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 Reprints from newspapers will not be published.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.
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 or call the dedicated phone line 0300 365 4080.
Here is news of an exciting initiative for all those who appreciate the music of Phil Collins and Simply 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 Simply 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.

Tribute Concerts for Tackle

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
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

Free Help Line - 0800 035 5302
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.
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.”


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)

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**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.
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!

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 programme 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 programme 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

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.
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.

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.

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.
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.