Tackle Prostate Cancer held its AGM and Annual Conference on June 13th at Winterbourne House, Birmingham. In line with normal practice, the morning session was taken up by the AGM which included a report on current activities and finances. The Chairman (Roger Wotton) thanked everyone who had helped Tackle during the past year, particularly our outgoing Trustee Mike Harrison. A moment’s silence was also held for those who we have sadly missed this past year.

Roger reported that 2016 was the last year of transitional funding support from PCUK, and a review has taken place with PCUK on the value of the monies received. This was very positive. Further discussions will continue on how we might work together going forward, particularly in helping support groups thrive and develop.

On the Tackle Bus front, Roger reported that we were waiting for a proposal from the Birmingham QE Hospital Charity, which has an existing vehicle we might use for raising awareness, PSA testing and general men’s health. A pilot scheme is planned. Involvement of local groups will be very important to the success of the project.

Roger then reviewed some of the fundraising options available. These included re-introducing a subscription charge and asking pharmaceutical companies to continue their existing support. Whilst some of these options may be pursued, they did not offer sufficient income to cover our costs for the next 3 years. Accordingly, Roger believed that we should focus on the proposed ‘Cycle to the Moon’ fundraising event. This was enthusiastically received by all. It was agreed that we should prepare a proposal of how the event would be funded, managed, and put into practice. This would require someone with experience of this type of event and fundraising. Additionally, it was suggested that the strapline for Cycle to the Moon should include “...and Save a Dad” which would have the benefit of increasing awareness with young people.

Thanks to Gary Steele for use of the logo.

Following approval of the accounts it was with great pleasure that John Coleman was elected as a Director and Trustee of the Federation. He will be a real asset to the Board.

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Moving on to the afternoon session, the Conference was opened by Mr Julian Shah, consultant urological surgeon at UCLH. “If you don’t use it you lose it” were the opening words from Julian which set the meeting off to a fast pace of a serious yet amusing presentation. He was of course referring to erectile dysfunction.

He went on to recommend 21 orgasms a month to keep things in good working order, much to the amusement of the audience. He then went on to speak on the management of male incontinence.

Many men are minimally incontinent due to the sphincter and pelvic floor muscles weakening. Incontinence can present as an overactive bladder or a minor outlet obstruction. Constipation causing pressure may also be a reason for bladder problems, as can a lack of general fitness and being overweight. Stress incontinence and slow stream with straining may also be problematic in men with bladder issues. The bladder may become unstable due to the ageing process which may sometimes be helped by surgery or Botox injections.

Other causes may include most of the treatments for prostate cancer such as HIFU, TURPS, brachytherapy, radiotherapy and radical surgery where part of the internal sphincter is removed. Some men experience incontinence after catheter removal and may have varying degrees of leakage from occasional to continuous. This may be distressing and embarrassing leading to the wearing of pads.

Julian’s session was followed by an equally enthralling session from Victoria Muir on the importance of physiotherapy for men affected by prostate cancer. Victoria is a Clinical Specialist Physiotherapist at Bedford hospital. She explained how important the physiotherapist’s role is in helping to get men feeling normal again. She explained the purpose of the pelvic floor muscle which is a key enabler to fitness.

This muscle controls both the bladder and bowel core muscles. Radiotherapy can also sometimes damage the anal sphincter causing leakage. The real impact of incontinence means some 60% of men suffering with the problem avoid leaving the home, 50% feel odd and different to others, 45% avoid using public transport and 50% avoid having sex. This can hugely change their lives and how they feel about themselves.

The role of the specialist physiotherapist, as part of the Multi Disciplinary Team (MDT), is patient centred with conservative intervention. The focus is on muscle strengthening, rehabilitation and lifestyle modification.

The symptoms of incontinence are many and include daytime frequency, going to pass urine “just in case”, nocturia, urgency and urge incontinence, dribbling, leakage, flatus incontinence and Erectile Dysfunction (ED). Recommendations include double voiding to remove residual urine. Bowel incontinence can be more difficult to deal with and needs a bowel regime such as emptying the bowel early in the day. This can be achieved with training.

