Shortly before Christmas, there was a flurry of excitement over the announcement of a new laser based treatment for early stage prostate cancer. The Telegraph, under the heading "Prostate cancer drug based on sea-bed bacteria brings complete remission for half of patients" called it “truly a huge leap forward” and the BBC reported that patients had been “totally cured”. What should we make of this? Can we expect a transformation in the treatment of newly diagnosed men? Probably, not yet.

To put this in context, we need to remind ourselves of some of the dilemmas that face newly diagnosed men, particularly those with so-called “low risk” cancer. These are those with a PSA of less than 10ng/ml, a disease staged as T2a or less and a Gleason score of 6 or less. For them there is a strong likelihood that their disease will never progress to the degree that it is a problem or represents a threat, and the current preferred management is Active Surveillance, in which they are carefully monitored for signs of progression in the hope that this will be detected in time for curative, radical treatment such as prostatectomy or radiotherapy. But, as explained to the Tackle 2013 Annual Conference by one of the chief researchers in this trial, Prof Mark Emberton, there is a half way stage between the extremes of active surveillance for men at very low risk, and radical therapy for men at high risk (for whom the consequences of treatments are matched by benefit). This is the idea behind focal treatment, in which only the diseased part of the prostate is treated. It is an intervention that preserves prostate tissue (and function) where it possible to do so.

The trial being reported with such enthusiasm is of one such treatment, called photodynamic therapy. In this case the prostate is injected with bacteria that, in the absence of light, are totally harmless, but which, when illuminated, become toxic. It is, indeed, as the Telegraph so excitedly reports, found at the bottom of the ocean. Shining the laser light onto areas of tissue containing the drug causes a chemical reaction that kills the nearby cells.
The trial was conducted between 2011 and 2015 in 47 cancer centres across Europe. Between March 8, 2011, and April 30, 2013, 413 men with low risk prostate cancer were randomly assigned (1:1) to either vascular-targeted photodynamic therapy (PDT arm) or active surveillance (AS arm), and then followed up for a further 2 years. Over that short time, the trial has produced interesting and encouraging results:

- The likelihood of progression (detected through e.g. rising PSA, upstaging of biopsy, MRI indications or development of symptoms) at 24 months in the PDT arm was half that in the AS arm. (But note, it was still as high as 25% - it is very significant that 58% of the men on active surveillance showed cancer progression after 2 years, which must raise doubts about this management approach being the “standard of care” for low risk prostate cancer.)

- Where disease progression was detected, the period of “remission” was twice as long in the PDT arm as that in the AS arm.

- Subsequent radical treatment, following disease progression, was much less (20%) likely for those in the PDT arm.

- Over the 2 year period the average PSA of men in the PDT arm fell from 6.2ng/ml to 3.2ng/ml (compared with a slight fall to 5.3ng/ml in the AS arm).

- Nearly 50% of the men in the PDT arm had a negative biopsy result (i.e. cancer no longer detectable) at 24 months. This was nearly 4 times as many as those in the active surveillance arm. It is from this result that the claims of “cures” arise, but it must be noted that a 2 year follow up is quite inadequate for talk of cures.

- Side effects were mostly temporary and can be attributed to the toxic nature of the drug, (according to press reports – the trial report in the Lancet Oncology is not specific) but it is significant that 37% of the PDT arm patients experienced erection problems.

So, all in all, it is an interesting trial of an interesting new technique, but still a very small sample and a very short follow up. It may be a game changer, but there’s still a long way to go.
downs, personally speaking. Six years ago, a familiar story perhaps – minor waterworks problems at aged 60, a PSA test and a GP who said “don’t worry old chap, we’ll keep an eye on this”, as my PSA results over 18 months went from an initial 4.8 to 6. I knew nothing about the significance of this at the time. So, on reaching 6, he sent me off to the local hospital for the finger test and a biopsy, as a result of which I spent three weeks in the urology ward with a serious infection and a Gleason score of 3+4. I wonder how common these infections really are - More than most people believe? Anyhow, no hesitation in my mind when offered a radical prostatectomy – in fact I don’t think I even took in the rest of the conversation about the radiotherapy options. When someone says “I can get rid of this for you” you don’t ask questions. Still familiar territory? I’m sure it is. What I didn’t realise at the time was the significance of the histology from the op – Gleason 4+5 T3b N1 MX, particularly the N1 which indicated cancer had been found in some lymph nodes that were removed.

