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

Newsletter No. 66 - June 2018

DESNT & Prostate Cancer - Latest 'The Tiger Test'

By Geoff Walker - Editor

In our last edition, I wrote about the exciting development Prof. Colin Cooper and his team have made in the way prostate cancer could be diagnosed more accurately.

Those who were at our meeting in December heard his most-inspiring presentation and how his research had been greatly assisted by **£1 million of funding from the Masonic Charitable Foundation**, the charity arm of the **United Grand Lodge of England**.

During his presentation, Prof. Cooper explained the project had reached the stage where *"...our work is now heavily focused on trying to produce a test for DESNT cancers that can be used in the clinic. There are a number of significant challenges but rapid progress is being made. I must say this is one of the most exciting discoveries that I have made in my career and the discovery that has the biggest potential for patient benefit..."*

One of those significant challenges is to acquire a piece of equipment called an Affymetrix Microarray Scanner. I spoke to Prof. Cooper and enquired about the cost of that piece of kit. He told me it was in the region of £140,000.

I Being a Freemason I knew just how supportive Freemasons are of any ground-breaking medical research. Without any promises, I said I was prepared to submit a request for further funding to the Provincial Grand Lodge of Norfolk, which I have done. I am now delighted to announce that the submission has received the full support of my **Provincial Grand Master, Right Worshipful Brother Stephen Norman Allen**, who has made this appeal his **Charity of the Year**.

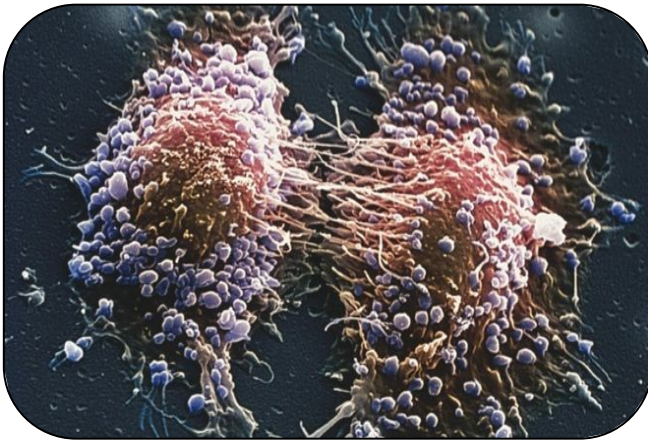
I know that the 76 Lodges and 26 Chapters in the Province of Norfolk will pledge as much as they possibly can to this most worthy cause. Prof Cooper spoke at the Norfolk Freemasons' Annual Meeting on 24th May, and got the 'Tiger Test Appeal' off to a good start. Donations to the fund from non-masons are also needed and will be gratefully received.

On how to do this, see the article on the next page.



Prof. Colin Cooper

Prostate cancer: Four in 10 cases diagnosed late, charity says



A report by charity **Orchid** found a very "worrying trend" of late diagnosis of prostate cancer with 37% of cases diagnosed at stages three and four. It found one in four cases was diagnosed in A & E. As reported later on this page, latest figures show the number of men dying from prostate cancer has, for the first time in the UK, overtaken female deaths from breast cancer. With an aging population, the charity has called for urgent action to prevent a "ticking time bomb in terms of prostate cancer provision".

Orchid chief executive Rebecca Porta said: "With prostate cancer due to be the most prevalent cancer in the UK within the next 12 years, we are facing a potential crisis in terms of diagnostics, treatment and patient care. Urgent action needs to be taken now." The report canvassed the opinion of the UK's leading prostate cancer experts and looked at previously published data to get a picture of the prostate cancer care across the UK. The data came from organisations such as NHS England, charities and the National Prostate Cancer Audit. It says that 42% of prostate cancer patients saw their GP with symptoms twice or more before they were referred, with 6% seen five or more times prior to referral.

There is still controversy over the effectiveness of the standard PSA test used to detect the cancer. Prof Frank Chinégwundoh, a urological surgeon at Bart's Health NHS Trust said: "it is still vital that patients are diagnosed early to assess if they need treatment or not as advanced prostate cancer is incurable". The report also said there needed to be renewed efforts to develop better testing methods.

