

prostate matters

The Newsletter of The National Federation Of Prostate Cancer Support Groups

Free Help Line - 0800 035 5302

tackle

prostate cancer

Action for patients

Registered Charity No. 1163152

May 2017 issue 36



Tackle AGM & Conference
EAU Congress and Patients Symposium
Here We Go Again!
National Prostate Cancer Audit Challenged
Golf As An Aid to Recovery
100,000 Genome Project
PROMIS Trial
News From The Groups

Borough Market London

Are you getting enough fruit and veg? How many members eat five or more of these each day

tackle AGM and Conference 2017

“Trials and Tribulations”.

Tuesday 13th June, Winterbourne House, University of Birmingham, Edgbaston

The theme for this year's conference is:

“Trials and Tribulations”.

We have secured some excellent speakers for what will be a very interesting and informative event. The conference is free of charge and lunch will be provided. We would like to see as many support groups represented as possible and travel expenses will be reimbursed.

This year there is also a vacancy for an elected Trustee to the Board, to be nominated by members.

Come and join us for a great day and find



out the latest news about ED, incontinence, drug trials and how to join them. This could be life saving.

See the agenda on page 2

In the lunch break, there is an opportunity to go and look at Winterbourne Gardens. One of the finest gardens in the Midlands

Tackle Prostate Cancer would like to thank Prostate Cancer UK for its financial support for the conference

Continued on Page 2

tackle AGM Winterbourne Gardens, Birmingham B15 2RT
13th JUNE **SAVE THE DATE!!**

Free Help Line - 0800 035 5302

tackle AGM and Conference 2017

“Trials and Tribulations”.

Agenda

1000-1030	Assemble, Networking, Refreshments
1030-1130	Annual General Meeting, including Trustee election
1130-1215	Members Open Forum
1215-1315	Buffet Lunch
1315-1415	Incontinence and ED - Managing the issues for men : Julian Shah, Consultant Urological Surgeon, UCH London and Victoria Muir, Clinical Specialist Physiotherapist, Bedford
1415-1445	Challenging the variation in Clinical Nurse Specialist support & ED Services Prostate Cancer UK (speakers to be advised)
1445-1530	Clinical Trials post-STAMPEDE : Professor Nick James, Clinical Oncologist, University Hospitals Birmingham
1530-1545	Refreshments
1545-1630	Panel Discussion
16.30	Close

FOR BOOKING, PLEASE CONTACT: simon.lanyon@tackleprostate.org

Prostate Cancer Cardiff Support Group.

Tony Barnwell-Treasurer

The Group was formed in 2002 and until January 2017 met at the University Hospital Cardiff.

Following a show of hands in late 2016 members authorised the Committee to seek alternate meeting accommodation outside the hospital.

Three venues were considered. Cardiff Golf Club, Sofia Gardens Bowling Club, and the European Cancer Stem Cell Research Institute.

Both the Cardiff Golf Club and Sofia Gardens Bowling Club were excellent venues but required a room hire fee.

The Group were delighted when Dr Richard Clarkson of The Institute offered free meeting facilities.

The building in Maindy Road Cardiff was built 4 years ago, and it is state of the art!

We were also offered free parking for our evening meetings and light refreshments before sitting down in an excellent meeting room with excellent audio and display facilities.

Dr Clarkson had been introduced to our Group by Keith Cass MBE, a Tackle Prostate Cancer Trustee.

Dr Clarkson explained that The Institute had received significant funding from Prostate Cancer UK and that funding encouraged The Institute to create links with Prostate Cancer Patients. He had been delighted to welcome our Group to The Institute as part of that commitment.

Our meetings for the remainder of the year are:-

8th May Dr Loretta Sweeney-Velindre Hospital

3rd July A talk on the work of MacMillan Cancer Care

4th September Professor Howard Kyneston-The work of The Urology Dept. Cardiff Hospital

6th November Dr Richard Clarkson-The Stem Cell Institute(to be followed by a tour of the facilities)

We welcome new members, and the details of our Group can be found on:

www.prostatecancercardiffsupportgroup.co.uk



EAU Congress and Patients Symposium

By Ken Mastris Secretary of Tackle and Chairman of Europa Uomo

The 32rd annual congress of the European Association of Urology was held this year in London at the Excel centre on 24-28 March 2017.



