Some seventy or so people affected by prostate cancer attended the workshop at John Foster Hall, University of Leicester, on Thursday 27th Oct 2011. The list of speakers looked to be varied and certainly turned out to be so!

The first speaker was Tanju Thevar from iMEDicare, topic “Penile Fitness in your hands”

He talked about erectile dysfunction and prostate cancer and how after surgery men experience “dry” orgasms. Nocturnal erections keep penile tissue healthy, these are lost with many prostate cancer treatments. The penis actually shrinks and shortens with scarring commonly found.

ED treatments may be vacuum erections/oral medication such as Viagra/penile injections.

Oral medications usually work well in healthy men but there may be multiple side effects. These cannot be used by cardiac patients.

Penile injections show a 70% success rate but possible side effects may include penile pain, infections, bleeding, bruising, fibrosis, Peyronie’s disease (curvature of the penis) and palpitations. A contra indication is a patient on Warfarin which thins the blood making clotting difficult.

Vacuum therapy replicates morning erections, works well with bodily functions, improves the vascular system, is non-invasive and has minimal side effects. The vacuum pump is 2/3rds cheaper to produce than drugs or injections and can be prescribed either manually or battery operated. There is no restriction on its use and has a penile rehabilitation effect.

Contra indications are an abnormal INR, Sickle cell disease, Hodgkins lymphoma, haemophilia

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Continued from page 1

and polycythaemia. The earlier the man uses the pump the better, but even men who have long term ED may benefit. Often patients try this after failed drug therapy.

The pump is available in five different sizes and it is important to be prescribed the correct size, too large and the scrotal skin may be sucked in, painful and uncomfortable.

Use of the pump promotes a penis gym effect, the more it is used the better. Sex may be resumed four weeks after surgery, with 77% of men getting normal erections after nine months.

Dr Jasmin Hussein, Chief Medical officer Sanofi Aventis, spoke on “Continuum of care in patients with metastatic prostate cancer”.

Metastases affect some 30-40% of men diagnosed with prostate cancer. Typically 80% of spread is to bones which may cause pain/immobility/paralysis.

1996 - Mitoxantrone was used for palliative bone pain.

2004 - Docetaxel (Taxotere) a three weekly mainstay for 1st line metastases works for up to nineteen months.

2010 - 2nd line drug, Cabazitaxel from the Taxane family, a microtubule stabiliser in combination with oral Prednisolone 5mg given every three weeks.

2010 - Abiraterone Acetate, an oral androgen blocker was licensed following Docetaxel failure.

The morning session was rounded off by Sandy Tyndale-Biscoe introducing the Federation’s new ‘Marching Song’ to demonstrate our opposition to the term ‘Castration Resistant’. It is sung to the well known tune ‘Are We Down Hearted’ used in the film ‘Oh What a Lovely War’. The words can be found on the bottom of page 5. Try it! Our preferred option is ‘Hormone Resistant’. After all, Sandy explained, you wouldn’t describe a woman who has had a double mastectomy, a ‘flat chested woman’!

After a pleasant lunch, the third speaker of the day Professor Robert Thomas from Cranfield University talked on “The evidence for practical self-help initiatives after prostate cancer”.

Although the incidence of prostate cancer is increasing so are survival rates. Light exercise preferably supervised is proving beneficial. Men on a trial of Hormone Therapy plus exercise found their side effects were actually reversed! Psychological wellbeing is of great importance with Yoga and nutritional advice most helpful. In one trial there was found to be a 70% reduction in cancer cell growth in men who exercise. The level of exercise should be about three hours a week of brisk walking. Prof Thomas said there was a higher rate of disease recurrence in obese men and went on to speak about diet and the effects of various foods on prostate cancer.

Beneficial foods: soy, polyphenols, selenium, oily fish, vits E and D, tomatoes(lycopene), allium veg (onions), cruciferous veg.

Legumes, Soy, Phytoestrogens. Pods and edible seeds such as peas, beans, lentils and peanuts. Soya beans have a high content of phytoestrogens as do Tofu, soya milk, fruits, nuts and seeds. Non fermented soy products such as Tofu and soya milk reduce prostate cancer risk. The benefits reduce PSA levels and PSA doubling time. Target intake per week 3-4 portions.

