THE
WEST
WALES
PROSTATE CANCER
SUPPORT GROUP
REG. CHARITY NO.1229395
www.westwalesprostatecancer.org.uk
Patron: Rhodri Glyn Thomas A.M. Ret.d

NEWSLETTER
June 2016

Dear Member,

The Western Mail reports that a recent poll showed an alarming 93% of men in Wales have no idea of the function of the prostate. The poll was conducted by 'Opinium Research LLP' for Prostate Cancer UK. Prostate Cancer UK has embarked on a new awareness campaign in the media after a similar initiative last year. In addition the national press does a pretty good job of keeping prostate cancer in the public domain. Rarely does a week go by that the Daily Mail fails to come up with a related story. So why is it that so many men remain in ignorance? Perhaps only those who have been touched in some way take a close interest in prostate cancer stories.

When TWWPCaSG goes out in the community spreading the word we do find a proportion of men who simply bury their head in the sand and don't want to know. Over the eight years we have been attending health fairs, giving talks or raising funds in local stores things have improved and more men are stopping to chat and take information away to digest later. However the poll suggests that we have a long way to go. Too many men are diagnosed too late for curative treatment. When diagnosed, they are not well placed to make an informed treatment choice. Most of us will have experienced the steep learning curve which follows diagnosis as we absorb the information which will allow us to make that choice or to understand why we are being advised on a particular course of action.

You may receive conflicting advice from clinicians, making the treatment choice more difficult. I suspect this happens less now, as each case is discussed by a multidisciplinary team before the patient is given his diagnosis or treatment advice. Conflicting opinions muddied the water a little at the time of my own diagnosis, but in hindsight I didn't mind being given different interpretations of the same tests and scans because by that time I was acquiring enough information to be confident in my choice. I am often impressed how new members are frequently taking the initiative as they explore the range of options on offer.

If only we could interest men in all aspects of their health at an earlier age. As patients we do have a duty to those we know to pass on information to friends and family. Many of you undertake this role diligently.

Hywel Dda UHB Urology Department Update.

In May Ken Jones and I represented TWWPCaSG at our most recent liaison meeting with the Health Board. Representing the Health Board were Keith Jones, Senior Manager with an overview of Cancer Services, Caroline Lewis, Senior Service Improvement Manager, and Mr Yeung Ng Consultant Urologist. Steve Bennett also from the HB represented Patient Appointments and related matters.

The Agenda was our own and mostly concerned matters of capacity and follow up appointments and patient access to test results. It is over two years since outgoing Chief Executive Trevor Purt explicitly promised an end to 'Partial Booking' of follow up appointments and a return to a 'Full Booking' System. We had argued over a period of six years that partial booking was never in the interests of prostate cancer patients and allowed patients to 'disappear from the system.' Evidence supported our arguments. We were more than delighted when in his letter to me of 31 January 2014 Mr Purt said, "*We are currently reviewing all follow up outpatient capacity to ensure that we provide patients with the service they need. In addition, we are working to introduce full booking for appointments that will give more control to patients and open up the potential for GPs to book their patients into clinic during their consultation. We hope to be able to introduce this over the next 12-24 months and we believe it will significantly improve the service to **all** out-patients.*" The contents of Trevor Purt's letter was preceded by a 'confirmation phone call' to me from Matthew Willis, then Head of Cancer Services. The move to full booking for all was also confirmed by Manager Brett Denning at our next liaison meeting with the Health Board. We had campaigned on behalf of PCa patients but were offered a solution applicable to all patients requiring follow up. We were very happy!

However, since January 2014 a number of you have continued to experience problems with follow-up appointments which we have tried to deal with on your behalf. Two years have gone by and we felt it was time to write formally to the new Chief Executive Mr Steve Moore to see what progress had been made to achieve the promise of full booking made by his predecessor. After much prompting and delay a reply was received in February this year claiming to report some progress on the question of full booking. Steve Moore's letter continues "*… there does appear to be some ongoing confusion regarding commitments offered by the Health Board and this has been the subject of considerable discussion between our Urology and Patient Booking Teams.*" The letter continues "*… I do wish to extend my apologies to you and your group members if previous correspondence has offered you a slightly different impression of the Health Board's commitments in this regard.*" We were not given a slightly different impression of the Health Board's commitments. Instead a very clear offer was made and welcomed. The new Chief Executive now claims this cannot be achieved. **We are not amused and not prepared to accept this is the end of the matter!**

As it stands Trevor Purt's offer will not be available to **all** patients requiring follow up appointments. Neither will it be on offer to **all** patients with urological cancers. There will be exceptions. Urological cancer patients (incl. PCa patients) who have chosen Active Surveillance will be offered 'full booking' i.e. the date of their next clinic appointment before they leave outpatients. If you are in this position you must ask for that next appointment date. In addition, those patients classed as high priority by their Consultant will also be offered their next appointment before they leave outpatients. How will you know if you have been listed as 'high priority'? To be frank, I do not know unless your Consultant tells you. However my advice to you **all** is to ask for your next appointment before you leave. Ask your Consultant, Registrar, Specialist Doctor or Key Worker; don't wait till you get to reception as this will be a lost opportunity.