For ED the pelvic floor muscles need to be strong and pelvic floor exercises should be done daily by everyone. Victoria talked everyone through pelvic floor and anal sphincter exercises which was very well received! The key message is - be patient, as it can take 3-6 months to strengthen these muscles, so don’t give up!

Morven Masterton, Head of Outreach at PCUK then outlined her organisation’s strategy going forward. The emphasis is on better diagnosis, better treatment and better prevention and support. Also the improvement of treatments for ED. Of the men currently treated for prostate cancer some 76% suffer from ED with only 30% finding the treatment met their needs with 47% finding that it impacted their relationships. According to the 2016 survey few men were offered help with ED. Some felt that their life had been destroyed and that their sexual life was over. Generally these men were not referred for help. There was found to be inequality in ED care and support. A postcode lottery seemed to be operating and many healthcare professionals could not even confirm the availability of vacuum pumps. An associated online campaign called the “Better Care Platform” was launched in Nov 2016.

PCUK is looking to help healthcare professionals to improve services, with an advisory group, a campaign platform, bespoke...
ED and primary care masterclasses. They have set up an online self-management guide helping men to embrace the initiative.

The next campaign hopes to improve access to Clinical Nurse Specialists who will provide written and verbal information, point of contact, signposting of services, explanation of results, a consultation on treatment options and help with making informed decisions.

Morven went on to outline what PCUK will be doing in 2017. This includes working with governments, NHS cancer alliances and other stakeholders across the UK, inspiring existing nurses to specialise in prostate cancer and urology through promotion and education bursaries and developing the urology cancer pathway to help nurses understand the urological opportunities.

Professor Nick James, Clinical Oncologist University hospitals Birmingham

Professor James talked about clinical trials post STAMPEDE. He reminded the audience that hormone therapy has been the mainstay of treatment since the 1940’s. These days, Abiraterone is known to prolong survival in men relapsing after first line hormone therapy treatment. So adding Abiraterone for men with high risk prostate cancer starting long term Androgen Deprivation Therapy (ADT) – also known as Hormone Therapy - at inception was thought to improve the survival outcome.

In the STAMPEDE Trial, One arm of the trial has shown that Abiraterone plus ADT offers a 25% relative improvement in overall survival. The Trial Consisted of Men who were:

- Median 67 yrs of age
- 78% able to carry out normal activities
- 52% distant disease spread of whom 88% had bone metastases
- 48% confined to pelvis
- 95% newly diagnosed.

Professor James said that these results were the most powerful he had seen from a prostate cancer trial. In addition to survival improvement and time without relapse this trial also reduced the rates of severe bone complications. Adding Abiraterone to ADT reduced the risk of dying over three years by 37% compared to men on ADT alone. It lowered the risk of the cancer worsening by 71%. In conclusion, Abiraterone alongside ADT could now become a first-line treatment for men with advanced prostate cancer.

After a very full and informative afternoon the Conference was then closed by Roger Wotton. Feedback from attendees showed that this was the most successful conference in recent years.

To watch a video of the Open Forum go to https://tinyurl.com/ydyxvk7n (start at beginning), Julian Shah and Victoria Muir (start at 6:00), Morven Masterton (start at 1:08:00) and Nick James (start at 1:26:00). This also has Bob Arty from FOPS singing his song (start at 1:05:00).

Gary Steele MBE retires from Chairman of Leighton Hospital Prostate Cancer Support Group.

Gary Steele has stepped down as Chairman of the group that he founded some 17 years ago after having been diagnosed with Prostate cancer himself. He has been the driving force behind the group since its formation culminating in the award of a richly deserved MBE in 2012.

Under his direction the group has tested many thousands of men, not only in the local area but further afield in Lancashire, Cumbria and North Wales.

In addition to the Support Group’s activities with patients with Prostate Cancer Gary has overseen donations of equipment to the Urology and several other departments at Leighton Hospital.

In an emotional AGM of The Leighton Hospital Prostate Cancer Support Group, Gary said ‘If I could be remembered as one who has saved men’s lives through my efforts it will have all been worthwhile’

Editor’s Note
There were times in our early days when ‘The Fed’ bank account was rather depleted, but through Gary’s actions, the Leighton Hospital Group generously helped us out. We will all miss your wisdom, enterprise, energy and wicked sense of humour.