Polyphenols found in fruit, veg, green tea, pomegranate, potatoes, and raspberries also reduce prostate cancer risk.

Selenium present in Brazil nuts, offal and all sea food are beneficial.

Lycopene found in tomatoes, watermelon, rose hip, guava and grapefruit are also excellent although tomatoes should be processed (tinned), also tomato sauce.

Cruciferous veg such as broccoli, cabbage, sprouts, turnip, swede and kale, are also valuable.

Good PSA lowering foods are garlic (allium family) tomatoes, vit D, pomegranate juice and a high soy diet. Foods recommended for advanced aggressive prostate cancer are cruciferous veg, selenium, green tea and fish.

Interestingly, organic milk is not recommended because it has about 40% less iodine than non-organic milk.

The day was information packed with lots of self help ideas. The most important outcome of the day was hope for the future with new drugs, treatments and clinical trials.

Hope for the Future:
Sipuleucel T, a vaccine (Provenge) Alpharadin, a treatment for bone metastases.

Detrimental foods: dairy produce, saturated animal fats, processed meats, overcooked barbecued meats.
The results of a large trial have found further evidence that treating men with locally-advanced prostate cancer with external-beam radiotherapy in addition to hormone therapy improves survival, compared to hormone therapy alone.

The randomised controlled trial, known in the UK as MRC PR07, recruited patients between 1995 and 2005. It involved 1,205 patients with locally advanced prostate cancer, predominantly from the UK and Canada. Half were treated with hormone therapy and the other half were treated with a combination of the same hormone therapy with an additional course of radiotherapy.

By providing radiotherapy in addition to hormone therapy, the researchers found that 74 per cent of men were still alive after seven years, compared with 66 per cent of those who did not receive radiotherapy (see figure 1). The researchers found that those who received radiotherapy were about half as likely to die from their disease. The additional side-effects from the radiotherapy given in the trial were minimal.

Although radiotherapy with hormone therapy is a fairly common approach to treating locally-advanced prostate cancer, some men with locally-advanced prostate cancer are treated with hormone therapy alone and there had been doubts as to whether radiotherapy improved the outcomes of men treated with hormone therapy. The evidence now available shows that radiotherapy (given in addition to hormone therapy) does improve survival, so this should be the standard of care for these men.

The results are being published in the Lancet in November. For more information about the trial, visit http://tinyurl.com/7fntaeu. A policy brief that explores this issue in more depth is also available from this web page. The trial registration number is ISRCTN24991896.

The PR07 trial results provide strong evidence that using a combination of radiotherapy and hormone therapy can improve the survival of men with locally advanced prostate cancer, compared to hormone therapy alone. However, there are still many questions that remain about what the optimal treatment strategies are for prostate cancer. Ongoing clinical trials are essential to answering these questions. For example, the STAMPEDE trial (Systemic Therapy in Advancing or Metastatic Prostate Cancer: Evaluation of Drug Efficacy) is examining how effective three new drugs (in addition to hormone therapy) are at increasing survival. Being part of clinical trials like this can help improve the treatment of prostate cancer for men in the future.
Another Friday dawns and we quickly fall into the usual routine. Up at 5.30am. Bag filled with plenty of reading matter, drugs, pain diary, bottles of water and on the road by 6.45am. to travel the sixty odd miles to the chemotherapy unit. This has been the routine every third Friday for the last five months. At least we have left the dark days of Winter behind and the journey seems less foreboding on bright Spring mornings.

We know all the staff well now and what is to follow. The blood tests, the weighing, the height measuring and the form filling and then several hours later the drip is set up and treatment begins. The first time was terrifying, watching the life giving, but also life threatening chemotherapy dripping slowly into his arm. How did we come to this?

Until December 2005 we lived a normal life. We ran our own business and we had an active family life with two daughters, but then my husband started to feel very tired. He was also losing weight and having difficulty peeing. As a man who only went to the doctor to have his ears syringed, he went to our G.P. quite unconcerned and came back saying he had to go to travel the sixty odd miles to the chemotherapy unit. This drugs, pain diary, bottles of water and on the road by 6.45am.