Professor Chris Chapple

The Secretary General of the EAU, Professor Chris Chapple of the University of Sheffield, opened the congress to the beat of drums and the blare of trumpets played by a uniformed 20 plus group.

Sir Bruce Keogh, NHS England's Medical Director and Commissioner of the Commission for Health Improvement (CHI)

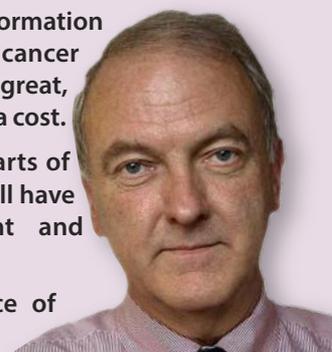
addressed the congress saying "Professional links are crucial to counter challenges"

Europa Uomo participated in the congress and attended the sessions on prostate cancer.

We were given up to date information relating to prostate cancer treatment and while this is great, the fact is that this comes at a cost.

Inequality in Europe and parts of the UK means that not all will have access to best treatment and available dugs

Europa Uomo, as the voice of Prostate Patients in Europe, receive funds from the EAU. With this help, they work with National organisations in each country. At this congress it was Tackle Prostate Cancer



Sir Bruce Keogh

PATIENTS SYMPOSIUM



Professor Frank Chinegwundoh MBE

This was held in the morning of the last day of the congress and was chaired by Professor Frank Chinegwundoh, Trustee of Tackle and Chairman of the Clinical Advisory Board

We were delighted to have great speakers to deliver a cross section of topics

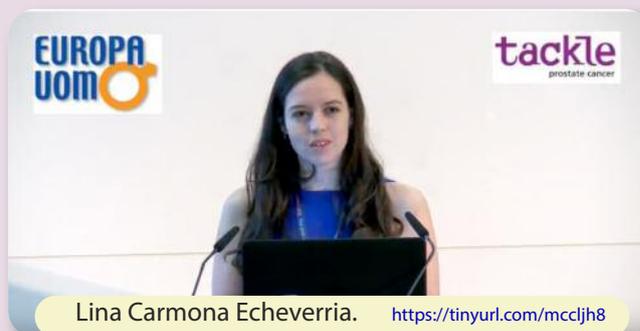
Lina Carmona Echeverria (UCL) on developments in Prostate Cancer

Lawrence Drudge- Coates on Bone Health

Rebecca Porta On the role of Orchid Male Cancer

Chris Booth on PCA testing debate

Over 65 people attended including 55 members of Tackle.



Lina Carmona Echeverria. <https://tinyurl.com/mccljh8>



Lawrence Drudge- Coates. <https://tinyurl.com/m9kbv6c>



Rebecca Porta. <https://tinyurl.com/k9v6too>



Chris Booth. <https://tinyurl.com/mzcufxe>

As it was based in London, not all could attend so Europa Uomo agreed to pay to have the Patients Symposium videoed our member groups

All of the presentations are on the Tackle and Europa Uomo website. You can also see the presentations on the Europa Uomo YouTube site. They are well worth a look!

<https://www.youtube.com/channel/UC1rmACnr0pc5Z6gV-QW4NBQ>

<http://www.tackleprostate.org/>

<http://www.europa-uomo.org/>

Here We Go Again

Hugh Gunn

After four years of enzalutamide, with a rising PSA, I found myself back to where I have been several times before, over the past eleven years. It became obvious that something else was required to treat my prostate cancer. CT scans showed a new growth on my pelvic wall and it was decided that Cabazitaxel would be the best option. Ten sessions, every three weeks taking six months over all.

I got to know room 621 at Queen Elizabeth Hospital Birmingham very well over that six month period. Although coping with a heavy work load, the nursing staff treated me with kindness and a sense of humour, helping to take out some of the tension that is inevitable, but the going got harder as the weeks rolled by.

