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Gayle Beck in Hawes - Roger Wotton

## Editorial Changes and the Future.

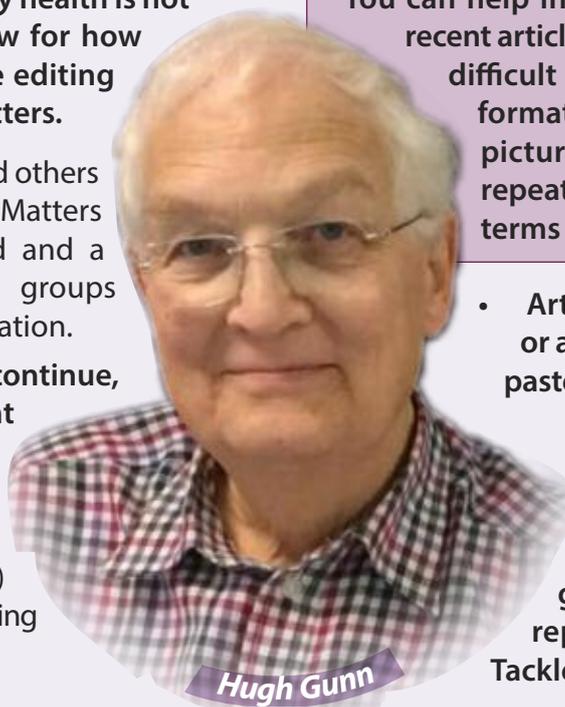
Hugh Gunn, Editor Prostate Matters

As you may already know my health is not as it was and I do not know for how much longer I can continue editing and producing Prostate Matters.

It is clear from feedback I and others have received that Prostate Matters is well received, well read and a useful way of keeping groups connected across the Federation.

I would like to think it can continue, even under different leadership.

We do have a willing helper who is ready to step into my editing shoes (David Marsh) but he will have a steep learning curve in front of him



You can help in this matter. Some of the recent articles I have received have been difficult to incorporate because of formatting and particularly poor picture quality. It is worth me repeating here what is required in terms of article submission.

- Articles must be in Word format or an email which can be cut and pasted. Reprints from newspapers will not be published

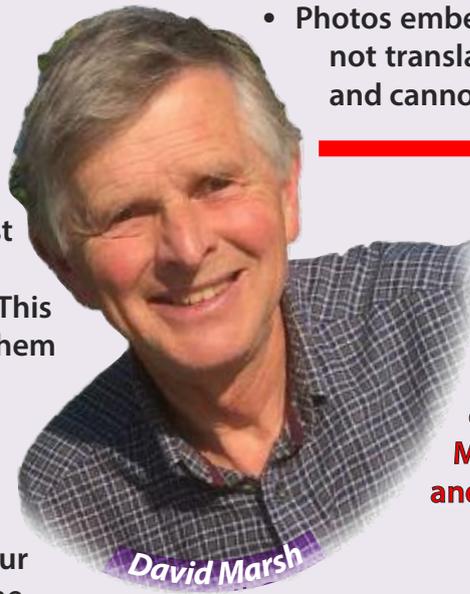
Please remember that this is a Federation newsletter and we should keep it as a grass roots publication representing our organisation, Tackle Prostate Cancer.



tackle Has now produced a Lapel Pin Badge. Each group has been sent a complimentary ten. If you need more, we would suggest a donation of 50p each plus P.P. Please contact [rob.banner@tackleprostate.org](mailto:rob.banner@tackleprostate.org).

## Editorial Changes and the Future.

- **Articles need to be a half page (about 300 words), or a whole page (about 600 words) accompanied by a HIGH RESOLUTION photo.**
- HI RES means file size of at least 1 Mb. Please do not send multiple photos in one email. This compresses them and makes them unusable.
- All mobile phones can take HI RES photos so this should not be a problem. Just check the settings on your phone and your email to make sure you have the highest resolution possible.



- Photos embedded in word documents will not translate to our publishing software and cannot be used.

**I apologise if all of this sounds a bit onerous and picky, but if you want Prostate Matters to continue we will have to observe these guidelines, particularly with a new person on board. I do hope Prostate Matters continues to flourish and keep those articles coming!**

## Sign up for Cycle to the Moon, Save a Dad,

As you will know, this is our major fundraising (and fun!) event planned for May 2018. We want to get as many of our support group involved to cycle for prostate cancer awareness.