Thank you Gary!!
Some personal thoughts nearly 10 years down the line.
Stephen Allen. Chair Reading PCSG

It is now over 9 years since I was diagnosed with Prostate Cancer (PCa) and underwent open radical surgery. I was only 59 when diagnosed. My PSA was at the upper limit of normal for my age group. Prostate biopsies indicated a disease of relatively low aggressiveness (Gleason score 6-7) but biopsies were positive from both sides of the gland. MRI and bone scans indicated no secondary spread. However, my prostate was enlarged and I had classic symptoms of significant frequency, urgency and low urine flow rate. My treatment options were thus limited to a choice between ‘watch and wait’, external beam radiotherapy or radical surgery. I chose the latter. Post-surgery I became totally incontinent of urine, albeit currently well controlled after implantation of an AUS (Artificial Urinary Sphincter). I also became impotent and it took 18 months before I was able to achieve any form of spontaneous erection – aided by a maximum does of Cialis. My PSA levels remain low at around 0.01ng/ml.

Good outcome or bad outcome?
I suppose it depends on how you look at it. By today’s standards I was almost certainly over-treated – with now long-lasting and life-changing consequences. But having regrets is very negative. The management of PCa has changed dramatically since then. Things are very different now.

The positivity from such an experience has to be the drive to ensure other men are both diagnosed with PCa early and then go on to have the appropriate treatment and support. I am passionate that we need to continue to raise awareness of PCa and PSA testing – some would comment that I am almost evangelical about it!

Today we have a vastly improved array of tools to investigate PCa. Multi-parametric MRI has totally changed the diagnostic process – we can now ‘see’ inside the prostate gland and ascertain whether the tumour is deep or near the capsule and thus more likely to spread. Pet scanning and now PMSA (Prostate Specific Membrane Antigen) scanning can identify secondary deposits only a few mm in size. The tools needed for a reliable ‘watch and wait’ programme are dramatically better than when I was diagnosed. Treatment options have also improved: brachytherapy can now be used on much larger prostates than before, robotic surgery has changed the face of the surgical approach, radiotherapy is now highly targeted to reduce damage of collateral tissues.

But the foundation stone remains the PSA test. Some people swear by it, others just swear at it. At times it has been grossly mis-represented – often by those who should know better than to use language such as ‘inaccurate’ or ‘unreliable’.

The PSA test is highly sensitive: it accurately and consistently measures a very wide range of PSA levels. It is specific: it only measures PSA and results are not skewed by the presence of other substances. But it is not selective: it cannot distinguish between PSA produced by cancerous or non-cancerous cells. It is not the test itself that is the problem but the interpretation of the more equivocal results that can give rise to difficulty.

However, it is the best that we have at present and in combination with improved investigative techniques can achieve early diagnosis of localised disease, earlier and less invasive treatment, less long-term side effects from treatment and ultimately a better outcome and quality of life.

There is also now emerging evidence that a PSA at the upper end of normal in mid-life may well indicate an increased risk of developing an aggressive PCa in the future. We may well have to re-examine the way we interpret even seemingly normal results.

The arguments for and against a National Screening Programme continue. Many would argue that the decision of the National Screening Committee in 2011 was a deeply flawed process relying on data of arguable credibility. The data from the recently published ProtecT trial could also be criticised. Whilst it involved a large cohort of men (2644 diagnosed with PCa), their original diagnoses were made many years ago – between 1999 and 2009 – when treatment options were very different from those used today.

The major ‘sound bite’ to come from this has been that after 10 years the same number of men will be alive whether they were treated or not. But no mention is ever made of the increased disease progression in the untreated group or such things as the overall quality of life of patients at 10 years. Such data is not easy to extract from the paper and sadly does not make for an easy headline statement in the media. I have very major concerns that such sound bites can only serve to fuel the opinion that says there is no need to be tested for PCa at all. This would be a tragedy.

But opinions on PSA screening are softening. PCUK, while still not supporting a full nations PSA screening programme, are positively encouraging men over the age of 50 (40 in black men and other high risk groups) to seek advice about PSA testing. A new NICE guideline for GPs was published in 2014. Even official opinion in the USA is now beginning to change from the very hard anti-screening stance it used to have. How much further will this progress? Only time will tell.