Towards the end of my chemo, my oncologist thought I might benefit from going on a possible Trial at The Royal Marsden, Sutton. The trial is called **TOPARP** where a PARP inhibitor is given. To take part you have to have the defective **BRCA2 gene** and to find that out, you need to have a bone biopsy. An unknown and frightening prospect, especially when performed before a three hour train journey to get home.

TOPARP uses a drug called **Olaparib**. Cancer grows insidiously slowly, so the body doesn't recognize it as an invader. Olaparib makes the defective gene grow out of control (explode was the word used). The body's own immune system then recognises this as an invader and attacks it and kills it.

With my ten sessions of chemo finished, I had a whole body MRI scan to find out what progress had been made (or not) The scan showed that I still have active cancer in my bones, but no soft tissue or lymph node spread.

OK, so what's the plan?

It seems that I will have my bone biopsy, which will then be

genetically sequenced to find out if I have the defective gene. This is a real double edged sword. If I have the defective gene, I may be able to take part in the trial, but there is the possibility that I have passed it on to my children.
Not a good legacy!

Whilst the biopsy is being sequenced, It is suggested that I am given Radium 223 to control the bone metastases.

Interestingly, this will mean that I have had every treatment we fought so hard for in the NICE appraisal committees.

If I am not suitable for **TOPARP**, the Royal Marsden are conducting another trial called **RE-AKT**. This uses a drug to reverse the body's immunity to Enzalutamide, so that Enzalutamide can be given again.

So that is where I stand at the moment. My battered body is a bit weary and worn out after a total of seven treatments so far since diagnosis and as far as I am concerned a holiday is what I need most. A bit of sea gazing and time away from hospitals and the computer would be the best medicine for me now. Then we begin again.

Update

Unfortunately, the result of my biopsy was unexpected. It seems that the samples didn't contain any tumour tissue and were unsuitable for analysis. Because of the state of my bones it is not possible to repeat the process. As these two trials require a biopsy before being accepted, I am not eligible for either of them.

Radium 223 will be the next option, the treatment Tackle fought so hard to become available on the NHS. After that, there are some interesting stage 1 trials being held at The Royal Marsden which will not require a biopsy, BUT I will have to travel to the Royal Marsden once a week (3 hour journey) for as long as the treatment works. Do I have the stamina and energy for this? I am really not sure!



Salford Hits Hospital Radio 'Airtime'

Brian Robinson

On 16th February 2017 members of the Salford group were invited to take part in a radio presentation. The host was "Northern air" which is in fact Hospital Radio. The studio is based in the North Manchester hospital. "Northern air" seem to have a policy of devoting some time to local community activities. Three members attended, the Chairman (Brian Robinson), plus Peter and Patricia Millership. Peter has the illness and his wife came along to offer the perspective of the wife or spouse.

The show lasted an hour and had a "Desert island discs" format. We chose the music and in between it informal chatting took place, all skilfully guided by the host (Stephen Woolfe). Basically we talked about who we are and where we are.

We did touch on the various treatments but were careful to point out that our group is not a clinic, and we do not offer

medical advice, although we did talk about our own experiences. Towards the end we did talk about the existence of other groups like Prostate Cancer Support (N.W). Whilst an hour seemed a fair amount of time, it passed like and express train and was soon over.



Pictured from L to R. Brian Robinson, Pat Millership, Pete Millership & the presenter, Stephen Woolfe.

National Prostate Cancer Audit shows that men with locally advanced prostate cancer are still undertreated

Sandy Tyndale-Biscoe

Although overtreatment of prostate cancer is a big concern to many, and largely drives the anti-PSA argument that patients are fighting so hard to counter, the opposite problem, under-treatment, is looming large. In particular, the latest data suggest that in England, nearly 40% of men with locally advanced prostate cancer (LAPC) may be undertreated.

Figures from [National Prostate Cancer Audit](#) (NPCA) show that only 61% of men with LAPC received radical treatment, such as radiotherapy or surgery. The remainder received hormonal treatment alone. These disturbing figures were revealed at the European Association of Urology (EAU) 2017 Congress in March 2017. The results, presented by Mr Arun Sujenthiran a Clinical Research Fellow for the NPCA, show that up to 40% of patients diagnosed with high-risk or locally advanced prostate cancer may not be receiving the best available treatments in combination with hormonal therapy.