We will continue to campaign on this issue on behalf of all Urological Cancer Patients and we did so again at this most recent meeting. Mr Ng agreed with us and spoke strongly in support of our own stance. I earnestly believe that he was speaking on behalf of his Urology Department colleagues. At the moment, there is still the possibility that those patients not given their next appointment at outpatients could be lost to the system. If you are not offered the date of your next appointment please be proactive on this matter and get in touch with the hospital if your appointment doesn't turn up in the post. To ensure that full booking becomes a possibility the HB has promised an audit of patients with a view to greater efficiency. Some patients for example are on the lists of more than one Urologist. A promise was also made to see if a further upgrade of the Myrddin 'appointments' software is possible. We learned that West Wales was the first to adopt this software. Patients are living with the consequences. Later, more flexible, software is used by other Welsh HBs. Some HBs including Cardiff do not use Myrddin software in any format. I am grateful to Keith Jones for this suggestion but have to wonder why this possibility has not been considered by the HB before. Myrddin as it stands is not fit for purpose and Hywel Dda Managers must adopt a 'can do' approach to this issue! There has been too much negativity.

At the root of the problem is lack of capacity. As I write this, two replacements have been advertised to work from Bronglais Hospital following the move to a permanent post at Wrexham Maelor of Mr Jameel. In addition, two Macmillan Nurses have been appointed to Urology and should help to resolve capacity issues. Some CNSs who are already very experienced will be trained to take on further responsibilities particularly with regard to prostate biopsies. Given the increasing number of West Wales PCa referrals the need to recruit and retain Urology Department staff must remain uppermost in the minds of Hywel Dda Managers. PB

TWWPCaSG helps fund a Cancer Research Wales Project.

We have been very fortunate to have received enough money in the 2015-16 financial year to enable us to spend more on research. We gave small donations to Cancer Research Wales (CRW) in 2013 and 2014. Early in 2016 we were able to donate £50,000 to CRW which has a sound history of prostate cancer research. CRW have agreed to spend an identical sum in a joint project i.e. a total spend over three years of £100,000. The project will look at diagnostic journeys in prostate cancer in Wales. The project will be overseen by Prof. Richard Neal from Bangor University. Prof Neal has considerable research experience and his background is in Primary Care; very appropriate since GPs are crucial to the diagnostic process. Co-investigators are Prof. Clare Wilkinson from Bangor University and Dr John Staffurth from Cardiff University.

Newly diagnosed patients will be recruited and questioned via a detailed survey about their experience. The project aims to describe in detail the ways in which men with prostate cancer are diagnosed from their first experience of symptoms or PSA testing and to identify all the factors and influences that contribute to the diagnostic journey. Similar surveys will be conducted with GPs and Urologists. The aim will be to ensure best practice and effective diagnosis. Hopefully this will be a step in the direction of ensuring early diagnosis of prostate cancer. Within our membership of c 270 men we have a huge body of patient experience. I hope there will be an opportunity for TWWPCaSG to get involved in this study. As I write, the project awaits the outcome of a peer review to enable it to proceed. Trustees Di Bell and David Parmar-Phillips represented TWWPCaSG earlier this year and attended Cancer Research Wales 50th Anniversary celebrations. David reports:

Cancer Research Wales 50th Anniversary Symposium, Swalec Stadium Cardiff.

A report by Trustee and Vice Chair David Parmar-Phillips

St. David's Day 2016 - Di Bell and I found ourselves among the early morning commuters eagerly awaiting the 6.40am train at Carmarthen station to convey us to Cardiff Central. We both reflected (thankfully) that our days of joining such merry throngs, on their daily pilgrimage to work, were well and truly in the past.

But today we had voluntarily chosen to rub shoulders with the working masses in response to an invitation to attend the above symposium organised, not only to celebrate 50 years since its founding, but also to share some of the very latest research into precision cancer medicine.
All of the twelve main speakers are renowned specialists in their field, and the subjects covered included: early cancer diagnosis, development of better cancer diagnostics, immunotherapy, precision radiotherapy and improved targeting of conventional and molecular targeted agents.