Routine. Up at 5.30am. Bag filled with plenty of reading matter, another Friday dawns and we quickly fall into the usual losing weight and having difficulty peeing. As a man who only went to the doctor to have his ears syringed, he went to our G.P. quite unconcerned and came back saying he had to go back in a few days for some blood test results.

Unsuspecting, he went back to the surgery and came home a shattered man. He said that his PSA was 760 and felt that the doctor thought he should get his affairs in order. I can remember feeling the room start to spin as total disbelief and bewilderment overwhelmed me. In our terror we read everything we could find and tried to learn as much as we could. We learned a whole new vocabulary including androgen deprivation and the worst sounding of all – chemical castration. A horrible phrase that hardly helps to make a man feel good about himself, when his self esteem is already on the floor.

We were honest with each other and went to all the appointments together, so there were no secrets between us. It's a difficult role to try to keep up the spirits of the sufferer and deal with the one hundred and one thoughts and emotions that keep running through your own mind. The waiting just seems endless and as each test and scan confirm the worst diagnosis, it is difficult not to show the strain. It seems as if a fissure opens up between you and the rest of the world and with each bad piece of news it just gets wider and isolation sets in. The prognosis was as bad as it could be and in the blink of an eye we appeared to have no future and it becomes a twenty four hour a day battle to stave off the darkest of thoughts. It is also a difficult balancing act between telling the family everything and yet wanting to shield them from the very real fact that they could be losing their father. Always trying to put a positive spin on bad news is extremely wary and fraught with danger. It is very easy to tie yourself in knots.

After three months of hormone treatment, the PSA has stabilized and the improvement makes my husband feel more positive. He announces that he will run a half marathon. He has never run a race in his life and at the age of sixty and with advanced prostate cancer he is going to run thirteen miles! My first thought is that he has gone mad and will kill himself, but his oncologist is fully on board. Exercise is good and it will give him a goal.

Well he did it and I died a thousand times as I saw the pain he was in, but the determination to finish got him through. It also gave him the will to cheat this disease of another victim and started him on a whole new life of involvement with charity work. It's a difficult road to travel after diagnosis. The initial shock lasts a long time and you walk a mental tightrope. Do we plan a holiday? Do we buy things when he may not be around to get the full use out of them. All the attention is directed at the patient and you can start to feel like a carer instead of a wife. Your physical relationship is changed because of hormone treatment and you always fear the day when the PSA might start to rise and you will be left alone. All of this creates a tremendous amount of tension and eventually anger, frustration and fear will out and harsh words are said, but it's almost a relief to be more normal with each other.

Sometimes it takes a super human effort to keep your relationship on track and to not let emotions build up to an explosive point. It is not surprising to learn that many relationships break down under the strain and it is very important to have ways of relieving the pressure, whether that is through an activity or friends or even through a support network. Attending appointments with your husband is a good reminder to medical staff that it is not about a man in isolation, but about a couple or whole family.

However, to remain positive and retain a sense of humour are paramount and here we are five and a half years later, hormone refractive and having chemotherapy. It's been a rough ride with extreme tiredness and chest infections, but he has only two treatments to go and the PSA is dropping nicely. We are already planning a holiday and desperately want to get our lives back on track. New treatments are around the corner and we are determined to keep going forward and to do it with as much optimism and humour along the way, as we can.

Please Check Your Details

Please would all affiliated members check on the PCSF website, that their details are correct on both the map:

http://tinyurl.com/429ee7f

and the contact web page:

www.prostatecancerfederation.org.uk/membershipList.htm

If there are any alterations, please contact:

Sandy Tyndale-Biscoe

Email webmaster@prostatecancerfederation.org.uk

By Kate Gunn
**PATCH trial: Are oestrogen patches a safe treatment for prostate cancer and do they work as well as anti-hormone injections?**

**John Dwyer**

What is PATCH about? Prostate cancer relies on the male hormone, testosterone, to grow. So, one of the main ways to treat it is to lower the level of testosterone in the man's body by giving him anti-hormone injections. Some men have these injections for many years. They can be very effective in shrinking the tumour, but they can also cause side effects which may become serious, particularly if they are taken for a long time. For example, they can cause bone-thinning which might lead to fractures. They might also increase the chance of men developing diabetes or heart disease.