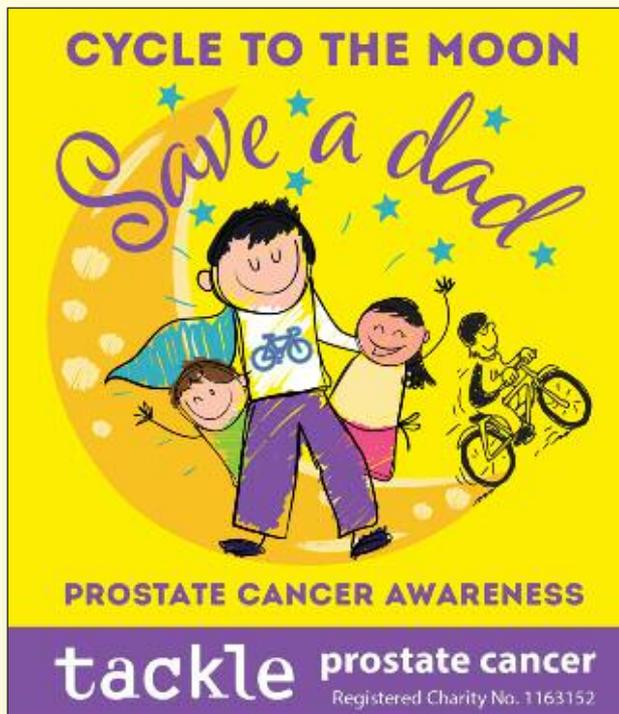
Our campaign manager Dave Fergus is putting the final touches to the web pages, press releases, merchandising and all the sponsorship details which will enable you to take part in the event. We should have everything in place by the time you read this article.

The idea is to raise as much as possible towards the target of £250,000 (one pound for every mile from here to the moon). I hope that as many of our groups as possible in the Federation take part, whether it is sponsoring someone to ride in a cycling event we hope you are able to organise or indeed just members or their families cycling in the gym.

Either way I'd like to think we can cycle together to provide future funds to continue to raise awareness, campaign on behalf of our membership and running projects such as our "Save a Dad" initiative in schools or our wellman initiative with the "Tackle Bus".

I believe having the support of our groups nationwide is

essential for "Cycle to The Moon" to be successful, otherwise we will struggle. We will, of course, be making contact with cycling groups but having our own organisation involved is critical to the success of this important initiative.



Dave Fergus will be contacting groups to talk to them about the event and to answer any questions. Rest assured we will provide all you need to put on a successful cycling event, with publicity, social media support, merchandise, sponsorship forms, online support and incentives.

The Federation Board agreed we will offer 10% of any money raised locally back to your support group as an incentive for you to participate.

We will be putting an ad in the cycling press but if you have contacts with a local cycling club please let us know, either by email or phone – see below.

So, please discuss this in your support groups and consider

registering your interest in the event. To do this, or if you have any questions, simply email Dave Fergus at [dave.fergus@tackleprostate.org](mailto:dave.fergus@tackleprostate.org) or call the dedicated phone line 0300 365 4080.

## Tribute Concerts for Tackle

Roger Wotton

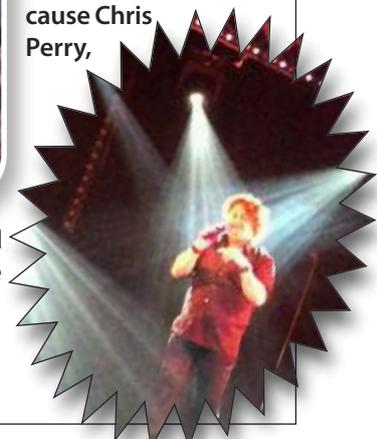
Here is news of an exciting initiative for all those who appreciate the music of Phil

Collins and Simple Red. We were approached by Jackie Dijon of JPS Promotions who represents two great tribute acts - Chris Perry as Phil Collins and Andy Lee as Simple Red. The team have been working with our Droylsden support group and now would like to support Tackle nationwide. The team is embarking upon a countrywide tour in 2018 and as soon as we have more details we will let support groups know, so you can go along and enjoy the musical

experience and support prostate cancer at the same time. Jackie and the guys will be making a donation to Tackle from every concert. Between Roger Wotton, John Coleman and Steve Wilson from the Droylsden group we attended the four concerts held at the end of last year in the Manchester area, which resulted in a total donation to Tackle funds of £1000. To show their interest in the prostate cancer cause Chris Perry,



Andy Lee and two of the crew had a PSA test done courtesy of the Leighton Hospital Group.