Much of the content was, of course, highly technical and required a somewhat deeper understanding of medical practice and terminology than either Di or I possess. Nevertheless, we agreed that the interest of these individuals in their various areas of expertise shows a remarkable commitment to discovering the means to fight, and eventually defeat, this disease that affects so many of our lives.

A highlight of the day was having the opportunity to speak with a number of PhD students who were displaying their research projects in the form of large posters. These students are tomorrow's experts in the world of cancer research, and we were impressed with the dedication shown by these immensely talented young scientists to their different areas of interest.

We, as a support group, can be grateful to Cancer Research Wales for all the work they have carried out over the last 50 years. You, as members of TWWPCaSG, can be proud that you have enabled us to play a small part in helping to fund the next generation of researchers in their vital work.

I can do no better than to end with a quote by Dr Malcolm Adams, Chairman of the Scientific Committee, Cancer Research Wales:

"During the last 50 years, the survival of people with cancer in Wales and elsewhere has more than doubled with research playing a major part. Cancer research and treatment is increasingly tailored to match the particular genetic and biological characteristics of the individual tumour. New treatments have been developed with the improved understanding of the complex biology of cancer, which in turn has presented fresh challenges, not least, how best to optimally target specific patient populations with these novel treatment approaches. The delivery of precision cancer medicine will be critical for the provision of future healthcare." Thank you David.

Phil's Story - Part 3

An account of my experience of prostate cancer by Phil Battison.

Treatment Holidays.

My first recollections of holidays are from the mid 50's when, on a Saturday morning in early August, my family would be found at the end of our street, waiting for a bus to take us into "town". Later we would wait on the concourse of Manchester Central Station for the gate to be opened and allow us onto the platform to board the North Wales train for Rhyl. There we would again wait for the local bus to take us to Wincups Caravan Park (it's still there!). At the Camp Reception we would, once again, have to wait to register and be allocated our caravan: the "home from home" in which we would enjoy our annual week in the sun!!! There was a lot of waiting involved with travel in those days…

45 years later, in my early 50s, I was, once again, waiting! A watched pot never boils! Well, it certainly seemed to take its time. The months passed and my PSA stayed down (Good!) but then so did I. (Not so good!) Of course, I should have realised that nothing would happen "in the trouser region" overnight, so to speak. Just as my impotence had crept up on me at the start of my hormone treatment so it was that my returning libido was in no rush. However I'm pleased to report that after 6 months or so Anne and I were once again enjoying each other's "company" in the fullest sense of the phrase! My hot flushes, too, waned and life seemed to be getting back to something resembling normal. It was now summer of 2002. My PSA, at 0.1, was very encouraging and we had a family wedding ahead, which we were looking forward to with great excitement. Our son Evan married Christine in the August which involved us in a lot of planning and preparation but was a wonderful gathering of families and friends. In the spring we had decided that, following the wedding, Anne and I would have our "Retirement Holiday" – a trip to Egypt. One week cruising on the River Nile followed by a week in Luxor relaxing by the hotel pool. It was wonderful and I can honestly say that, blood tests aside, prostate cancer rarely crossed my mind for a good few months.

2003 passed with nothing more than my normal follow-up appointments with my Urologist, Mr Betts, and my Oncologist though my PSA began to suggest that my "little friend" was becoming active again! In the August it was 1.3 but by March 2004 it was 6.7! My rising PSA had been discussed with my Consultants and it was agreed that a value of 10 would be the trigger for me to resume hormone treatment. Happy Easter 2004! – My PSA hit 10 and I renewed my acquaintance with Zoladex. We always knew that this treatment holiday was a holiday, not the end of treatment (no matter how much we secretly hoped it would be). From the outset, if I'm honest with myself, I think I knew I could not be cured, despite the Radiologist in September 2001 saying that my radiotherapy was intended to be curative. My best hope has always been that I can be treated successfully, at least in the short to medium term and that is exactly how things are turning out.

My radiotherapy may not have cured me but then neither did it do me any serious long term damage. I have been lucky – no back passage problems and only minor collateral bladder consequences (more on that next time).

Here we go again!

So, with my PSA at 10, it was back to the 12 weekly injections and a re-run of the events of 3 years previously. We knew what to expect this time round - hot flushes, fatigue and of course impotence. Hey ho, life sucks and then you die!!! Well, no, not really. As I have aged (lucky me!) I have come to realise that nobody gets everything they want in this life. We all have to come to terms with accepting compromises. For Anne and me that boils down to accepting that the side effects of my treatment are the price we have to pay for me still being around and Anne avoiding premature widowhood. Even at this relatively early stage (2004 – 3 years dealing with cancer) my treatment had already enabled us to enjoy our son's wedding and see a part of the world we had both longed to visit. It had also enabled me to complete a number of long awaited DIY projects much to Anne's delight!!!