In the past, tablets (taken by mouth) containing the female hormone, oestrogen, were used as hormone treatment to lower the levels of testosterone. They were as effective as anti-hormone injections in shrinking the cancer but, for some men, there was an increased risk of heart problems/strokes or blood clots. This is thought to be caused by large amounts of oestrogen passing from the stomach to the liver. One method of avoiding this is to give oestrogen through a patch that is placed on the skin.

Oestrogen patches might be able to effectively treat the cancer without causing bone-thinning or increasing the chances of heart problems. However, before the PATCH trial started, oestrogen patches had only been used in a small group of men in the UK, and so they need to be tested in a larger group. The best way to do this is in a randomised clinical trial. So, the aim of PATCH is to find out if oestrogen patches are a safe treatment for prostate cancer that can work as well or better than anti-hormone injections and avoid some of the side-effects.

What happens in the trial? Men who decide to join the trial are divided at random into two groups (see diagram). One group will be treated with anti-hormone injections in the same way as if they had not joined the trial. The other group will be treated with oestrogen patches. Initially, this will be 4 patches which need to be changed twice a week. After 4 weeks, if hormone levels are lowered as expected, the treatment is normally changed to 3 patches changed twice weekly from then on. Both the injections and the patch treatment can continue indefinitely.

As well as monitoring the cancer, doctors will also regularly monitor their patient’s hormone levels, side effects and how the treatment is affecting their daily life.

What has the trial shown so far? More than 250 men from hospitals across the UK have already joined the first stage of PATCH which aimed to look at whether patches caused any problems. An independent committee looked at all of the results and didn’t have any concerns about the safety of the patches and so the trial could move on to the second stage. The safety of the patches will continue to be monitored as the trial goes on.

In order to assess whether the patches are an effective treatment, a larger group of patients followed up for a longer period of time is now needed. So we are inviting more men to join for this second stage. When there are 660 men who have all been in the trial for at least 2 years, we will be able to look at whether the patches have worked as well or better than the anti-hormone injections in treating the cancer and whether they reduce some of the side effects associated with the anti-hormone injections.

Which men can take part in PATCH? Many hospitals across the UK are taking part in PATCH. If your hospital is involved in the trial, your doctor will be able to tell you more about it. Men who have advanced prostate cancer, or cancer that has spread to other parts of their body (metastatic), who would normally be treated with anti-hormone injections can join the trial. This includes patients whose cancer has come back after surgery or radiotherapy. Men having anti-hormone injections alongside prostate radiotherapy may also be eligible. If the trial is suitable for you, you will be given an information sheet to take away and read so that you can decide whether you would like to take part.

It is best to talk to your doctor about the trial, but you can also find further information at www.ctu.mrc.ac.uk

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**Are we castrated? No!**

Sandy Tynadle -Biscoe

Readers will have noticed the recent adoption by clinicians of the term “Castration Resistant prostate cancer” to denote men whose cancer is no longer responding to conventional androgen ablation. The justification for using this offensive term in reference to men who, except for the few that have undergone orchidectomy, are in no sense castrated, is that it is technically more correct.

This is not true. There is nothing about the term “castration resistant” that is any more correct than “hormone resistant”. Indeed it is less so. The reason the treatment is no longer working is because other organs in the body, including the tumour itself, are manufacturing testosterone, and so the man is in no sense castrated. The term “castration” is offensive to most men, and using it in this context is akin to calling women who have had a mastectomy “flat-chested”. We will not have it! We urge all members, when talking to clinicians who insist on using the term, to politely ask them to refrain from an insult, which, whilst not intended, is very painful for men already suffering from the psychological impact of hormone treatment.

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**To the Tune of ‘Are We Downhearted?’**

from Oh What A Lovely War’

Are we castrated? No!
Not while Viagra’s there for use,
Not likely!
While we have
Caverjet and MUSE,
And Medisure’s ingenious little kit,
It’s a long long wait for Abiraterone
But we’re not castrated yet!

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Women have done a terrific job of bringing breast cancer to the fore; let's do the same for our men! I'm very proud to be a part of the 'My Man Ladies Lunch campaign' and I am calling on women up and down the country to show their support, get their friends together and organise a Ladies Lunch of their own. This fantastic cause and our men need us to act.’ Baroness Jan Royall of Blaisdon.