Locally advanced prostate cancer is treated in several ways, and long-term studies have shown that radical treatments that aim to destroy all cancer tissues (e.g. radiotherapy and prostatectomy) can improve survival compared with the use of hormonal treatment on its own. Hormonal treatment slows the growth of the cancer but doesn't result in its complete eradication.

The new figures are the first to come from linking the NPCA audit to other major UK databases including the National Cancer Data Repository and the Hospital Episodes Statistics database, and so give the most robust estimate of treatment rates. The study analysed data from the 2014–2015 records of the NPCA and includes details on 11,957 men with LAPC. Of those who received radical therapy in addition to their hormone therapy,

- 42% were treated with external-beam radiotherapy;
- 18% were treated with surgery (radical prostatectomy);
- 1% were treated with brachytherapy (radioactive pellets implanted in the prostate).

The remainder of the group (39%) received hormonal treatment alone. Whilst these figures show an improvement on previous years, it is still very much a cause for concern, as it is generally recognised that hormone treatment alone for LAPC is not appropriate.

In attempting to analyse why patients are not receiving radical treatment, it was noted that age and comorbidities are factors. Patients older than 75 and those with two or more comorbidities were significantly less likely to receive radical treatment. So it may be that some of the men who were described as being “undertreated” were too frail or infirm to undergo radiotherapy or surgery.

It may also be that a significant proportion of these men are under-treated because they are not referred to one of the 48 prostate cancer centres in England, where clinical practice is more likely to reflect current best practice. **[Note to patients: this is one very good reason not to moan if you are sent to a treatment centre miles away – it is undoubtedly the case that the centres that treat the most prostate cancer patients get the best results.]**

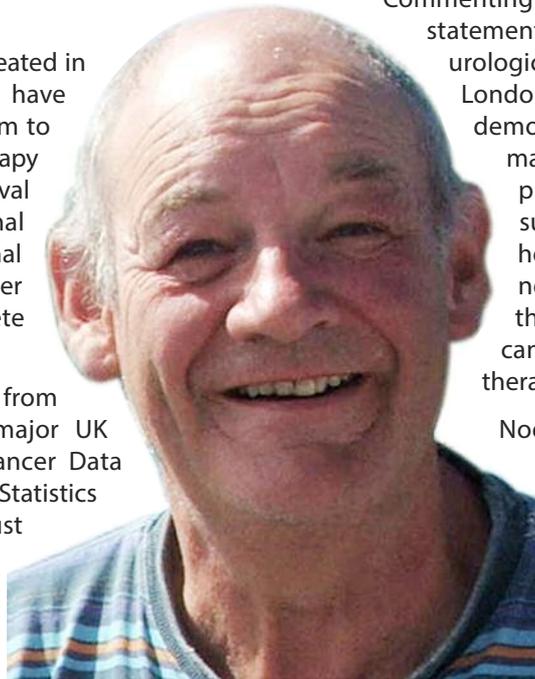
Commenting on the new findings in a press statement, Mr Prasanna Sooriakumaran, urological consultant at University College London Hospital, said, “This study has demonstrated that in current practice many men do not have their high risk prostate cancer treated by radical surgery or radiotherapy and hormones. The true reasons for this need further investigation to ensure that all men with this type of prostate cancer receive maximal curative therapy when it is clinically appropriate.”

Noel Clarke, NPCA urological clinical lead professor, said, “There is strong evidence that radiotherapy to the prostate combined with hormone therapy before and for a period after improves overall survival. The evidence for the use of surgery in this setting is less strong but some men are likely to

benefit. Some healthy older men may be at risk of under-treatment. Further work is required to follow the long-term outcomes of these men but also to understand what factors contribute to some men in this cohort receiving radical treatment and others not.”

Reacting to the findings at the EAU meeting, chairman of the session asked: “What is the main issue driving the under-treatment? Is it patient preference, or is it a reluctance to treat because of competing risks of death, such as comorbidities?”

