Autumn Workshop – 19th November – Birmingham

“Getting Fair Treatment from the Health Service”

The Federation will be holding its usual Autumn Workshop on Tuesday 19th November in the Nettlefold Room (http://tinyurl.com/ptm7m8j) in the Nicolson Building at the University of Birmingham.

The intention is to make the day more interactive than in our past workshops and conferences, with discussion leaders taking the place of presenters. For this reason discussion will be led largely by our own members with experience in the fields concerned. Final details of the programme and cast are still to be worked out, but topics to be covered will include:

- how patient support groups can work with (and influence) the new NHS commissioning arrangements
- getting access to new drugs
- working with sporting organisations to raise awareness (and funds)
- working with Prostate Cancer UK
- campaigning.

Included in the day’s events will be a briefing on the progress of the Tackle prostate cancer campaign, including demonstrations of the new website which will go live shortly and of early examples of a new batch of information leaflets that will be made available to all member organisations.

As usual, attendance, including lunch, is free to members of support groups. To book a place, send an email to bookings@prostatecancerfederation.org.uk, stating your name(s), the support group of which you are a member and any dietary requirements. Bookings will close on 13th November.
There has been a tendency over the past few years for urologists (or at least those who have access to it) to describe surgery using the da Vinci robot (above) as invariably the best form of prostatectomy. Two recent interviews published in the on-line Elsevier journal Practice Update (http://tinyurl.com/n9ng8e7) suggest that this may not always be the case, and that if your surgeon says “you’re lucky, we’ve just taken delivery of a brand new da Vinci machine”, you may want to ask some questions.

The first interview is with Dr Alan Partin, Fellow in Endourology at the Brady Urological Institute at Johns Hopkins Hospital (inventor of the Partin Tables, which play such a key role in determining whether surgery or radiotherapy is better for early stage prostate cancer). He suggests that in due course the vast majority of prostatectomies will be robotic, his only major concern being that there is a only single vendor for the machine, which stifles development. His view is that the robot is better in terms of blood loss and gives better visibility for the surgeon where the amount of space in the pelvis is limited. But Dr Partin is one of the few surgeons who still practice open surgery as well. He does this in certain cases where he believes the results are better. A further point that Dr Partin makes is that there is some evidence that, contrary to some claims that the robot evens out the effects of surgical skill, the learning curve on the robot is longer than that for open treatment. For the first 50 or so operations with the robot, there seems to be a higher proportion of positive surgical margins (i.e. not all the tumour is removed) when compared with a surgeon learning open surgery."

The second interview is with Dr. Roger Dmochowski, Professor of Urologic Surgery at Vanderbilt University, where he discusses what he calls the overutilization of robotics in prostatectomy. In his view, the growth of the technique has been driven by marketing, and not by any clinical benefit. Whilst there is a slight advantage in terms of in-patient length of stay, when we look at other factors, the comparisons overall don’t show much benefit in terms of either morbidities or outcomes for any of the indications for which robotics has been evaluated. It is not clear that the questionable clinical benefit justifies the added cost. The beast itself comes in at some millions; consumables for each procedure are more expensive than those for the comparable open procedure, and the whole procedure takes longer so throughput is reduced. In America this is leading to some hospitals capping the number of robotic procedures. The same (and possibly greater) financial constraints apply to the NHS here in the UK, so might we expect to see restrictions on robotic procedures? And, bearing in mind Dr Partin’s comments, is that necessarily a bad thing?

What does this mean for the (as ever, confused) prospective patient? Once again, here is strong evidence that the surgeon’s experience is a key determinant in successful outcomes. A few years back, Prof Sir Mike Richards, then the “Cancer Tzar”, asked the members of the Prostate Cancer Advisory Group which was better, robotic, laparoscopic or open surgery? The unanimous answer from the assembled group of roboticists, laparoscopers and open surgeons was: it doesn’t matter; it’s the number of procedures the surgeon’s done that counts. And, as we said in the Spring 2012 edition of Prostate Matters, if your surgeon hasn’t done at least 100 prostatectomies, and isn’t doing at least 20 a year, ask to see an oncologist and then go for radiotherapy or brachytherapy.

**Adults with Learning Difficulties**

As well as the round of Probus, Bowls and Rotary Clubs etc Prospect (the Bristol and District Prostate Support Group) has started to give presentations to organisations supporting adults with learning difficulties to help raise awareness of prostate cancer amongst this much neglected section of our communities. We have produced our own presentation slides (examples above) as we could not find anything suitable to use. They have been vetted by representatives from South Gloucestershire People First and the Brandon Trust and also a Bristol based urology consultant.