### Are you on Active Surveillance for Prostate Cancer?

#### **SO ACTIVE: Exploring significant other experiences of undergoing ACTIVE surveillance for prostate cancer: an exploratory study (REC Ref: 29805)**

The University of Southampton is undertaking a research study to explore the experiences of men undergoing Active Surveillance for Prostate Cancer, and the experiences of their significant others (wife, partner, other relative or close friend).

Please note, to take part in this study your significant other must also be willing to take part.

The study involves completing a questionnaire, and possibly taking part in a telephone interview.

**If you are a man on active surveillance go to the following link online to read more and complete the questionnaire:**

<https://www.isurvey.soton.ac.uk/25011>

**OR, if you would rather complete the questionnaire on paper, we'd be happy to post you one out. Let us know using our contact details below:**

Contact details:

Email: [sh3r11@soton.ac.uk](mailto:sh3r11@soton.ac.uk)

Tel: 023 8059 1787 (Please leave a voicemail if there's no answer)

\*Address: SO ACTIVE Study

C/O Stephanie Hughes

University of Southampton

1st Floor Aldermoor Health Centre

Aldermoor Close

Southampton

SO16 5ST

**100,000 Genomes Project.** Fiona Maddocks,  
with thanks from PCaSO

Fiona is a genomic project nurse and sonographer at the Royal Devon & Exeter Hospital. The 100,000 Genomes Project aims to sequence 100,000 genomes to see if a person has a predisposition to a certain condition, and if so, it is hoped that specific drugs can be targeted to treat that particular variant, rather than a standard generic drug being given. At present NHS patients with certain types of cancer – of which prostate cancer is one – and those with certain rare conditions are eligible.

Genomes were first sequenced in 2003 at a cost of £2.5 billion internationally. The Cameron government was behind this, and started the project in the UK, and £100 million is going in to this from the current government. Since this time the cost has come down, and the price of sequencing a single person's genes is just £600.

Fiona then explained that a genome is one whole set of all a person's genes, plus all the DNA in between. There are about 3.2 billion genes in the body, and they are like a kind of instruction manual. Some errors will be there, and some bits missing. Some are minor errors and relatively insignificant and may well repair themselves; others are larger errors which cause disease, called 'pathogenic variants'. To obtain the genomic sequence, blood samples are taken from the arm and also from diseased tissue (e.g. from a biopsy result) and the two are compared to identify the fault.

Some diseases are caused by lifestyle or the environment,

and the project aims to identify which are caused by these, and which are caused by the errors where a person is predisposed to a disease. Clearly this is very new technology, and the project has been running in the South-west since 2015. Once the variant has been identified, drugs can be developed to target this particular variant.

The UK is leading genomic sequencing, and has the advantage as the UK's NHS joined-up health system is unique. The government sees this as the way forward in medicine. It sees cost savings in this, as drugs are targeted to the individual and not given to those who will not benefit from it.

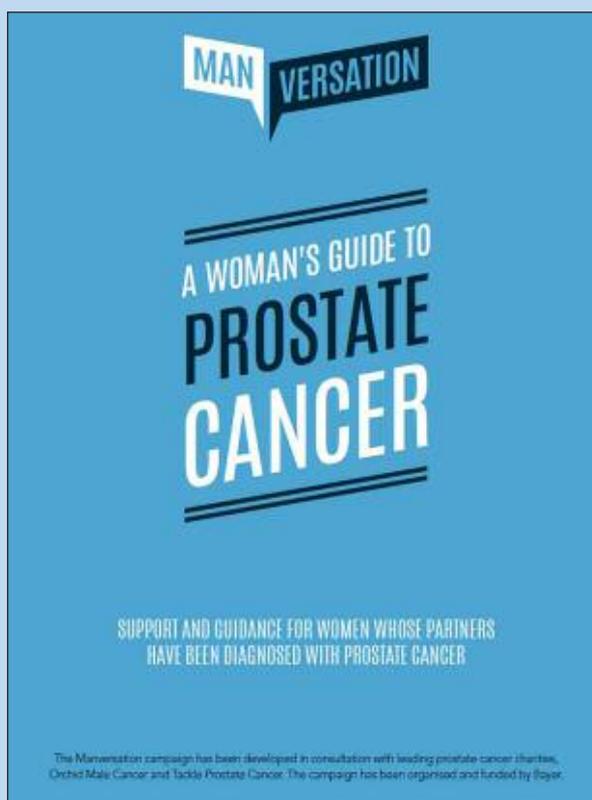
Fiona responded to a large range of questions. Although the scheme is only targeted at cancers and certain rare diseases, the next stage is for diabetes, Alzheimers and neurological diseases. Eventually babies may have their genome sequenced. The scheme is running until 2018, so any