The Launch
Baroness Royall, Leader of the Opposition in the House of Lords, was one of the inspirational women who took part in the launch of our ‘My Man Ladies Lunch’ campaign with its clear objective of empowering the great ladies behind the men who are, all too often, reluctant to discuss their own health.

Guests arrived the historic Goldsmiths Hall shortly after midday and made their way up the grand stair case, passing the string quartet before being greeted by a gorgeous Butler and handed a glass of champagne. When asked to take their seats for lunch guests were lead through to the beautiful Drawing Room, where none other than Prince Charles himself had dined the week before, and served a stunning three course lunch.

Clinical Oncologist and Chair of British Urology Group, Dr Heather Payne kicked off the discussion, once coffee had been served, by introducing the panel made up of Baroness Royall, one of the UK's most successful entrepreneurs; Lara Morgan, celebrity publicist Max Clifford and the PCRC’s former Director of Fundraising Jane Arnell, who was to play host.

Baroness Royall, who lost her husband to prostate cancer in May 2010, was the first to share her experience and highlight the importance of awareness and testing. Having lost her father in law to prostate cancer Lara gave an emotional but encouraging message to guests of making a difference where ever you can. Finally, Max Clifford, who from personal experience, spoke of living, treating and beating the disease and also the importance of putting back into the community and why he thinks this is such an important campaign.

For a more in-depth look at launch and important issues raised during the discussion please visit our website where you can also see footage of each panelist giving a one to one interview. The SAE Institute kindly filmed the whole event, including the discussion and one to one interviews with the panelists, for free!

All in all the day was a great success enjoyed by everyone and not only raised over £4000.00 for the charity but also saw the first of our Ambassadors sign up to the campaign; including Baroness Royall who will be organising her own lunch at The House of Lords.

Become an Ambassador! The PCRC’s aim is to have ambassadors all over the country representing the men in their lives by organising a lunch of their own. From a three course meal to tea and cake, no lunch is too big or too small as long as you’re spreading awareness.

To find out everything you need to put together your own My Man Ladies Lunch contact Georgina on:
0207 679 9595
or email
gwilson@prostate-cancer-research.org.uk.
It is recognised that a prolonged erection problem can lead to shrinkage of the penile tissues and a reduction in penile circulation (non-use atrophy). Regular use of a SOMAerect vacuum therapy device will duplicate the benefits of nocturnal erections, reversing penile shrinkage, reconditioning penile circulation and promoting a return to good penile health. This therapeutic benefit of regular device use is perhaps best understood as the SOMAerect ‘Penis GYM’ concept. In other words, we can talk in terms of regular device use equating to penile ‘exercise’ with a resulting improvement in penile ‘fitness’ - hence a physiotherapeutic effect.

PROSTATECTOMY PATIENTS:

There is evidence to suggest that post radical prostatectomy patients can also benefit from the use of vacuum device therapy. When oxygenated blood is drawn into the penile tissues by a vacuum therapy device, it is believed that the NO system of the tissue may be enhanced, and hence, help erectile function be restored. This is a hypothesis and needs to be proven by formal studies, but is believed that in these patients low oxygenation is one of the main reasons for vital first messenger deficiencies which contribute to the ‘non-use atrophy’ of the corporeal smooth muscle and corporal fibrosis. It is possible that erectogenic agents like VTD’s may modulate the expression of TGF-beta (leads to collagen synthesis and tissue fibrosis), or other factors, independently of tissue oxygenation.

Regular penile tissue engorgement by use of a SOMAerect vacuum therapy device (VTD) will duplicate the benefits of nocturnal erections, by stretching the erectile tissues to achieve maximum tumescence, reversing penile shortening (shrinkage) and improving and maintaining a good penile circulation. Therapeutic intervention post-surgically with VTD’s may restore nocturnal erections (both frequency and duration), may facilitate vascular perfusion of the corpus cavernosum, and can subsequently inhibit corporeal hypoxia and fibrosis.