**Is robotic prostatectomy always better?**

David Casley - Prospect, Bristol

Some of our members have a specific interest in working with adults with learning difficulties and are keen to progress these presentations locally. To date the awareness talks have been well received by men and their carers though the sessions can prove challenging.

If any group is interested in extending its awareness activities to cover this area of our society we can make the presentation available to you and share our experiences. Please contact Malcolm Gamlin or Mike Broxton at prospect.bristol@gmail.com
The Misconception About Palliative Care

If not, please do take the trouble to sign it. It is at least one cycle of docitaxel the patient must have had at the end of life and "palliative care" are posted in the Johns Hopkins Prostate Disorders which can be found at http://tinyurl.com/pq6pgld.

As you probably know, the new advanced prostate cancer drug, enzalutamide, is now available from the Cancer Drugs Fund. However, there is a nasty sting in the tail. The CDF have made the ruling that Xtanti cannot be given if the patient has already been prescribed abiraterone, thus precluding the very men who may need it. The good news is, that NICE have published their draft proposal for the use of enzalutamide and this nasty caveat has been removed. The only stipulation now being, that the patient must have had at least one cycle of docitaxel based chemotherapy. The timeline for the draft proposal to become an official recommendation is February 2014.

My concern and that of Tackle Prostate Cancer, is about the men who can’t wait until February 2014 to be given this lifesaving treatment. Our hope is that the CDF will soften their stance in the light of the NICE draft proposals. There is a petition doing the rounds which I hope you have all signed. If not, please do take the trouble to sign it. It is at http://tinyurl.com/pq6pgld.

Tackle Prostate Cancer alone cannot bring about this change, so we need your help. Please consider writing to your MP.

The problem is that palliative care, also known as “comfort care” or “supportive care,” is so strongly associated with the end of life that it’s typically initiated too late to have a meaningful effect on quality of life. Fortunately, efforts are underway to reverse that trend.

What is palliative care? Palliative care is any form of treatment that focuses on:

- Preventing and relieving suffering, but the intent of the care is not to cure the disease
- Achieving the best possible quality of life
- Providing psychological, social, spiritual and decision-making support

Reduce pain and discomfort. Prostate cancer (and its treatment) may cause pain, fatigue, loss of appetite, nausea, shortness of breath, pneumonia and insomnia. Many of these symptoms can be relieved with medication, nutritional therapy, physical therapy or deep breathing techniques. Chemotherapy, radiation or surgery can also be used as palliative measures to improve quality of life by shrinking a tumor, slowing its spread or removing it. Useful non-drug treatments may include acupuncture, relaxation techniques, biofeedback and massage therapy.

Address emotional concerns. Palliative care specialists can help you and your family members cope with depression, anxiety, fear and other difficult emotions that often accompany cancer diagnosis and treatment. They may provide counseling, recommend support groups, hold family meetings or make referrals to mental health professionals.

Explore spiritual matters if desired. A cancer diagnosis can trigger questions of faith. A counselor with expertise in palliative care can help you explore your beliefs and values. He or she may also refer you to a hospital chaplain or faith-based organizations in the area. Other aspects of palliative care include coordinating care across a range of settings (hospital, home, nursing home and hospice), as well as arranging help with finances, medical forms, legal documents and advance directives. Your team may also direct you toward local and national resources for assistance with issues such as transportation or housing.

Enzalutamide

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The more pressure we can bring to bear, the better the result is likely to be.

The other issue which is of importance concerns bone health. One of the side affects of all of these advanced drugs is spinal compression. This is relatively rare in prostate cancer, but has a much higher risk in the new advanced drugs. This is because patients usually died before this became a problem, but now they are living longer because of these new ground breaking treatments, it is becoming one.

These awful events could be greatly reduced if bisphosphonates or denosumab were part of the NICE recommended treatment pathway for advanced prostate cancer.

Tackle Prostate Cancer is also campaigning on this and letters to MPs, would be of huge help.

To finish off, I was fortunate enough to be given enzalutamide after abiraterone and after nearly a year, so far, I am fit and healthy and would like other men to have the same opportunity as I have been given.