patient can ask his consultant whether he or she is suitable to join, and if so, it is free. Thereafter it is hoped that it will become embedded into general healthcare. In the South-west the scheme covers Cornwall to Yeovil, and about 30 patients per month are being sequenced.

This proved a fascinating talk, and many people came to her afterwards with specific queries. Terry and the audience thanked her for what proved to be a special and unique presentation.



**Manversation - A Woman's Guide to Prostate Cancer**



Hot off the press is the latest in the family of "Manversation" guides we have jointly produced with Orchid Male Cancer and generously supported by Bayer. This one is different. It is written from the perspective of five women whose husband or partner has been living with prostate cancer. We hope women will find this booklet of real help as it reflects heartfelt feelings and experiences along the diagnosis, treatment and support journey.

You can view and download a copy from this page on our website

<https://tinyurl.com/yaeymqdh>

Just scroll down to the "Manversation guides" and you will see the latest one for women.

## STAMPEDE trial finds upfront abiraterone improves survival

Giving the drug abiraterone alongside standard hormone therapy improves the survival of men with high-risk or advanced prostate cancer who are starting long-term hormone therapy for the first time. These are the latest results from the STAMPEDE trial.

Abiraterone (also known as abiraterone acetate, or Zytiga) is a type of hormone therapy that works in a different way to standard hormone therapy. Abiraterone is currently licensed to treat prostate cancer that has spread and has stopped responding to standard hormone therapy. STAMPEDE tested using it earlier, when men were starting standard hormone therapy.

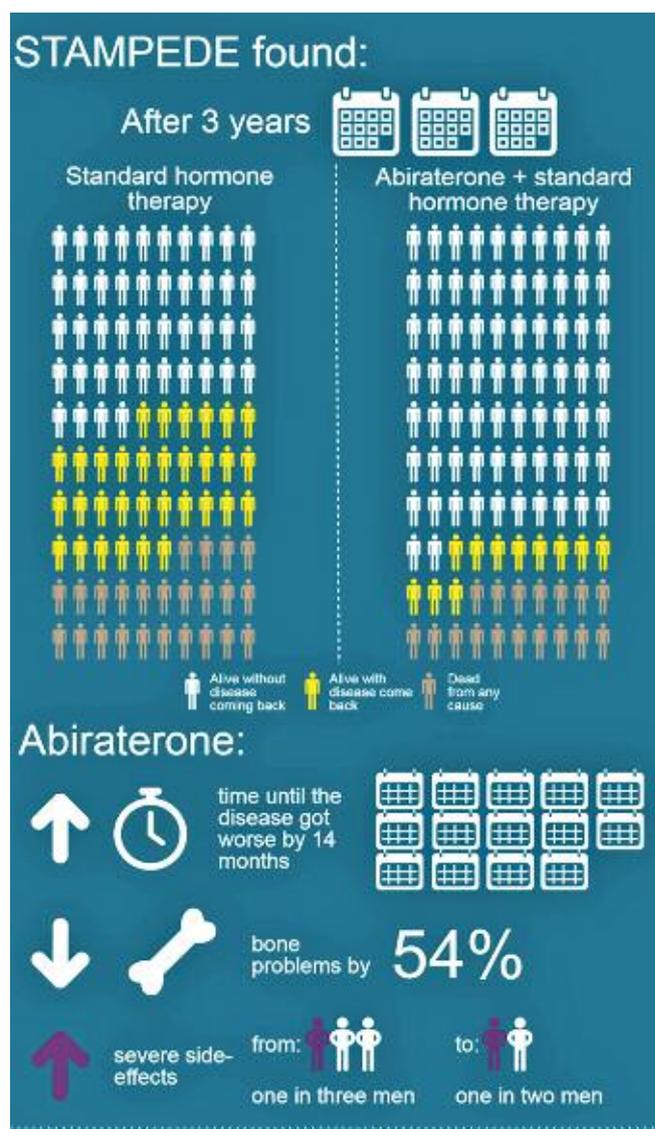
In the "abiraterone comparison" in STAMPEDE, 957 men who were randomised to receive standard of care (hormone therapy with or without radiotherapy) were compared to 960 men who were randomised to receive abiraterone plus prednisolone plus standard of care (hormone therapy with or without radiotherapy). Men in the abiraterone group had four abiraterone tablets and one prednisolone tablet a day.