My personal view…?

The need to raise awareness of PCa has never been stronger. The newer treatment regimes have a much lower incidence of side effects but are only appropriate in early stage disease: i.e. contained within the prostate capsule and, even better, if only present on one side of the prostate. To me it is a ‘no-brainer’. PCa needs to be diagnosed as early as possible. Obviously this can only be achieved if men are aware of the disease.

And it is not only patients that need to be made more aware. Sadly, far too many GPs still have opinions based at best on old knowledge and at worst based on flawed data and inaccurate sound bites. We still consistently hear of men who have been given poor advice, men who are diagnosed too late when secondary spread has already occurred.

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There is a similarity here with the early days of breast cancer when many women were over-treated. A lot has changed since then and much of it due to the constant peer pressure for the women themselves. Breast cancer is now far less feared than it was 30 years ago.

We must do the same for prostate cancer.

There is a lot of work to be done.

I know that by today’s standards I was probably over-treated and now have permanent life-changing consequences. I could be very angry and resentful, rejecting the PSA test as worthless. But I cannot do that. Life has to move on. I made decisions that were relevant at the time. We cannot afford to reduce the resources and energy put into Awareness Programmes. They are the bedrock of achieving the best outcome for men with PCa. I will continue to play as active a part in this as I can.

An ‘Evangelist’ is defined as: ‘a person who seeks to convert others to their beliefs especially by public speaking’

A ‘Zealot’ is defined as: ‘a person who is fanatical and uncompromising in pursuit of their ideals’

An Evangelist I may be, a Zealot I certainly am not.

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The things you get involved in…. By David Hurst, PCaSO

One of the jobs as secretary of PCaSO is that I get various surveys and questionnaires from companies and academics wanting to find out about aspects of prostate cancer. Some of these look interesting so I complete them and then maybe then forward the questionnaire to my group members and to the PCaSO Executive Committee to distribute to their group members.

One of these came from Aberdeen University asking what effects of my prostate cancer treatment I thought were important. I dashed off an answer without thinking too deeply. A bit later this came round again but also included the consolidated opinions of some clinicians and I was offered the opportunity to change my opinions. This sparked my interest and I looked a bit more closely and made some additional comment.

Next thing I knew I was invited to a one-day expenses-paid conference in Aberdeen (in February!!) to look at the relative importance of the effects of various treatments.

Medical professionals may find it difficult to use the results of current prostate cancer medical trials to decide on best treatments for patients because each trial focusses on a different specific outcome and measures it in a different way.

There is also a large number of different treatments for prostate cancer, which complicates things further.

“At the moment, we are effectively comparing apples and oranges when it comes to prostate cancer studies,” explains chief investigator, Thomas Lam, a consultant urological surgeon at NHS Grampian and an honorary senior clinical lecturer at the University of Aberdeen.

“Some studies only look at incontinence, some look only at erectile dysfunction, others will look at different outcomes, and they often have different scales of success and failure. As a result it is incredibly difficult for patients and surgeons to make informed decisions about which treatments will yield the best results for them personally.”

Aberdeen University decided to explore this and obtained funding from a local source to carry out the three-year programme, led by Mr Thomas Lam and Dr Steven MacLennan, to develop a core set of outcomes for localised prostate cancer effectiveness trials.

The team started by looking at over 17,300 academic abstracts and from these and structured patient interviews distilled 84 outcomes to rate in importance. In the survey that I completed – along with other patients and clinicians – we were asked to rate each of these in importance on a nine-point scale.

The conference was fascinating. There were eight patients plus clinicians and academics from UK, Europe and the US. We patients were encouraged to contribute our opinions and to ask for explanations when we didn’t understand the jargon. We were listened to without condescension and our questions answered.

The conference went through the 84 outcomes mainly arguing about the outcomes that were in the middle range of importance. There was electronic voting available so if there were mixed opinions a definitive result could be obtained.

Dr Steven MacLennan, Research Fellow at the University of Aberdeen said: “This is the first step in standardising the outcomes we use to demonstrate how effective treatments are in prostate cancer research - ultimately helping men with prostate cancer and the doctors who treat them make a more informed choice about treatment options.