Editorial Correction In issue 21, the article entitled “Broccoli as a high-tech research tool?” was attributed to the Norfolk & Waveney Group. It should have been David Paull who is a member of the Norfolk & Waveney Group.
Although opinion regarding the effect which positive thinking may have during illness, healing and recovery remains very mixed, an increasing number of studies is highlighting the health benefits that are associated with positive emotions. Moreover, psychological and/or behavioural factors have been shown to influence the incidence and/or progression of cancer. It is also my belief that a positive attitude can help individuals cope with disease and fight it more effectively - “attitude” matters.

Although we are the result of the genes that we have inherited from our parents it is wrong to believe that we have little direct control over “our genetic fate” to suffer from such or such disease, and that there is nothing one can do other than “cope”. We do indeed inherit all our genetic material from our parents and as a consequence are predisposed to certain diseases, including cancer, but genes expression can be switched on or off in response to the environment and experience. An interesting study by Ornish and colleagues in 2008 showed that intensive nutrition and lifestyle intervention in men with low-risk prostate cancer under careful surveillance for tumour progression reduced the expression of many genes that are associated with promoting tumour growth compared to the men who did not take part in the intervention. This demonstrates that external factors can affect us even at the cellular and gene expression level and illustrates that we might, to a certain extent at least, have some control over our fate.

We live in a society which subjects us to a range of physical and mental stresses and it is worth remembering that the National Cancer Institute has reported that 80% of cancers are actually caused by environment causes which include exposure to toxins and lifestyle factors such as smoking, diet and stress. However, when it comes to stress, the reaction to stress differs from person to person. The issue is whether this stress will be used to fuel/boost our energy and immune system or will consume and inhibits these valuable resources. People who have the ability to convert even the negative into something positive can make the most of any circumstance and find themselves better able to handle stress, maintain resistance to illness and recover from it more quickly.

People suffering from cancer often lose the sense of purpose, gaining instead a feeling of guilt for the trouble and inconvenience their illness might be causing others. Even worse, many may experience moral and psychological pressure to ‘think positively’ about their disease in order to ‘fight’ cancer. This is not what is meant by positive thinking - it has to be based on feelings from “within”, and supported by others. The support of nursing staff and family members is, indeed, invaluable in strengthening one’s life force. Talking about the disease and meeting people who have survived and dealt with the disease may positively influence the path to recovery.

Positive attitude/thinking is much more than just being happy or displaying an upbeat attitude. Positive thoughts can actually stimulate the production of endorphins/opioids in the brain which, amongst other effects, stimulate and strengthen the immune system, indeed opioid peptide have been shown to increase the immune cells’ ability to kill tumour cells or even act directly on reducing tumour growth.

As a researcher who studies the relationships between cancer and the immune system and is developing new approaches for ‘vaccinating’ against the disease (a ‘Tumour Immunologist’), I can say that the immune system can prevent disease and that interventions which are designed to stimulate the immune system to attack cancer can prevent the growth of tumours when correctly administrated. It is therefore logical to assume that any strategies which can boost one’s immune system should be actively promoted and any situations which can impair the effectiveness of the immune response should be avoided. Since it is well established that a healthy diet and regular exercise can enhance the immune system, particular attention needs to be paid to life style, especially by those with cancer or other diseases that can be influenced by the immune system.

It is extremely important to continue to strive to find joy and hope in order to bring one's life to a fulfilling and satisfying completion. Nobody can avoid old age, sickness and death. Although our bodies might be afflicted with a disease, if our mind is strong it can exert a positive influence on our physical condition. The strength and soundness of our attitude, our inner determination to be well, are crucial to our health and well-being. A positive mental attitude does matter!

“Death is not the greatest tragedy that befalls us in life. What is far more tragic is for an important part of oneself to die while one is still alive. There is no more terrifying tragedy than this. What is important is to accomplish something in this life time".
In July 2009 a wonderfully engaging young couple Phil (52) and Tina (39) came along to the Oldham group and we were all stunned and upset that he had a week earlier been diagnosed with stage T4 Prostate Cancer. He had presented with a PSA of 2,015 had had a bone scan and had vast bone metastasis. He was a roofer by trade and the day he was diagnosed was told he would never return to work.

Phil has 3 children and 4 grandchildren and was divorced when he met his old (in time not age) friend Tina they subsequently had their first date in November 1997, and got married in 2003. Tina was Landlady of the Old Bulls Head pub in Shaw, and she and Phil lived on the premises.

Phil did start having hormone therapy, went onto a trial at The Christie, but at Christmas 2010 he ended up on life support in hospital. Mercifully he recovered and their friends raised money so that they could go back to Mexico to renew their marriage vows. In 2011 they decided that in order to manage Phil’s condition she would give up the pub and move back into their home which was more suitable for adaptations.