**The proportion of men alive three years after joining the trial was 83% in the abiraterone group compared with 76% in the standard therapy group. Abiraterone also lowered the relative chance of treatment failure (measured by worsening scans or symptoms or elevated PSA level) by 71% compared to standard therapy.**

Overall, side-effects were similar between the two groups. Worse side-effects were more common in the abiraterone group, occurring in 47% of patients compared to 33% of patients in the standard therapy group. The main unwanted side-effects occurring more frequently with abiraterone were cardiovascular problems such as hypertension; there were also more liver problems.

**"Abiraterone not only prolonged life, but also lowered the relative chance of relapse and reduced the relative chance of serious bone complications" said STAMPEDE Chief Investigator Nicholas James, Professor of Clinical Oncology at Queen Elizabeth Hospital in Birmingham. "Based on the magnitude of benefit, we believe that the upfront care for patients newly diagnosed with advanced prostate cancer should change. However, before this can happen, there will need to be an extension to the licence for the drug and funding approval from the NHS and NICE. This is likely to take many months and perhaps even longer."**

You can watch a short film about the STAMPEDE abiraterone results here: <http://bit.ly/STAMPEDEabiresults> (a longer



version of this film is available [http://bit.ly/abiraterone\\_12m](http://bit.ly/abiraterone_12m))

The STAMPEDE trial is ongoing, with two new comparisons currently recruiting men:

- Metformin comparison
- Transdermal oestradiol (hormone patches) comparison

The research team would like to thank all the people who are taking part in the trial and everyone who has supported them.

For more information, visit [www.stampedetrial.org](http://www.stampedetrial.org)

Good luck Hugh, Bill Black - Weymouth

My wife and I read your wife's article "Lady's Talk" in Tackle November Issue and completely agreed with the points she made. I was diagnosed with metastatic prostate cancer in 2001 and it has been a long struggle since for us both. My cancer nurse said the stress and strain involved in fighting cancer often breaks couples apart. So well done to your wife and mine for sticking by us.

I am due to see my oncologist on 17 January to discuss whether or not I could be eligible for Radium 223 treatment. I've had a CT scan and a nuclear bone scan to provide the necessary info. In case he decides I am not suitable for Radium treatment, I was wondering if there now was a second Enzalutamide treatment available? Like yourself, I got 4 years out of my first Enzalutamide treatment. (Ed Note: Enzalutamide cannot be given twice)

To stay active, I go swimming, now using webbed gloves as my leg kick is not easy due to bone tumour growth in my pelvis. I swim half of my mile per week using back stroke and no leg kick. In the swimming group, a few people have no leg kick at all and I can vouch that it is possible to swim breast stroke, front crawl and back stroke with webbed gloves and no leg kick. This is a useful fact for prostate cancer patients to know if they are trying to stay active.

### Active Beyond Cancer - Leeds Prostate Cancer Support Group

The first twelve week programme run by Leeds Rhinos Foundation and Yorkshire Cancer Research that we - Leeds Prostate Cancer Support Group - were involved in, has now finished. Eight of our members took part in the session, some attend all, others less. Nonetheless, all agreed that it has been beneficial. It was a very practical application of new information on healthy eating, exercise and reduction of stress. All the factors that help reduce and manage cancer. The participants were divided into three groups – mixed gender, women only and men only. The programmer was open to all cancer sufferers in Yorkshire.

I attended the mixed group and was impressed by the enthusiasm shown. It was infectious. The physical activities were very varied, included such things as ballroom dancing, Tai-Chi and Intermediate Body Weight Circuit.

All participants were assessed on their capabilities/health status before the start of the programmer and you only did what was comfortable and safe for you.