Or, one might well ask, is it cost?



It with great pleasure we welcome the following groups to Tackle:

Nottingham Cancer Patients and Carers Support group

Catchment Area:

Nottingham, Leicester, Lincoln, Derby

Contact: Freda Ingall

Email: fredaingall@talktalk.net

Tel: 0115 9313541

Royal Derby Hospital Prostate Cancer Support Group

Catchment Area:

Derby/Derbyshire/Burton/Nottinghamshire/Chesterfield

Contact: Kathy Keegan-O'Kane

Email: kathy.keeganokane@nhs.net

Tel: 0115 9313541



Golf as an aid to recovery and increased well-being after Prostate cancer treatment.

By Professor Tim Oliver, Professor Emeritus in Oncology and co-founder of Orchid Male Cancer Appeal

In 1850, Dr Penny Brookes founded the Wenlock Olympian Society to encourage sports in schools and workplaces as an answer to urban ill health. Over the next 100 years the UK, through the work of the Sanatorium movement and sports in schools, established that education about the benefits of outdoor sunshine and exercise was a major component for improving general health. Between 1900 and 1948 when the NHS was first established, deaths from TB fell by more than 2/3rds. At this time the first antibiotics became available and people rapidly forgot the lesson about outdoor exercise and sunshine. Taking us up to the present day where we reside in ever more densely built cities, mental disease, dementia and cancer are being linked to the decline of outdoor activity, lack of sunshine and low fat diets (which reduce Vitamin D and Vitamin A absorption as they are fat soluble). This scourge has again become a major cause of health inequality in the 24/7 modern motorised urban life.

Twenty years ago Colin Osborne and I founded Orchid, a men's cancer research charity. One of our main focuses was understanding how exercise and sunshine delays growth of cancer even after diagnosis. The latest Orchid research has suggested one mechanism explaining the links between lack of sunshine and exercise and development of Prostate cancer. The study found that individuals have less effective immune surveillance systems due to Vitamin D deficiency leading to an increase of anaerobic bacteria in the prostate. These type of bacteria, as has been shown with the bacterium *Helicobacter pylori* in stomach cancer (and possibly similar organisms in Pancreas, Colo-rectal and breast cancer), sets up chronic inflammation and this leads to enough genetic damage to cells in the prostate leading to cancer 40 or so years later. This emphasises the need to develop an exercise habit over a life time as a life time lack of Vitamin D is as bad as smoking 10 cigs a day for 40 years.

Colin Osborne, my co-founder in Orchid, was a keen golfer. Golf can increase the exposure to natural vitamin D from sunlight, improve general physical and mental health and helps promote an active lifestyle. It is a sport which adults and children can play together from the age of 8-80 or more. This was accelerated six years ago when the charity developed an on-line golf competition using First touch SNAG Golf equipment. This is fun, eco-friendly game (like 20/20 cricket) (fig 1). Today more than 4000 children, 400 adults and 22 with learning or physical disability have taken part in awareness events through Orchid, mainly in London. More than 500 recorded their scores and 170 took part in on-line competitions including a match between a school's club in Tower Hamlets and one in Cape Town.

Since we commenced our efforts, there have been studies and articles promoting the health benefits of golf, I recently debated the latest study at the All Party Parliamentary Golf Group in Westminster. The study concluded that "playing golf is likely to increase life expectancy, help prevent chronic diseases and improve mental health". However we need to go further, Orchid are now planning to work with cancer patient's support groups across the country setting up self-funding partnerships with local golf professionals to increase awareness amongst patients and their families about this potential health benefit. Next summer we are proposing that six member teams from Cancer Centres across the UK, all with Prostate Cancer will partner with their 8- 16 year old family

members using SNAG Golf equipment to compete via the internet monthly for 4 months and build up scores for handicaps. At the end of August they will meet in Hull as part of the City of Culture events face to face to compete for the Orchid Cancer Survivors Shield. If this is achieved it is planned that the following year there will be a similar competition with the winners going forward to represent the UK in a European wide competition to be held in September 2018 just prior to the Ryder Cup in France. If this proves successful, in 2020 it is hoped to hold an internet based global competition for all types of cancer patients just prior to the Golf Competition in the Tokyo Olympics.