The Oldham Occupational Therapy department authorised and paid for adaptations; the front of the house was completely altered to enable a wheelchair lift to be installed, the bathroom was turned into a smart new wet-room and to get there a stairlift was added.

Unfortunately in autumn 2012 Phil’s PSA rose to 288, he was in a lot of pain and his mobility and health rapidly declined and he was on quite large amounts of morphine. He was not fit enough for conventional chemotherapy but he was then screened to see if he was suitable for one of the new trials at The Christie. Thankfully he fitted the strict criteria and was accepted so at the moment he is on Zoladex implants, Ranitidine, Paracetamol and the trial drug ODM20. Since the very first tablet of the trial drug he has been able to live without the morphine, and there has been a significant improvement in his health and mobility; he rarely uses his walking stick, has ditched his wheelchair and only uses his motor scooter for longer trips out.

Phil has once again started to go and watch his beloved Manchester City and saw the final at Wembley. He is now the proud owner of a 2013-14 Season Card. He attends the local hospice, Dr Kershaws, where he takes advantage of all the weird and wonderful therapies on offer and he has rediscovered his love of drawing and painting.

They both thought they would never be able to manage nights away from home but he is managing so well at the moment that in August they are off to Majorca for 2 weeks. Tina’s hope is that when the current trial finishes there will be something even better that will enable Phil to carry on as he is at present. We can only all echo that sentiment.

What we’ve done this year …

**We’ve started to Tackle Prostate Cancer**

Since last November, when we held workshops to get members’ views on what the Federation was for, what it should do and where it should be in five years’ time, we’ve been busy. We created a new and more dynamic image for the Charity: “Tackle prostate cancer, action for patients and their families”.

The aims of the Tackle campaign are to raise awareness of prostate cancer, encourage early detection of prostate cancer, seek to ensure that men with prostate cancer always get the best treatment whatever the stage of their disease, and to remove injustices in treatment pathways offered to prostate cancer patients. The full launch of the campaign will take place in next few months.

We reviewed our Governance and concluded that under the current structure it is difficult to communicate with our Members and to represent their interests. We will be introducing a programme of regionalization to give us a structure that will allow improvement. We reviewed the composition of the Board of Trustees. We decided that, in addition to patient representation, we needed greater expertise and specific skills. We recruited as a new Trustee, the top urologist Frank Chingewundoh.

We have set up a Clinical Advisory Board to add clinicians’ expertise to our already considerable bank of patient expertise. We will be showing the design for our new website at our Autumn Workshop and look forward to your feedback as to the resources you would like to see included.

We continue to work with Prostate Cancer UK to review and improve resources for support groups.

In short, we put the building blocks in place to allow us to start some serious fundraising to allow the charity to achieve its independence and be recognised as the Voice of prostate cancer patients and to get on and Tackle Prostate Cancer.
Droylsden Support Group

John Coleman

This group has been revitalised over the past year by the Urology Specialist Nurses from our local hospital (Tameside). The nurses attend every meeting and encourage their patients to attend as they feel that meeting other patients helps them to decide upon the type of treatment to have and to deal with the effects of any treatment.

The total raised from the concert was over £1,250 and the group decided to increase it to £1,500 which was presented to the Consultant Urologists from our local hospital who attended our Christmas Party. This concert was the first we have ever done and it was such a success we plan to do more in the future.

York and Selby Prostate Cancer Support Group Awareness Day at Morrison’s

Bryan Metcalf

The Selby section of the York and Selby Prostate Cancer Support Group held an awareness day in Morrison’s supermarket entrance on September 7th.

From about 10am until we ran out of leaflets at 3.30pm, we handed out leaflets.

As usual some walked by not interested, some said that they have been checked, we said great! Some men walked past but their lady then picked up a leaflet.

We were offered money, but felt it more important to offer awareness.

We were also happy that some PCa patients stopped to say that they were free of progression and side effects after x number of years and were pleased that some stopped to share concerns....... All in all a good day.

Please Check Your Details

Unless otherwise requested, your details will appear on the list of groups on our website.

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
An account of the visit by South Warwickshire Prostate Cancer Support Group to the John van Geest Cancer Research Centre at Nottingham Trent University on 15th August 2013.

