



Awareness Support Information

Registered Charity No. 1108384
Website : www.prostatesupport.org.uk
e-mail : nwpcsg@hotmail.co.uk

Patron: Martin Bell O.B.E., President: David Haines

*a Founder Member of the Federation of
Prostate Patient Support Groups, known as 'TACKLE'*

Newsletter No. 75 - September 2020

Message From Your Editor's Wife



In the last edition my husband made a plea, on behalf of Ray Cossey and himself, for articles of relevant interest to be submitted for inclusion in future Newsletters. Not surprisingly, no such submissions have been received. Ray, nor Geoff, cannot always be expected to research and find items for publication themselves. Their roles are to design and edit respectively and input from others is essential if this splendid newsletter is to remain of significance. So, c'mon ladies; let's put the men to shame and tell their stories from our perspective. We go through a lot too and sharing our accounts might help to put other wives' anxieties to rest.

To hear a diagnosis of cancer is a shock to most people and when it's your own husband it's like being given a death sentence. Geoff didn't have any symptoms at all; his father had died from the disease six weeks after his 70th birthday in 1985 and his uncle had contracted it too. Thinking that the genes of the male line of his family were suspect, Geoff asked for a PSA test in December 2001. Initially, this was refused as he was only 58 (see *page 3 – Sadly, it's still happening!*). Had his then GP not been so arrogant and condescending about the refusal, Geoff would have accepted the doctor's decision, but, being mindful of looking after his own health, he insisted that he should have the test.

Low and behold, there it was, his PSA was 7.5 and 7 on the Gleeson Scale. He was continually urged to have a radical prostatectomy, despite the obvious side effects. Prostate cancer didn't have then the high profile it has today. There was extraordinarily little research or support for those diagnosed; I only had family to talk to really and I felt alone. Although we asked questions, we didn't really know what questions to ask or where to go for support. It was an extremely anxious time. If things could have been explained, like they are today, I'm sure we would have got through the ordeal with less fear. I remember not being able to think properly because that 'word' was on my mind all the time; a black cloud hanging over me. His operation was in March 2002, but despite those side effects, he is still here, 18½ years after the event. Take heart because there is life after cancer and if he hadn't have insisted on a PSA test, I could have been a widow year's ago.

Ladies, we need your stories in order to support and give hope to those who are going through the same times and for those who will in the future.

Thank goodness, today's and tomorrow's men and loved ones do have more choices and a splendid support group to stand by them. There are many sources that explain what options are available now and how to combat those side effects; don't be afraid to use them. I am so proud of our daughter Helen who went into nursing and chose to become a prostate cancer nurse- specialist because of her dad's experiences. She now triages all new referrals and runs the prostate cancer clinics and surgery school.

Just tell your story as if you were talking to a family member or friend. If you aren't comfortable about putting pen to paper, talk to Ray, or Geoff, that's what I've done. I told Geoff what I wanted to say and he 'edited' and put it together. That's what he's here for.

But, whichever way you choose, it is particularly important to share your story; it could help so many others, and Geoff will only publish what you want him to after you've agreed and signed-off your article.

Eileen Walker

Prostate Cancer Clinics & Surgery School, during the Coronavirus Pandemic

Further to my update in the June Newsletter, I can now announce that the presentations given in the Surgery School have been filmed and will shortly be available via the internet, on 'YouTube'.

The filmed-footage is still being edited and when it is finally completed, I will send the link details to the Support Group for distribution to members.

This is yet another way we are endeavouring to serve our patients to the best of our ability, during the Covid-19 pandemic.

Helen Walker, BSc (Hons)
Prostate Pathway Nurse Specialist

Tiger Test Project Update

Those who have been following the articles relating to this project must wonder how Prof. Cooper's discovery is developing.

A Diagnostic Screening Laboratory has been set up and is suitably equipped for clinical trials to begin. Unfortunately, the COVID-19 crisis and subsequent lockdown restrictions forced the research team to postpone commencement of the trials until a time when they could work safely in the lab, and the NNUH had the necessary capacity, time and resources to support the work without limiting their response to the COVID-19 crisis.

Despite these limitations, there has been a determination to progress the research where possible. Certain analysis has remained viable and every effort has been made to ensure vital findings are circulated, an important step in promoting the project within the scientific community, garnering support and forging external links to advance the research into a clinical test once it has been validated through trials. Two papers have been published reporting advances in how to use the Tiger Test in a clinical setting as well as introducing a new approach to the challenge that is even quicker than the previous method.

The team also used this time to finalise the structure of a home urine collection kit for the PUR test. 1,500 kits are currently in production ready to send out to collect the necessary data for their clinical research. With the easing of lockdown restrictions the team is now preparing to begin clinical trials as soon as possible. We will be updated as matters progress.

Financial support is still much needed to make this vital research a reality, which will bring hope to millions of men and their families across the world. We should be immensely proud that this world-wide, ground-breaking development is being carried out in our Fine City. I make no apology for once again appealing to your philanthropic nature; if you have a spare bob or two laying around, please consider making a (further?) donation to Prof. Cooper's project. You can do this at www.uea.ac.uk/difference just click on the 'Donate Now' photo. This takes you to the 'Ways to Give' page, where you will have several options; donating on-line is easiest. Click on 'Make a Single Gift' or 'Make a Regular Gift' and follow the instructions. Whichever you choose, please ensure you select 'Cancer Research – Prostate Cancer' in the 'Fund' drop-down box. I've said before, I believe in making things happen and together we can make this happen, too. Every donation of whatever value will be greatly appreciated.

Geoff Walker - Editor



Our appreciation to Adrian Raeside for allowing us to use his cartoons

When will some GPs ever learn?