“If all trials record the same outcomes in the same way, it will be far easier for patients and surgeons to interpret the data and understand clearly what their options are with regards to treatment and what the likely side effects could be.”

Thomas Lam adds: “This is a solution made for patients by patients, in equal partnership with surgeons, cancer specialists, nurses and numerous other specialists.

“Different treatment options have different outcomes. One might lead to increased chance of incontinence, but better sexual function, another might result in better quality of life, and there are many more. Everyone has different priorities, and we want patients to be able to decide what the most important outcomes are for them and choose treatment that will meet their needs. This core outcome list is the first step towards us achieving that.”

The full report was published in BJU International, 3rd May 2017, ref: 10.1111/bju.13854 and I’m listed as one of the (42) authors.
Prospect is a support group for prostate cancer patients, their wives, partners and carers in Bristol and district. It is run by prostate cancer survivors for the benefit of the local community.

Our friendly network aims to:

• Support men who suspect they may have prostate cancer or who have been diagnosed and feel they need more information or support to decide on the best way forward.

• Provide a local informal meeting place for prostate cancer patients, where personal experiences of treatments can be exchanged. Meetings are held at BAWA, Filton, and we organise such things as walks and visits to the Penny Brohn cancer care centre at Pill, near Bristol.

• Keep patients in touch with medical professionals and up-to-date knowledge of medical developments and local arrangements for treatment.

• Champion the cause of prostate cancer patients and encourage all men over 50 to receive an annual PSA check, as they entitled to one.

• Raise awareness of prostate cancer.

We have found that knowledge is of great benefit to the patient. It enables him to play an active part in the decision-making process, for example in selecting the best treatment. A wealth of information is available on Prospect’s website: http://www.prostatecancerbristol.org.uk

As part of the move to encourage patients to get active, a dozen or more members braved the early morning sunshine last October to join Chris Millett on a walk he had organised starting from the Braithwayt Arms at Lansdown.

The walk had spectacular views from the Lansdown hills above Bath and beyond to the Bristol Channel. Chris certainly knew his history of the area and his commentary about the battle of Lansdown added tremendously to the interest of this walk.

A well-earned lunch at the Braithwayt Arms concluded a very enjoyable morning’s exercise.

Metro Walnut is a London based prostate cancer group primarily for gay and bisexual men and our partners, and we also welcome Trans women and lesbians, which is explained further on our website. Since our first meeting in February 2014 our group has grown to over 60 men with our monthly meetings in Greenwich usually attracting between 10 and 20.

Our group provides a venue where our members feel safe talking openly about how prostate cancer affects us and our partners, something many of us do not feel able to do in most mainstream groups. It has also provided a channel to help disseminate information about LGBT focused initiatives from larger organisations. For example, Macmillan’s LGBT & Cancer Taskforce, which is looking at how to address the inequalities experienced by LGBT people with cancer and their partners.

As all men affected by the disease know, prostate cancer impacts greatly on our sex lives but, until a few years ago, only gay and bisexual men with prostate cancer knew how this disease could impact on us differently from straight men. The publication in 2013 of “Prostate facts for gay and bisexual men” by Prostate Cancer UK has helped increase awareness, but our members continue to report how doctors still assume they must be straight and have a female partner and give them information based on those assumptions. When some of our members have challenged the assumptions they’ve been met with shock or hostility or even been ignored. For many of our older members it doesn’t come easy standing up to a doctor and even less easy having to “out themselves”, which probably stems from having grown up in a more hostile time. Fifty years after The Sexual Offences Act 1967 decriminalised sex between two men over 21 and it’s only when they’ve come to our meetings that many members have found the information they needed but doctors never gave them. There’s still a long way to go.

We welcome new members and are reaching out online where you can find out all about us.