Eight members of the South Warwickshire Group were welcomed with coffee and cakes to the very new Centre by Professor Robert Rees (research director), Dr David Boocock, Dr Stephanie McCardle and Sue Dewy OBE (fundraiser for the Centre). For the next few hours we were treated to an intriguing and fascinating account of the work of the centre. It was an opportunity to observe cutting edge interdisciplinary research with the fields of immunology, cell biology, nanotechnology and advanced statistical and computing techniques all informing each other. This process was enabled by extremely high-tech labs, an open plan office and excellent coffee!

The visit started with presentations of the work of the centre. There was lots of encouragement for us to ask questions and this allowed a wide ranging discussion of many aspects of cancer research. We soon learnt that there are many forms of every cancer and that each form or variant needs its own targeted treatment. In addition to this the advances in genetics mean that treatment will in the future be geared to the specific strengths and weaknesses of the individual’s immune system.

After a working/talking lunch we had a tour of the centre’s many laboratories. We all got to wear lab coats and immediately felt our scientific understanding had increased hugely! It was a great day for us all and a privilege to be given an insight into the research process at a laboratory level and to understand more of the lengthy and expensive processes involved before any new treatment or test can be offered to patients such as us. It was a shock to discover that Stage 2 clinical trials must be conducted by an independent organisation, contracted to the research Centre. So although the centre that makes the initial breakthrough will conduct the study, it will be run by the independent contract research organisation (CRO) and that this has to be paid for with an average bill of £1M. However it was also most encouraging to meet scientists who were so aware of and sensitive to the needs and concerns of patients and clinicians.

Our visit was an education in how nano-technology is allowing investigations to proceed at the cellular level. One of the most remarkable parts of our tour was watching a tissue sample made visible through a high power microscope being cut by a laser and the diseased portions “pinged” into a test-tube for further analysis. We also saw a mass spectrometer with the capacity to complete the analysis of blood or tumour samples in seconds; this technology is now being used to diagnose bacterial hospital infections, which would normally take days to grow and analyse in hospital pathology labs. If you ever do lose a needle in a haystack this would definitely be the team to go to for help! My guess is that not only would they find the needle but would return it disaggregated into its component parts with a detailed analysis of its characteristic peaks and troughs.

At the same time as glimpsing the amazing possibilities of research at cellular level we also came to understand that research into our immune systems shows that it weakens significantly with age which may well be key to building a model of how some cancers develop and in turn how that may be treated. We received a clear message about the importance of good nutrition, exercise and psychological well-being to strengthen our immune systems (not forgetting those friendly bacteria in our digestive systems which are more numerous than the cells in our bodies!).

Dr. Stéphanie McCardle (left) with members of the research team at The John van Geest Cancer Research Centre
Is Cialis a Breakthrough For Erectile Dysfunction?

Dave Beesley - Oxford Prostate Cancer Support Group

Well, after lots of consideration, we thought it has to be worth a try as the idea of an applicator or injections did not seem to be on top of the agenda. Also, I am a spontaneous person, so as they are only available on prescription, I asked my doctor and then sent off the prescription to ‘Pharmacy 2 You’ together with a cheque for £58. I received the tablets within 3 days.

Hoping for a new start in life, as soon as the tablets arrived, I could not wait to take the first one. Nothing happened.

Day 8 was the result we were looking for and after 2 years, what a memorable success.

We are now nearly at the end of month two and I have to say life gets even better. Spontaneous night-time erections have returned and the treatment has stopped me getting up in the night for a pee. Also, the urine flow has been better than I can ever remember. The good news is that I reported this side effect to my doctor and they have given me the next two months tablets on the NHS as result of the urinary improvement.

More people should know about this drug as the wellbeing feeling has been a tremendous result and I expect we are not told about it as it has to be on a private prescription which is a real shame.

I only wish I knew about this drug when I started hormone treatment, as it may have worked even then. It would be good to know if anyone has had, or is using this treatment and currently on hormone treatment.

It would be a real breakthrough if it could work for everyone.

Prostate Awareness Progress Report

As reported in the last issue of Prostate Matters, Colin Peach from Teesside has bought a race horse and called it Prostate Awareness.

So far it has run at Doncaster and come fifth, Newcastle, ninth, Newcastle again, fourth and Nottingham fourteenth.

What ever the results, what a superb way to raise awareness! Let’s hope that some of us can go to future races to support Prostate Awareness.

At Nottingham, Graham Fulford took advantage of the appearance of Prostate Awareness by carrying out a PSA testing session. He was made very welcome and carried out 24 tests. The results of which were 21 green, 1 amber and 2 red!