Anyway, PSA went down for several months but started to creep up so I had salvage radiotherapy a year after the op – the traditional 33 sessions of seemingly drinking a lot of water, straining to hold a full bladder, all for two minutes on the table! That wasn’t so bad - it was the side effects of bladder bleeding a year later that took its toll with bouts of retention, late-night self-catheterisation (were they really 14 inches long?) A&E visits and eventually, after three cystoscopies it was sorted, albeit now with a bladder half the normal size. But hey-ho, what followed was four years of undetectable PSA results, so it was all worth it. Still fairly familiar to many?

Now the problems begin. During the four years of freedom (and I'm using the words I actually felt!) I threw myself into helping others, both locally and Nationally. This was really enjoyable, just like being back at work after 35 years in the global oil industry. It was when the PSA started to rise a year ago that I realised the significance of the N1. I remember a urologist once telling me at a support group meeting “this will come back to haunt you”. A Choline PET scan found a cancerous lymph node between the kidneys so the latest radiotherapy treatment, the Cyberknife was brought into play and I was zapped three times, each for around 50 minutes on the table. No problem, except it didn’t work and then a few months later a further scan showed four more nodes in the abdominal area with PSA rising again to 2.4. There’s me naively thinking all radiotherapy worked on cancer but apparently not!

So, what’s the point of this story? Well, what I have come to realise is that giving advice to others is much easier than dealing with one’s own problems. When responding to the question “How are you?” with “I'm fine!” what one really feels is a combination of “I would rather talk about others than myself, there are a lot of people worse off than me, I'll get round to dealing with my problems in my own time, and I have commitments to others I must fulfil”. To be honest I realised I was more comfortable visiting an 80 year old on palliative care, having a discussion with a newly diagnosed man, or standing up and dealing with Q&As at a support group meeting. I suppose what brought it home to me was, with radiotherapy no longer being an option, my oncologist recently prescribed hormone therapy of an injection plus bicalutamide tablets to deal with the testosterone spike associated with the injection. I asked a second oncologist I knew for an opinion and it was suggested I just start on the bicalutamide tablet and save the injection for later. Luckily the first oncologist was happy with either option (apparently they both trained together anyway) and said to me “I don't mind which option you take – you decide and let me know”. Oh my goodness, what a simple choice but what a dilemma – I have to make a choice about myself! I look back at those easy multi-million dollar investment decisions I made in my business career but fall apart when faced with a simple choice for myself!

I suppose this silly little example does highlight how human we all are, and how complex dealing with cancer can be, whether it is for the patient or for their wife or partner. We are all good at showing a stiff upper lip but there are times when one feels relatively helpless making a simple decision.

Anyway, enough of the story. Is there a happy ending? Who knows, but I decided to just start with the tablet, my PSA has come down from 2.4 to 0.23 after one month and I feel better having spoken about it. Can't ask for more than that!
Over fifty souls were packed into Rootz Bistro in Main Parade Chorleywood for the annual Tiger Prostate Cancer Awareness Evening which was, as always, splendidly hosted by Phil and Cathy. The Friends of Prostate Sufferers Monstrous Movember as it was advertised this year, more than lived up to its name as Bobs Boys, all FOPS Singers, and Paul Jones’ Open Mikkers entertained us regally as we ate delicious ‘home made’ watercress roulades, from the Chess, fresh tasty salads and pies and drank one or more glasses of bubbly.

After the interval we were all entranced by Donna and Mick Flinn singing a medley of their favourite songs, many being chosen from the New Seekers portfolio as they starred in this world famous group.