All the participating patients will need to provide information on their disease status prior to taking part, to see if there is a direct benefit such as a decline in PSA level. It's my hypothesis that this regular physical activity, played with friends and family in local surroundings cannot fail to have a positive impact on men affected by prostate cancer.

How to play:

1. Register your interest with the Orchid nurse (nurse@orchid-cancer.org.uk) who will provide further information
2. Enlist at least 6 adults and 6 children (aged 8-16 years old)
3. Appoint team Captain and Vice Captain to be trained in SNAG Golf no previous experience required
4. Find a suitable location such as a local golf course (but park or field also OK) to host the activity
5. Play together as much as like, invite friends and family to join in the fun
6. Play in our UK wide competition in August 2017.



Fig 1:



Fig 2:

About the author:

Prof. Tim Oliver studied at St John's College, Cambridge and at The Royal London Hospital. After training in cancer medicine at St. Bartholomew's, he moved to the Institute of Urology and pioneered the drug treatment of men's cancer before returning to Bart's and the Royal London. In 1991 he was appointed to the Maxwell Joseph Chair in Medical Oncology. He has also contributed to international research initiatives in prostate and testis cancer treatment through the European Organisation for Research and Treatment in Cancer (EORTC). Retiring from the NHS in Sept 2006, he continues both his research work and private practice. He is a passionate golfer and co-founder and trustee of Orchid Cancer Male Cancer Appeal.

100,000 Genome Project

Hugh Gunn

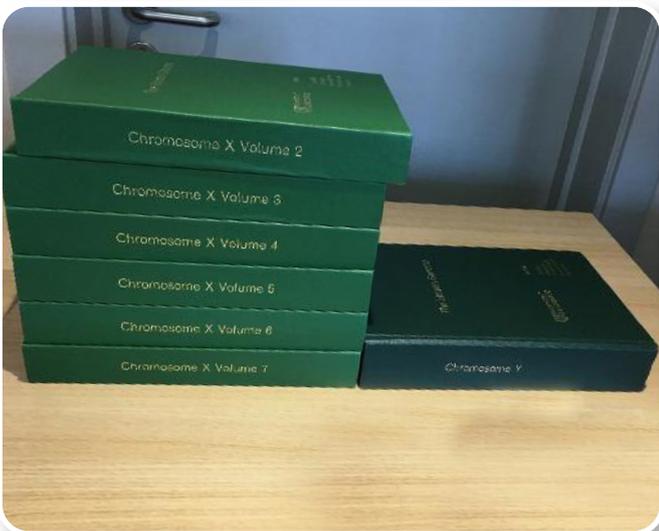
A conference on the 100,000 Genome Project was held at College Court Leicester to highlight the progress and the ethical problems being thrown up by this very exciting field of research. The eventual aim is to build a database of genes, which in the future can be referred to, to find genetically inherited problems and possibly cure them. It was attended by Geneticists, Health Professionals, Genetic Counsellors, NHS Commissioners and Interested Patients.

After the introduction by Dr. Julian Barwell, the conference opened with a very practical demonstration on how enormous this project is. Research has shown that the Human Genome holds some 19,000 genes. Each gene having its own unique set of letters called bases, and changes in these can cause rare diseases and increase the risk of cancer.



As a demonstration of the size of this, 100,000 Genome Project has published the entire genetic code.

It covers 190 volumes each volume being 700 pages long. Interestingly, the X chromosome is contained in 7 volumes and the Y chromosome in one. I always thought that the ladies were far more complicated than men!



One of the many problems being thrown up, is the ethical question of very sensitive information being found and how to use it. This is where Genetic Counsellors have an important role.



PROSTaid has been very active in supporting this project and together with 'First Bus', have provided a 100,000 Genome Project Battle Bus, which will tour the Eastern Counties Area (this does include Leicestershire), stopping at shopping centres, work places, leisure centres etc., to try to spread the word and encourage people to take part.