And this is exactly what Prof Cooper is determined to achieve (see articles headed '**DESNT & Prostate Cancer – Follow Up**' and the last issue of our newsletter). His research has led to a most exciting breakthrough. In practical terms, to enable him to set up a screening laboratory, apply his new test in

a research setting, and work with private laboratories to develop a commercially-viable, widely available test, the project will be rolled out in three phases. The new test, for obvious reasons, has been named '**The Tiger Test**' and the aim is to get this into the hands of clinicians for their patients by mid to late 2020.

Funding assistance is required in the form of generous support from friends and everyone who wishes to see how prostate cancer can be fought. To help deliver this project by 2020, please consider making a donation to the Tiger Test Fund by contacting the UEA Development Office through giving@uea.ac.uk or call 01603 592945. Norfolk Freemasons are already on board!

Deaths From Prostate Cancer Overtake Those From Breast Cancer

Figures show that the number of men dying from prostate cancer has overtaken female deaths from breast cancer in the UK for the first time.

The latest data from 2015 show there were 11,819 deaths from prostate cancer compared with 11,442 from breast cancer. An ageing population means more men are developing and dying from the disease.

Prostate Cancer UK says advances in the diagnosis and treatment of breast cancer are paying off, and increased funding could benefit prostate cancer. The biggest cancer killers in the UK remain lung and bowel cancer, with prostate now in third place.

Although deaths from prostate cancer have been rising over the past 10 years or so, the mortality rate or the proportion of men dying from the disease has fallen - by 6% - between 2010 and 2015. For breast cancer the mortality rate has come down by 10%, meaning that deaths in women are declining more quickly.

Angela Culhane, chief executive of the charity Prostate Cancer UK, said the disease currently received half the funding and half the research that is devoted to breast cancer (but, see article headed '40,000 men on the back cover of this Newsletter')

She said developing better diagnostic tests that could be used as part of a nationwide screening programme would be a priority. At present, there is no single, reliable test for prostate cancer - the PSA test, biopsies and physical examinations are all used.

Men with prostate cancer can also live for decades without symptoms or needing treatment because the disease often progresses very slowly.

New Appointment of a Prostate Pathway Nurse Specialist

I am sure we are all pleased to hear that a new position has been created in the Urology Department, that of a Prostate Pathway Nurse Specialist.

The role is to be the lead Nurse Specialist, working as an autonomous independent practitioner to provide information, support, advice and specialist knowledge to patients, (and their families and carers), suspected of prostate cancer, from new referral through to diagnostic investigation.

The responsibility is to triage all newly suspected prostate cancer referrals and develop a nurse clinic with the aim of ensuring all appropriate investigations are complete (to include, PSA, repeat PSA, urinalysis, MSU, mpMRI, bone scan and CT as indicated) prior to a patient's first attendance in the outpatient clinic. Working closely with the Urology/Oncology Nurse Specialists, the aim is to facilitate a seamless handing over of care at the point of a confirmed diagnosis of prostate cancer.

My wife and I are delighted that our daughter, Helen, previously a member of the hospital's well-respected Uro-Oncology Nurse Specialist team, was successful in her application for the role, which she took up last month on her return from Australia.

Geoff Walker—Editor

Many of you will remember Helen and I'm sure we all offer congratulations on her achievement and wish her every success in this new responsibility. Those of us who have been through the trauma of being told they have prostate cancer know how important it is to have just one single point of contact to whom to speak, when first suspected of having this dreadful disease; Helen's wealth of experience and compassionate attitude will go a long way towards lessening any initial anxiety.



Helen Walker

Our featured cartoonist, **Adrian Raeside**, was born in 1957 in Dunedin, New Zealand. He began drawing cartoons on washroom walls as a kid. After being expelled from his first (and last) art class at the age of 15, he moved with his parents to England, then to Canada. While there, he worked at various jobs, from loading grain ships in Thunder Bay, Ontario, to surveying on the West Coast.