Saturday the 19 November dawned with not a cloud in the sky! The kabins were all warm and prepared for us, and, as good as his word, Graham and his well organised team were ready to go by 9:30. All we needed now was participants! And, sure enough, men began appearing at 9:45, and a trickle became a steady stream! All together, we tested 143 men (number 143 pictured).

Our thanks are due to Kevin Gamble, the prime mover in this event, his company, GF Tomlinson, for their generous support, to Graham Fulford and his team for their highly organised testing operation, and not least to Rob Blacklock (resident Consultant) and our volunteer stewards (pictured) who guided and chatted to the waiting men.
"The Isle of Wight is traditionally seen as a ‘retirement’ location and there is a lot of truth in the stereotype. It is however hardly the only location in the UK which attracts the classic target group for Prostate Cancer - so its hard to explain why it has the highest incidence of Prostate Cancer in England & Wales (according to NHS England). The Isle of Wight Prostate Cancer Support Group has been in existence for nearly 5 years and has quickly moved beyond establishing itself and organising support group meetings to taking on ‘Raising Awareness’ (of Prostate Cancer) as a priority.

Raising Awareness is now our number one priority. We have come to see the need for a two pronged message. In the first place we see the need to alert men to the need for PSA Testing and secondly we advertise the existence of our Support Group providing information about where we meet monthly. In order to action these messages we have sourced roadside banners and we have located these at strategic roadside locations around the Islands. These include cross roads, supermarkets, petrol stations, etc. We have a small team who keep an eye on the banners in order to maintain them - its amazing how quickly they can be shredded in South Westerly gales! Another method is to locate our A4 posters in Public Houses or Cafe toilets. We provide frames as well in order to make them fixtures as well as providing a more hygienic setting. All of this costs money and we are indebted to our fund raisers as well as to ‘Tackle’ for providing a grant towards the cost.

Is it effective? Well we know anecdotally that some men have joined our Support Group because of this advertising. We are also left wondering is there a connection between the high prevalence of diagnosis on the Island and our publicity campaign? There are of course many variables at work in this dynamic but one might be our contribution.

Another critical area for us is how to help our members recover from the side effects of treatment for Prostate Cancer.

It is one thing to recover from surgery or from radiotherapy but how do you recover from the treatment itself? After six months of germination and development we are now very close to publishing a leaflet entitled, ‘Dealing With the Side-Effects of Prostate Cancer Treatment’. This has been developed from members feedback on what has worked for them. It has been professionally presented in leaflet format. We see it as an attempt to fill a real gap in existing provision. The NHS understandably concentrates on primary care and unfortunately does not have the resources to focus on the after effects of treatment. This leaflet goes some way to addressing this gap. We see it as a ‘work in progress’ and will therefore from time to time look to absorb new ideas and re-publish - so if our members have any contributions or comments they are invited to let us know. This leaflet (one excerpt below) has an obvious Isle of Wight focus but it is easily adaptable to other locations. We are more than happy to share it with other Support Groups. If you are interested please contact Dave Kiely on davekielylow@aol.com.

Loose Bowels / Incontinence / Bleeding From the Rectum
Caused by radiation irritating the bowel lining and should disappear in a few weeks. It can however, persist and become long term. The incidence of bleeding can be a side-effect and may be exacerbated in men who have Diverticulitis.

Bowel movements. Life style changes may be required, but try to avoid becoming a prisoner in your home. RADAR keys can be obtained from the Council and your Support Group and give you access to the majority of disabled toilets all over the U.K. The presence of blood in stools may lead to confusing results when bowel cancer screening takes place. This should not deter you from having a screening test for bowel cancer. Organise your own ‘man-bag’ which contains spare underwear, panty liners, loo roll, baby wipes and an empty drinks or urine bottle. Keep spare trousers in the car. Peppermint oil / strong mints may help sooth the gut.