There is a new programme planned for March 2018. For more information please register your interest by emailing

[Health@leedsrhinosfoundation.org](mailto:Health@leedsrhinosfoundation.org)

I can heartily recommend it. The trend for better health, especially when we get older, is Lifestyle change. This programme helps you to achieve this. More information can be had from the email address above.

Best of all the programme is FREE.



### Roger Wotton's visits to Groups



I have had the pleasure of making several visits to support groups in the past three months, including those in Somerset, Cornwall, Plymouth, Cheltenham and Cornwall – a focus on the West Country this time. All were very worthwhile and we had some interesting discussions about where Tackle is going, the psychological aspects of dealing with prostate cancer and how it affects more than the patient himself. I have several visits to support groups lined up for early 2018 including Derby, Birmingham, Kidderminster, Isle of Wight, Reading and Cardiff. It's good to stay in touch with the grass roots of our Federation. My most recent trip to Truro was a good example of how much Clinical Nurse Specialists do for our members, often as unsung heroes in my opinion. I had the pleasure of speaking at their annual conference in Glasgow in November and I echoed this view there. See above the picture of me having supper with the Cornwall committee prior to the recent talk. Keep up the good work!

*Handwritten signature of Roger Wotton*

## East Suffolk Prostate Cancer Support Group Christmas Lunch

Ted Friend



26 members from the East Suffolk Prostate Cancer Support Group enjoyed a Christmas Lunch at the Royal Harwich Yacht Club, which is situated at Woolverstone, just outside Ipswich. The lunch was held on 8th December which was a beautiful sunny Winter day with a wall to wall blue sky. The RHYC club house was the ideal venue for the lunch, being on the bank of the picturesque river Orwell. The river was in full tide and added to a truly happy gathering and getting us all into the festive spirit.

## The FOPS. Christmas Lunch. Bob Arthy



The four splendidly prepared tables looked magnificent as the thirty one folk present took their places in the regal Bedford Arms Restaurant in Chenies.

They had come to celebrate nine years since former prostate sufferers David, Jim, Phil, Trevor, Derek and Bob vowed to alert all middle aged men to the need for Prostate awareness and to support fellow sufferers by forming the Friends of Prostate Sufferers (FOPS) Group.

Upon arrival at the venue, everyone was very quickly deep in conversation with their neighbours, Grace was said and scrumptious watercress soup served, followed by a choice of either delicious Venison or Chicken Supreme, then tasty puddings.

A Raffle and Silent Auction was ably organised by Kate which raised over £900 for the FOPS..

It was a wonderful Luncheon that everyone enjoyed enormously.

## Bedford Prostate Cancer Support Group Raises £2000



**From Left – Mr Chaudry (Senior Urologist, Bedford Hospital), Steve Pearce (Secretary BPCSG), Steve Williams and Ian Cole (Walking Football Bedford - donated £900 of the £2,000)**

On 07 November 2017, the Bedfordshire Prostate Cancer Support Group presented Mr Chaudry with a cheque for £2,000 towards the Fusion Software fund from BPCSG. This software is able, when used with template biopsy equipment, to increase the accuracy of detection of prostate cancer from 85% to 98%.

The fund currently stands at £14,000 and has a target of £35,000. BPCSG is a registered charity with the prime aims of raising awareness of the risk of prostate cancer, support to men who have been diagnosed and raising money for improving the detection and treatment of the disease at Bedford Hospital.

The Beds Prostate Cancer Support Group (BPCSG) meet monthly at Bedford Borough Bowls Club.



## Prostate Cancer UK Good Practice Award

MK Prostate Cancer Support is delighted to have been awarded Prostate Cancer UK's 'Good Practice Award' in recognition of the support offered to men with prostate cancer.

In granting the award Prostate Cancer UK noted 'This is the first time a Good Practice Application has ever been approved without any comments or feedback during or after the submission'.

Concurrent with the above award MKPCS has also been awarded Prostate Cancer UK Partner status.

In December MKPCS celebrated its third Annual General Meeting since its foundation in 2014. We were pleased to be able to welcome our Patrons, Henry Andrews and Tom Leslie – Consultants at Milton Keynes University Hospital's Urology Department – who have provided us with both encouragement and support since the Group's inception.

In addition to the formal matters of an AGM the Group enjoyed a wine and cheese party and the music of a local saxophonist.