Illustrating his mother Joan Raeside's children's books got him his start in the art business and Adrian began drawing editorial cartoons for the Victoria Times Colonist in Victoria, BC in 1979. He occupied the editorial cartoonist position until 2015. During that time, Adrian Raeside's editorial cartoons were reprinted in hundreds of publications worldwide. He now lives in Whistler, British Columbia.

www.raesidecartoon.com is Adrian's website where readers can view archives of his editorial cartoons, other Coast Daily and Sunday strips and upcoming projects.

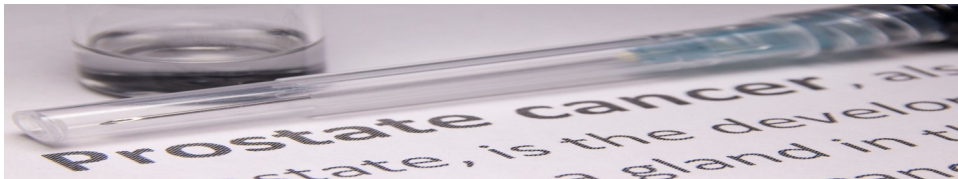
Adrian has kindly given our Newsletter permission to use more of his cartoons in any future editions, with his compliments.....We thank him for this.



40,000 men to be recruited in Government's new prostate cancer fight

The Government is to provide an extra £75m to try to boost early diagnosis and survival rates for prostate cancer.

One in eight men will develop the disease and it is the third most common cause of cancer deaths in the UK .



The disease is now the most common cancer in men, but can be hard to detect early.

Symptoms do not normally appear until the cancer has grown large enough to put pressure on the urethra, resulting in problems with urination.

The new programme hopes to enlist 40,000 men for trials to help better diagnosis and treatments and will target those at high risk including men over the age of 50, those with a family history of the disease and particularly black men, who have a much higher incidence of the disease.

Ahead of the launch Theresa May said: *"Too many people endure the loss of a loved one because cancer diagnosis comes too late in the day. Our cancer treatments are world class and survival rates are at a record high, but prostate cancer still claims thousands of lives every year. I know we can do more. That's why I am setting out new plans to help thousands of men get treated earlier and faster."*

OUR WELFARE TEAM - GEORGE & JILL SIELY

Husband and wife, George & Jill, who live in Happisburgh, are our Welfare Team and are there to give help and support to any member, and/or their family, who requests it.

George and Jill have a contact list of fellow members of our support group and are able to put you in contact with someone who's been on the same prostate cancer treatment journey that you are on.

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

Diary Dates

Open Meetings with Speaker

Monday 4th. June

(7.00pm)
Benjamin Gooch Theatre
Norfolk & Norwich Hospital

Monday 3rd. September

(7.00pm)
Benjamin Gooch Theatre
Norfolk & Norwich Hospital

'Meet & Chat' Meetings

Saturday 14th. July

(11.45 am)
Louise Hamilton Centre
James Paget Hospital, Gorleston

Monday 6th. August

(7 pm) at the Big C Centre,
Norfolk & Norwich Hospital

Saturday 20th October

(11.45 am)
Louise Hamilton Centre
James Paget Hospital, Gorleston

Committee Meeting

Monday 2nd July

(7pm) at the Big C Centre

Whilst we are more than happy to provide members with a printed copy of our Newsletters, our Support Group does incur the costs for printing, stationery and postage

If you presently receive a mailed copy, but have the facility of the internet, you can view the Newsletter on the website and which you can print-off a copy should you wish to do so.

If you are willing to have your copy of our quarterly Newsletter emailed to you please send an email to:-

nwpcsg@hotmail.co.uk

Please type 'email me the newsletter'
on the subject line

How to Contact Us

Specialist Nurses:

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

Angie, Wendy & Simon
James Paget Hospital, Gorleston - 01493 453510

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

Help or Advice

We have a number of members who are available to help and there is probably one near you. **For more information please call :-**

George or Jill Siely
on 01692 650617 or e-mail us at nwpcsg@hotmail.co.uk

Letters to the Editor:

Email : geoffreyowalker@gmail.com