Early use of a SOMAerect VTD following RP facilitates early sexual intercourse, early patient/spousal sexual satisfaction, and maintenance of penile length/girth and, potentially, an earlier return of natural erections. Sexual activity that occurs during the first 9 months after surgery helps maintain the sexual interest and comfort between the couples that existed preoperatively. Patients who are motivated and sexually potent pre-operatively, and interested in maintaining post-operative potency should be encouraged for early prophylactic treatment options. The advantage of a VTD is that the erections produced are independent of endogenous vaso-active substance such as nitric oxide (NO) production, which is impaired by nerve damage.

Matters of Function:

In one randomised controlled study with 109 patients, daily use of a VTD began at an average of 3.9 weeks after RP. In Group 1 (N=74), 80% (60/74) successfully used their VTD with an erection maintenance ring for vaginal intercourse at a frequency of twice/week with an overall spousal satisfaction rate of 55% (33/60). In all, 19 of these 60 patients (32%) reported return of natural erections at 9 months, with 10/60 (17%) having erections sufficient for vaginal intercourse. The abridged IIEF-5 score significantly increased after VTD use in both the NS and NNS groups. However, in group 2 (N=35), patients randomized without any erectogenic agent, just 4 patients had erections sufficient for successful vaginal intercourse at 9 months. International Journal of Impotence Research (2006) 18, 77–81 - R Raina, A Agarwal, S Ausmudson, M Lakin, KC Nandipati, DR Montague, D Mansour and CD Zippe

Matters of Size:

In a paper published by a clinical group headed by Dr Manoj Monga of the University of Minnesota and presented at The World Congress of Endo-urology (18th August 2006), data from an ongoing clinical study have shown that early initiation of the use of a VTD, such as the SOMAerect systems, after radical prostatectomy not only improves sexual function but may also help to preserve penile length. Significant shortening of the stretched penile length was seen in 27% of the 'Early' (1 month after surgery) device user group compared to 64% in the 'Late' (6 months after surgery) device user group (p=0.06) at the last follow up visit.

Call 0208 207 5627 for the www.iMEDicare.eu SOMAerect ‘Prostatectomy Recovery Guide.’
It is with great sadness that we have to announce the death of our secretary, Mike Lockett. He was instrumental in the founding of the Prostate Cancer Support Federation, and worked tirelessly to help make it become a powerful unified voice for prostate cancer patients when dealing with the Government and other Authorities.

Mike passed away at 3am on Thursday 29th September 2011 at Ashgate Hospice, in Chesterfield. We extend our condolences to Beryl and the family and assure them that our thoughts are with them at this very difficult time.

Mike devoted much of his energy and skills to providing support for those affected by Prostate Cancer whilst he himself was coping with an ongoing battle with it. He was part of the Prostate Cancer Support Association for over 10 years and for the past 5 years he chaired their Executive Committee. For two years during this period he was Macmillan Development Co-ordinator for PCS. As a mark of appreciation and respect his peers recently elected him to become their Honorary President.

He was responsible for setting up many of the groups in the North West, there now being a total of twelve in the area.

Mike was also one of the most respected founding members of Europa Uomo: The European Prostate Coalition. He was, after their registration elected as vice chairman and guided them through many projects. There, his main concern was to help the suffering of members not so fortunate as ourselves. Condolences have been received from all of the twenty three European member prostate cancer associations.

Mike was a special person who brought comfort and hope to many; nothing was too much trouble for him. He was a fount of knowledge with regards to Prostate Cancer and helped many to understand the types of treatment available and their possible side effects. He will be sadly missed by all who benefitted from his help and guidance with their journey through the different stages of Prostate Cancer.

We in the Federation, will all miss his wise counsel, good humour and friendship.

Doug Gray and Stafford Scholes

It is also with great regret that two of the original members of the Great Drag Race team have also passed away. Doug Gray in August and Stafford Scholes October.

Both Doug and Stafford gave their all, whilst not in the best of health, to complete the 10k Great Drag Race at London Fields in June 2010 and were stars of the film.

Doug was the secretary of ‘National Screening Interest Group’ from Derriford in Cornwall and Stafford, the Secretary of ‘North Durham Prostate Cancer Support Group’

Both worked hard to raise awareness and treatment of Prostate Cancer and will be greatly missed.