The Walnut Group in Preston held an event called: ‘Show the Red Card to Prostate Cancer.’
It took place on Saturday 12th November 2016.

The event appears to have been a huge success with 269 men having a PSA blood test in the three hours. Out of 269 men tested 19 men (7%) were made aware that they would be well advised to seek further help. As we know, timely intervention is the key to fighting Prostate Cancer.

Gary Steele has kindly forwarded the following information for our review. All samples were sent to the laboratory and by now everyone will have received their results in the post (the timescale was within 7/10 days of the test):

- **269 MEN TESTED**
- **245 MEN TESTED GREEN**
- **5 MEN TESTED AMBER**
- **19 MEN TESTED RED.**

Green is of course a good result no need to be tested again for 12 months
Amber is considered to be borderline with a recommendation to be tested again in 6 months with the GP
Red is considered to be an abnormal result with a recommendation to see the GP as soon as possible (taking the letter with the results to show the GP)
Both Amber & red letters have these recommendations in the letters.

Dave Riley
Three questions I am often asked are:

(1) Should I have screening for Prostate cancer?
(2) How can you identify at an early stage potentially aggressive tumours that could kill, from those that can be safely monitored and hence reducing unnecessary side effects?
(3) How can I access the right treatment for me?

This is particularly topical given the publication of a paper suggesting that early stage prostate cancer with a low Gleason Score and PSA less than ten may be better monitored than actively treated. Some observers that extrapolated this to suggest there are two types of cancer: firstly, slow growing disease which by definition can be detected through screening, but treatment has little impact on survival and causes side effects. Secondly; faster growing and more aggressive disease which can be harder to identify at an early stage and treat.

There is no doubt that a number of large population screening programmes have struggled to prove a major survival benefit with screening, where treatment can cause impotence and incontinence. This supports some people’s concerns about over-medicalisation and could suggest that the body is constantly fighting tumours through the immune system and sometimes wins. The counter - argument is that detecting tumours before they spread greatly reduces the risk of dying from prostate cancer and sadly many years of potential good health are lost through this illness.

I believe that genomic medicine may provide some of these answers.

Genomic medicine involves six key elements:

(1) In depth analysis of the six billion bases of DNA passed on from parents to their offspring through blood tests to identify risk and inform screening and treatment doses ‘let’s end screening based on age alone’.

(2) Similar analysis of prostate cancer cells from surgery or biopsy to look for key cancer causing mutations that are driving the loss of control of the balance of cell growth, differentiation and cell death ‘Treat disease for what it is and not just on what it looks like down a microscope’.

(3) Analysis of tumours to identify weaknesses in molecular pathways which may help personalise treatment plans. These planned individualised treatments can now be tested in mouse models injected with tumour cells from the patient. ‘end of standard chemotherapy’

(4) Bringing together clinical records and sequence data alongside other information on chemical changes in the blood and urine such as gene silencing, circulating RNA & cell free DNA, protein levels changes and gene fusions to create a mathematical algorithm of prostate cancer. Creating an equation to make future algebraic predictions is called System Biology, a Single Equation’

(5) Linking anonymised electronic patient records to Genomic data and connecting to other clinical, academic and pharmaceutical networks both here and throughout the world to improve our understanding of genomic variation ‘connecting and coordinating our approach to cancer’

(6) Stakeholder partnerships, such as between the East of England Genomics Medicine Centre (Cambridge, Nottingham, Leicester, Norfolk & Norwich University Hospitals) and support from organisations like Tackle Prostate Cancer, to assist with implementation oversight, advisory insight, lobbying for commissioning, sign-posting to services and patient support.

‘Stronger together, improving access to genomic medicine’

Making genomic medicine a reality in routine clinical practice is immensely challenging, especially in prostate cancer due to the small size of biopsy material and the fact that the prostate may have more than one tumour within it with different genomic variants. To provide a boost to its implementation, David Cameron announced plans for the launch of the 100,000 genome project both for rare diseases and cancer at the end of 2012.