(This letter was published in the Eastern Daily Press on 19 June)

Dear Editor

During the past 16 years this leading, local prostate cancer patients' support charity has pursued one of its main aims, to promote and improve the awareness of this disease among men to a comparable level of that among women with breast cancer, and thus improve the level of early diagnosis, vital to treatment options and survival..

At our latest (virtual) Meet & Chat evening, we were concerned to hear from a new member of his experience with his GP three years ago when requesting a simple PSA (prostate specific antigens) blood test. He did this after reading in the media and hearing on TV from several leading celebrities who had contracted the disease, having been diagnosed after having had the PSA test.

In his case he was not asked about his family history and, having no obvious classic symptoms, was refused a test. He had no knowledge of the hereditary factor regarding prostate cancer, but his GP should have known this. In fact his father had died of prostate cancer, aged 70.

As a result of this vital question not being asked this patient now has a PSA level of 64 (anything over 3 gives reason to investigate further) and has advanced terminal, metastatic prostate cancer, with his consultant telling him that he now has a five year life-expectancy. With his particular prostate cancer taking up to 15 years to fully develop, it must have been well established three years ago, when he first consulted with his GP. Had his condition been diagnosed three years back, he may well not be facing the terminal condition he now has.

Over the sixteen years our support group has existed, we have seen many such instances and, once again, it becomes necessary to remind all men at risk, (those over 50 and/or with a family history), to insist on their right to have a PSA test, as per the current NHS Guidelines given to all GPs.

Furthermore, we implore GPs to understand that a patient can still have prostate cancer without having any of the classic symptoms associated with it and that a family bloodline history of prostate or breast cancer does mean that their patient is 3 to 4 times more likely to contract prostate cancer.

Nearly 12,000 men a year are dying from this scourge, many of whom could have been saved by awareness, PSA testing, and early diagnosis, leading to effective treatment and increased survival rates, now in excess of 70%. Full details are on our website - www.prostatesupport.org.uk

David Haines Ray Cossey John Ladd
President Chairman of Trustees Chairman
Norfolk and Waveney Prostate Cancer Support Group (Registered Charity)

Ever since our Support Group was formed, over 15 years ago, we have campaigned for some form of a national screening programme, without success.

In recent years we have advocated a more targeted screening programme, which would take into account men with a family-history of prostate cancer.

Of course, we appreciate that our members, reading the above letter, are only too well aware of the important part PSA testing can play in the detection of prostate cancer. However, we still have great concerns about the stance taken by some GPs.; the ones who decline such tests for a patient with no symptoms and do not appreciate the hereditary factors involved.

We very much hope some of them read this article and, in so doing, learn something that will greatly benefit their patients.

See the back page for details about our ZOOM Virtual On-Line Meetings

ZOOM with us

As you will be only too well aware, with the imposition of the Covid-19 restrictions, the Open Meetings at the Norfolk & Norwich University and the 'Meet & Chat' meetings, both there and at the James Paget Hospital, Gorleston, have not been possible.

Nevertheless, we have been able to keep in touch by online Zoom facility. We have already held a couple of 'Meet & Chat' meetings and also a Committee Meeting using this facility.

It is very user friendly and we invite more of you to avail yourselves of this means of keeping in touch.

Well in advance of a Zoom meeting our membership secretary, Steve Costin, sends out a mass email to all online members advising them of the link they can click on to connect with the meeting. It is that easy to join in. You are welcome to join in the conversation, or if you prefer, just look and listen in on the meeting.

There is no obligation to join in the start of the meeting, or stay till the end. You simply join in, or leave, at your convenience.

Zoom works equally as well on a PC, on Apple, or on an iPad or mobile telephone. There is no app to be downloaded, you just join in using the online link provided.

If you are registered with us as an online user and have not yet seen one of Steve's messages, might we suggest you check your 'Junk/Spam' box in case it has gone into there. Some ISP filters can be over sensitive when it comes to mass emailings



FUTURE MEETINGS for 2020

Free car parking

Light refreshments

Monday 7th. September (7pm) - Online ZOOM meeting with Speaker **ANDREW GABRIEL** - 'Surviving Hormone Therapy'

Sat. 17th. October - Meet & Chat Meeting (11.45 am - 1.15 pm)
Louise Hamilton Centre, James Paget Hospital, Gorleston.

Monday 2nd. November - Meet & Chat Evening (7 pm - 9 pm)
'Big C Centre', Norfolk & Norwich University Hospital

Monday 7th. December - Open Meeting with Speaker (7pm - 9pm)
Benjamin Gooch Theatre, Norfolk & Norwich University Hospital

MEET & CHAT MEETINGS - When prostate cancer patients can meet & chat to fellow patients and a specialist nurse

Any of the remaining meetings for this year might be cancelled, or be online ZOOM meetings, because of Covid-19 restrictions on public gatherings. Please visit our website for all up-to-date information
www.prostatesupport.org.uk

OUR WELFARE TEAM ARE GEORGE & JILL SIELY

who live in Happisburgh and are always available to give help and support to any member, and/or their family, who requests it. They have a contact list of fellow members of our support group and are able to put you in contact with someone who has been on the same prostate cancer treatment journey as you.

Call 01692 650617 if you would like to have a chat with either of them.

How To Contact Us

Specialist Nurses:

Sallie, Claire, Rachel & Elaine
Norfolk & Norwich University Hospital - 01603 289845

Wendy, Siji & Velda-Sarah
James Paget Hospital, Gorleston - 01493 453510

Sally, Clare & Anne-Marie
Queen Elizabeth Hospital, King's Lynn - 01553 613075

E-mail us at

nwpcsg@hotmail.co.uk

Visit our website:

www.prostatesupport.org.uk

Letters to the Editor:

Email : geoffreyowalker@googlemail.com