To take part, the person has to undergo some sort of surgical procedure (biopsy etc.) and give permission to have the tissue samples genetically analysed.



All of this has profound implications for cancer and for prostate cancer in particular. Already there are trials underway (TOPARP) to determine if you have inherited genes which cause cancer. If you have, there are drugs called Parp Inhibitors which can make these genes grow out of control so that the body's own immune system recognizes them as invaders and attacks and kills them. As a patient, this is a double edged sword. If you have the genes, you can be treated, but it also means that your children could carry the defective gene. Hence the need for Genetic Counsellors.

Over the two days, everybody took away valuable information and learned a great deal. Patients especially found it useful to realise the amount of research being carried out on their behalf. This gives great hope for the future.

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prostate cancer
www.tackleprostate.org

The National Federation Of Prostate Cancer Support Groups

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The Editor would like to thank everybody who has contributed to Prostate Matters.

Without you, we would not exist. Please keep the contributions coming.

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Please Check Your Details

Unless otherwise requested, your details will appear on the list of groups on our website.

We are asking all affiliated groups to check their details on the Tackle website. The information has been updated to include meeting times and places.

See the map at: <http://tinyurl.com/omp6y5e>

If there are any corrections required please

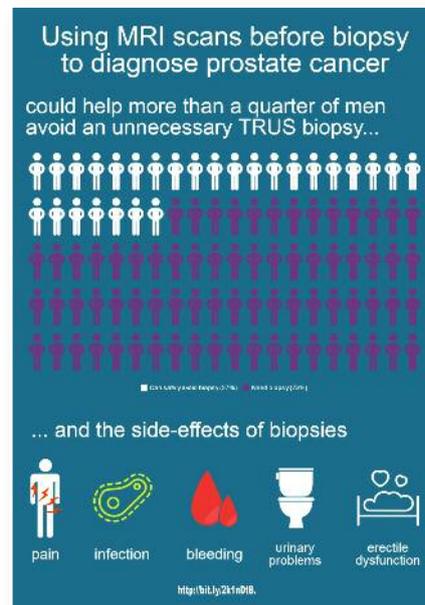
contact Simon Lanyon by email:

simon.lanyon@tackleprostate.org.

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National Help Line
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charge:
0800 035 5302**

PROMIS shows MRI scan could help a quarter of men safely avoid prostate biopsy

Annabelle South



Every year, in the UK, around 150,000 men have a transrectal-ultrasound (TRUS) biopsy to see if they have prostate cancer. This approach to diagnosing prostate cancer has its problems. TRUS biopsies miss about half of clinically important cancers. This means men often have to have extra tests (scans and more biopsies) if the first biopsy does not find cancer. TRUS biopsies can cause side-effects, including infections, pain, blood in urine or sperm and pain while urinating.

The PROMIS study tested whether having a MRI (magnetic resonance imaging) scan before biopsy could identify men who might safely avoid a biopsy. PROMIS compared the accuracy of MRI scans and TRUS-biopsy

against another, more accurate type of biopsy, called Template Prostate Mapping (TPM) biopsy. TPM biopsy is not widely used because it requires general anaesthetic.

Between May 2012 and December 2015, 740 men volunteered for the study. 576 men had all three tests – a MRI scan, followed by a TPM-biopsy and TRUS-biopsy.

PROMIS found that a MRI scan before biopsy would allow at least one in four men to avoid a biopsy safely. This was because the chance that men with a negative MRI scan had important prostate cancer was very low. The MRI scan identified more than 90% of patients who had important cancer. TRUS biopsies only identified 48% of the men who had clinically important cancer.

Men whose MRI scan suggests may have prostate cancer will still need to have a biopsy to confirm the diagnosis, however the scan results can help improve the accuracy of TRUS biopsy by showing doctors which part of the prostate to target.

If hospitals across the UK take up this approach, around 40,000 men each year could avoid biopsies and their side-effects. But it may take some time to make sure that hospitals have the right machines and training to do this.

You can read the full scientific paper here:

<http://bit.ly/2k1nDtB>.