# tackle

prostate cancer

[www.tackleprostate.org](http://www.tackleprostate.org)

The National Federation Of Prostate Cancer  
Support Groups

Tackle Prostate Cancer is the campaign name of  
The National Federation of Prostate Cancer Support  
Groups. Charity Registration N° 1163152.

Registered Office: Kemp House, 152 City Road,  
London, EC1V 2NX.

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Rob Banner

John Coleman Help Line Co-ordinator

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**Helpline Co-ordinator:** John Coleman

Helpline No. 0800 035 5302

**Information Officer:** Alan Ashmole

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John Coleman North West

John Burton London

Hugh Gunn Heart of England

Brian Jones - Wales

Robin Millman - North East

Sandy Tyndale-Biscoe Western Counties

Allan Higgin South East

### Our support:

Group Liaison Simon Lanyon

PR & Marketing Siobhan Connor

Fundraising Dave Fergus

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

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

## Prostate Matters Delivery IMPORTANT

Your individual copy of Prostate  
Matters is delivered to you from your  
local prostate cancer support group.  
If you have a change of address or  
any other notifications, please would  
you contact your local support group.  
Contact details can be found here  
<http://tinyurl.com/omp6y5e>



Follow us on Social Media

<http://tinyurl.com/o2blofo>



Tackle @TackleProstate



Text Giving - Text:

TACK13 £

## 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](mailto:simon.lanyon@tackleprostate.org).

## PSA Testing Events

If your group is holding a PSA testing event,  
we'll add it to the list on the Tackle website.

Email [info@tackleprostate.org](mailto:info@tackleprostate.org) with the date,  
time, town, post code, contact name and phone  
number.

Don't forget, the National Help Line  
is now Free of charge:

0800 035 5302

## GARY STEELE M.B.E.

David Laundon Chairman – Leighton Hospital Prostate Cancer Support Group  
Email : [chairman@prostateleighton.org.uk](mailto:chairman@prostateleighton.org.uk)

In November 2017 I had the task, as  
Chairman of Leighton Hospital Prostate  
Cancer Support Group, of informing as  
many people as possible of the very sad  
news that our great friend Gary Steele had  
passed away.

Gary Steele, aged 77, died on the  
morning of the 24th  
November in St Luke's  
Hospice in Winsford. He had  
been there for only the last  
2 weeks after the local  
hospital had informed him  
that his cancer was still  
spreading and his  
treatment options were at  
an end. Gary was initially  
diagnosed in 2000 and has  
been living with and fighting  
his prostate cancer ever since. He  
worked tirelessly to set up and develop  
the work of the Support Group and only  
stood down as Chairman at the AGM in May  
2017, when he felt that his health was  
continuing to deteriorate. He leaves behind  
his wife, Mary and 2 grown-up sons, Gary &  
Chris.

We had our bi-monthly Group Meeting  
planned at Leighton Hospital for Saturday  
the 25th, and as I am sure that Gary would  
have wanted us to do, we went ahead with  
the meeting. We started with an  
announcement of the news for any  
members that had not already been  
informed, followed by a minute's. Many of  
our early members had worked alongside  
Gary for quite a number of years.

Gary had done so much to raise awareness  
of Prostate Cancer and was instrumental in

setting up the PSA blood testing events that  
now take place regularly. He had overseen  
donations of equipment to the Urology and  
several other departments at Leighton  
Hospital, near. Crewe.

His work and devotion to raising  
awareness of Prostate Cancer  
saw him awarded with a richly  
deserved MBE in 2012.

Tracy Bullock, chief  
executive of Mid Cheshire  
Hospitals NHS  
Foundation Trust, which  
runs Leighton Hospital,  
said;

"Over the years Gary has  
made many friends at Mid  
Cheshire Hospitals and he will  
be greatly missed. He worked  
tirelessly to raise money for the  
hospital and his efforts have enabled us to  
buy equipment and other items that have  
made a huge difference to the experience  
of patients and will continue to do so. We  
will always be extremely grateful for Gary's  
time, passion and friendship and on behalf  
of our staff and our patients, I would like to  
say a very special thank you."

It is so important that the Support Group  
continues on all fronts, raising awareness,  
providing support, and PSA testing, to  
maintain the push for improvement. Gary  
really has left behind a huge legacy and it is  
essential that we work hard to carry that on.

Gary was so very well respected and I am  
sure that he will be missed by all of you who  
have come into contact with him over the  
years.