This is now available for rare diseases throughout the country and is due to open in the spring for prostate cancer patients with active disease, undergoing biopsy or surgery. If you are undergoing a procedure from Spring 2017 onwards please contact your urologist. Taking part involves generating an anonymised patient record, giving a blood and biopsy sample at the time of your procedure. You will be given the results and the opportunity to find out other inherited risks if you and your family are keen to know. You will then be able to ask questions like:

Why me? ...Should I?...What will happen next? What about the kids?

In the early days, answering these questions was very difficult, but exciting times lie ahead as we start to understand when, and how, to tackle prostate cancer.
Members of the Nottingham Cancer Patients & Carers Support Group would like to wish you all a Happy New Year.

It will be 30 years in February since we held our first meeting and to mark this event we are planning to hold a Drop in and Say Hello in our Regular meeting Room C2505 at the Queens Medical Centre on 21st March 2017 between 130pm and 7.30pm. Light Refreshments will be available to welcome everyone, also a large Birthday Card which we hope people will sign to express their love and support. As always we will have several of our Key Members to welcome and befriend people who drop by to see us. Many of our key members are long term survivors of cancer. Many of our Patient Members have completed the Macmillan Cancer Support Courses in order to develop the Communication and Supporting Skills. See attached a photograph of our group.

Best wishes to you all. May 2017 be a very Good Year for all. 

Ken and Freda Ingall and the members of this group

Each year the Rotary Club of Loughborough organise the Loughborough Santa Fun Run - many thanks to them for inviting PROSTaid to take part in the event once more. This is the 4th year that supporters of our charity have entered. The 5k circuit winds its way through the streets of the town centre, a colourful and joyful event with the competitors dressed in Santa Suits, complete with hat and beard, but the ladies don't like the cotton wool from their moustache and beard getting into their mouths!! However despite hormone therapy some of the men I know enjoyed looking at the mini skirted Santa's.

On a crisp and sunny Sunday morning in December 2016 approx 2000 Santa's, some with dressed up dogs took part to raise funds for numerous charities. Our very own Patron Alan Birchenall started the event, some of you may know he has now grown a real beard. There were also some competitors with blue Santa Suits running for the LCFC Foxes Foundation. It was very inspiring and motivational to witness several of our men with PC who were between sessions of chemo taking part, supported by their families - they demonstrated tremendous courage and determination, whilst raising awareness and funds to help other patients. Great, Well Done Chaps!!! “Team Allsorts,” from Hinckley Running Club, (one of whom ran a personal best) and a team from Tarmac Ltd also ran for PROSTaid.

Many thanks to everyone who took part to raise funds for PROSTaid and to all of their sponsors. Although monies are still coming in, we expect to raise appropriately £3000.
Bryan Metcalf - York and Selby Prostate Cancer Support Group

Bryan Metcalf passed away on 18th October at the age of 70 surrounded by members of his close family.

Bryan was first diagnosed with Prostate Cancer twenty years ago when he was aged 50. From the time Bryan was first told he had Prostate Cancer, he set out to learn everything possible about his illness and saw for himself a role to help other patients who were also having to live with a prostate cancer diagnosis and its consequences for both themselves and their families.

Sixteen years ago Bryan became enthusiastically involved with the formation of the York and Selby Prostate Cancer Support Group and became the Chairman of the group. This position he held until the date of his death.

In addition to Bryan’s work with the group he was also actively involved with Tackle and a number of internet based advice and information websites not only in the UK, but internationally as well. Bryan made full use of modern social media to provide support wherever and whenever it was requested.

Throughout the last twenty years Bryan was always supported by his wife Maureen who had a fine sense of humour.

Julie and I first met Bryan and Maureen six years ago on a train, while I was awaiting my biopsy results. We met as strangers, and left as friends agreeing to meet again at the next York and Selby Prostate Cancer Support Group meeting.

His positive attitude, hard work and enthusiasm in everything he did helped so many people. He will be very much missed, but never forgotten.

Vernon and Julie Janes