meeting and enter the ID and Password when prompted, which are also shown on the email with the invitation.

Meeting ID: 925 4871 734 Passcode: 6115

Once you have joined the meeting, you should be able to see options at the bottom of the screen. Try "chat" to send a message to everyone or individuals without interrupting the speaker and "reactions" to show a hand which indicates you wish to speak, or hands clapping, and others. You can also mute or unmute yourself by pointing to your picture to select the option, as well as rename yourself if you are shown as, say, iPad.

Quote – Unquote

The past is in your head. The future is in your hands.

Let go of the past, but keep the lessons it taught you.

Learn the past, watch the present, create the future.

Stop looking back at your past, you are not going that way.

Trustee Thoughts

The Trustees were looking forward to a time when we will be able to meet again and discussed whether to book the County Cricket Club Pavilion for 2021 as the venue for our members' meetings. We already have bookings until February, so it was unanimously agreed to go ahead and book the venue for 2021 to guarantee being able to acquire the dates we need.

With talk of the next PSA event in April 2021, there was a question as to had we sent a letter of thanks to our courier. The Trustees were informed both a thank you note and a follow up results of the event had been sent.

Four members would be representing the group at Peter Hunt's cremation, these being the most senior members who had been part of the original men that first started the group.

With the increased interest in our group from other support groups around the UK and the request to join in on our Zoom members' meetings, there was a general discussion about having non-members joining in. It was felt that the Trustees were happy to allow

other prostate cancer support group members join in as there were virtually unlimited spaces available.

The lockdown was discussed and the support that many of our members may need, especially newly diagnosed, and those with suspended treatments. A phone rota would be re-introduced and manned by two of the Trustees.

The request from the Macmillan nurse was approved and thanks to Pam Blayney for sorting out the Christmas speaker.

Fundraising seems to be a concern of most charities at present and so the Trustees were very grateful for those who were making efforts to contribute financially to the group.

The Chairman announced the role of design co-ordinator for the group, which had been accepted by Irene Dolby, who would coordinate and interpret ideas from all, for the needs of the support group.

Roy Colledge, having attended two war memorial events, suggested that perhaps next year the support group might purchase a wreath for one of the memorial sites on the Island.

Website/facebook Updates

I was very pleased when Sarah Gray from Tackle said how impressed she was with our website, saying how most of the sites she had looked at were very out of date and did not appear to have anything on them this year. Well done Tony Wheatley, a very timely update!! She also liked all the links, photos and general layout of the site, well done Norman Harris. Tony W has also made the site more secure and has proposed that he, Norman and myself spend some time working through the site to further update it.

The Facebook page has approximately 50 people liking it so there is plenty of room for more to join in and remember Tony W carefully checks all entries so that nothing unsuitable appears on it. If you are unsure of how to get on send Tony W an email at tony.wheatley@btinternet.com and he has offered to help you.

Zoom Meetings

Having reported both our last two members' Zoom meetings in our last newsletter, since then I have attended other support group's meetings to listen and perhaps find a prospective speaker for us, or PCUK's two-weekly event, one of which included Aidan Adkins who is going to speak at our meeting next week. I have also attended a coffee and chat Zoom meeting run by the Chestnut Appeal Support Group which could be an interesting idea, plus a Webinar run by Re Imagine, which lasted 2-and-a -half hours with 3 research Professors talking about Screening and different ways of screening the future may have without PSA. I have to say the PSMA screening did look really interesting, although it used heavy duty nuclear medium.

But I'm looking forward to our Zoom meeting next week, as are a number of other support group members from around the UK.

Christmas Special Members' Zoom Meeting 11th December

A special Christmas Zoom members' meeting has been planned with guest speaker John Hannam, who will relate stories of his interviews with the famous and infamous people he has met over his decades working in the media. We are so pleased that Pam Blayney has been able to organise this for us and because Zoom has an almost infinite size, the Trustees have decided to open this to all the prostate cancer support groups around the UK. The meeting will be held at 2 pm as usual, and you are encouraged to invite along any family and friends to the meeting.

An email with the Zoom link invitation will be sent out one week before the meeting. Contact Angela if you have not received it.

We realise that this is not the same as having our normal annual Christmas Dinner together, but we hope that you will join in this festive event, with maybe mince pies and your favourite tipple available to accompany you at the meeting.

Future Events

11th December

Special Festive Members' Zoom meeting at 2pm. Speaker John Hannam.*

16th January 2021

Ladies' Zoom meeting at 2pm.*

28th January 2021

Members' Zoom meeting at 2pm. Speaker Sarah Gray, Tackle's new National Support and Development Manager, talking about "How you can help Tackle and Tackle can help you".*

* Zoom link via email sent out a week prior to the meeting. Contact Angela if not received.

Cancelled due to Covid19

27th November

Cancer Awareness Event at St Mary's Hospital

1st - 3rd December

Brighstone Christmas Tree Festival

24th December

Christmas Eve Street Fair Sandown