Please visit our website: www.lgbt-walnut.org.uk,
Facebook page: www.facebook.com/LGBTWalnut/
Twitter account: @LGBT_Walnut

Fifty years on - Jim Peters
In July 1979, Sue Young received a call from her father to advise that her mother was seriously ill. Sue was 27 years old, with two young children under the age of three. Ten weeks later, Sue's mother passed away from advanced ovarian cancer. Two years later in November 1981, Coping with Cancer was founded. Today, Coping with Cancer helps hundreds of people a year in the Leicestershire and Rutland area who are affected by cancer within their family. The first meeting involved setting up a small committee with a nominal grant of £50. The purpose of this committee was to provide ‘emotional and physical support and friendship to those people suffering from cancer and their families’ – which remains the mission statement of Coping with Cancer to this day now termed as ‘practical and emotional support’ to clients, their families and their carers.

Separately, in 1993, Helen Webb, died of ovarian cancer aged just 29 years. Her husband pledged to raise money for her, together with her family. The Helen Webb Trust was set up in 1994 and raised over £150,000 after 6 years of fundraising. Helen Webb House at 35 Westleigh Road, Leicester was purchased in 1999 by the Trust. Initially, they rented the premises to Coping with Cancer but in 2007, the Helen Webb Trust was wound up and gifted the freehold property to Coping with Cancer.

In June 2003, Coping with Cancer was awarded the Queen’s Golden Jubilee Award, marking the Queen’s 50th coronation anniversary, in recognition of the services provided to cancer patients and their families.

Coping with Cancer continues to grow in strength year on year. The services now offered are varied and extensive; from complementary therapies, counselling support and support groups to befriending, meditation, a solicitors surgery and other recreational therapies. The charity has at any one time had a record number of 100 volunteers and averages up to 50 new clients each month.

A New brochure of our services is available for collection – Coping with Cancer in Leicestershire Rutland ‘Practical and emotional support provided to everyone affected by cancer’. Kalv Garcha Chair of Board of Trustees

I started PCSA Kent in January 2005.
Our members meet at the Kent & Canterbury Hospital and we have groups in Maidstone and Tunbridge Wells and Orpington area.

We started our fund-raising with donations from Masonic Lodges, Rotary and Lions clubs. Throughout Kent we have raised over £350,000 and last year £52,000 together with private donations and collections at supermarkets. The latter being an opportunity to distribute our leaflets.

We have been able to purchase 30 portable multi-scanners for hospitals within our NHS Trusts in Kent, also 8 Urine-flow machines

These machines help to monitor bladder, kidney and prostate cancers. As you know being in situ in the out-patients department helps expedite patient treatment and diagnosis.

We have provided a portable biopsy machine for the QEQM hospital in Margate costing £43,000 also medical standard recorder and monitor for the Da Vinci robotic operating theatre in the Kent & Canterbury Hospital totalling £6,000.

Last December we presented Bladder scanners to Margate, Folkestone, and Beckenham Hospitals. We have also donated to the Darent Valley and Chatham Maritime hospitals.

There is a bK scanner on order for Kent and Canterbury Radiography centre costing £48,800.

I have given around 50 power- point presentations to Kent Masonic Lodges lasting about 25 minutes plus time for Q&A.

We have regular talks from consultants and specialists and try to raise the profile of this male only cancer throughout Kent.
The first major event for The Bay Prostate Cancer Support Group of 2017 was held on 18th March. We ran a PSA screening event in Lancaster, with the aid of Leighton Hospital P.C.S.G. phlebotomists and Gary Steele MBE. We found 8% of those tested fell within the national average of men requiring further checks, making the exercise well worth the effort. For the rest of the year, we are promoting awareness of prostate cancer by running sessions with local industry, starting with the Lancaster City Council. We have held similar sessions at local power stations & Costain. Costain are the Contractors who last year completed building a relief link road from the M6 to Heysham Port. The Costain event was quite rewarding because we found from a substantial and varied audience of men of all ages, very few had a clue as to what/where/when the Prostate performed its functions. Rest assured, after our talk they were well aware.

Nottingham Cancer Patients Support Group Celebrates Their First 30 Years
Is this a record? Key Members of the Nottingham Cancer Patients and Carer’s Support Group, with Volunteer Manager Mr Kerry Harper, holding the banner. The banner was made by Margaret Collins (third from right). She has been a member for almost 25 years (as a Carer and a person successfully treated for cancer). Members are so very loyal, hard working and an inspiration to know!