This second course of hormone treatment soon showed my PSA what's what! By late summer of 2004 it was back down to 1.0 and still falling. Follow-ups and injections continued for 12 months and my PSA bottomed out at 0.4. My symptoms were as before: hot flushes, though less frequently, fatigue but being retired I could rest when I needed to (subject as always to Anne's permission!) and of course impotence. In the autumn of 2005 we discussed a second treatment holiday with my Consultants. At the back of my mind was the comment by my Oncologist, in April 2001, that such holidays might extend the effective overall life of my hormone treatment. I must also admit that another break from the side effects would also be very welcome. We were again cautioned that there was no hard evidence to support any extended effective life and that my PSA was certainly likely to rise, given my past experience. Following my Zoladex injection in September 2005 we decided to have another break. My PSA was 0.4 when my second treatment holiday began.

Living the dream.
In the mid 80s we enjoyed our first family holiday in West Wales – Cardigan to be precise. I distinctly remember, on our very first visit, taking a walk on Patch beach on the Teifi estuary and Anne saying how much she would love to live in this area. 30 years ago the best we could manage was to holiday here each summer which we did for ten or twelve years. By then Evan and Sian were mid teens and beginning to tire of Gwbert but Anne and I continued to harbour the dream of moving to Cardigan.

In 2006 we finally managed to create reality out of the dream and settled in Llechryd. As our relocation to Wales plans evolved we were concerned about continuity of care/treatment. At that time we had no idea of the standards of cancer care provided in West Wales. What we did know was that I could not have received better care from the teams at the Christie Hospital in Manchester and Salford Royal (formerly Hope) Hospital in Salford. On this basis we asked my Oncologist and Mr Betts if they were prepared to continue seeing me in their clinics after we relocated to Cardigan. To our delight and continuing appreciation they both agreed to "keep me on". So, to this day, I return to Manchester twice a year for my follow-up appointments. In late September 2005 and coincident with the start of my second treatment holiday, we made the move to Llechryd and have never looked back.

As with my first treatment holiday it took 6 months or so for my side effects to pass, by which time my PSA had risen from the Sept '05 low of 0.4 to 6.1 in Aug '06. It was pretty clear to me that this holiday was not going to last long at all. Sure enough my next blood test in November 2006 put my PSA at 19.6!!! Within 10 days of this result I saw my Oncologist who immediately restarted my hormone treatment – no ifs or buts and certainly no resistance from me.

Diminishing Returns.
My first treatment holiday had lasted some 20 months giving me about 14 months free of side effects. The second holiday lasted less than 12 months and through more than half of that I continued to experience, albeit to lessening degrees, the full range of side effects. The body takes time to adjust. I'm not complaining: both my periods without side effects were a welcome relief. However my track record strongly suggested that my PSA would rise, certainly more quickly and possibly more steeply, with each treatment break. It

wasn't rocket science to understand and accept that my wellbeing demanded that I remained on continuous hormone treatment for as long as it proved effective.

So in December 2006 I began my third course of hormone treatment and this time it was clear it would be permanent, ongoing for the foreseeable future and with no more holidays. So what about those side effects, particularly my impotence? Anne and I were accepting the compromise to which I referred above but perhaps we owed it to each other to look into what might be available to rekindle our physical relationship…

(Thank you Phil for sharing your story, and Anne's, and giving us a further insight into the meaning of 'living with prostate cancer.')

Members Brian and Janet Slate have raised £670 for TWWPCaSG

Brian Slate handing over the cheque to Chair Ken Jones at our April pub lunch.

Brian and his wife Janet raised the funds by foregoing gifts for their recent golden wedding. Our thanks go to them both for such a generous gesture.

The West Wales Prostate Cancer Support Group would like to thank all members who make donations to enable us to carry out our aims and to help fund prostate cancer research. We try to ensure that each donation is acknowledged. However we do have a small number of members who give regularly by direct debit. We extend a big THANK YOU to those who choose to donate in this way.

Alun's Voyage, month 63.

First, a reminder – I am 65 and was diagnosed with advanced prostate cancer over 5 years ago. I have been on Zoladex hormone treatment ever since and have received both chemotherapy and radiotherapy.

I started Enzalutamide 18 months ago when my PSA was 100. Prednisolone was added to my prescription in November 2015 and my PSA is now 23, this compares with 21 reported in the last issue of the Newsletter.

I am in remarkably good health, just get tired quickly. This may be caused by my age, the medication or the cancer. I consider myself to be very fortunate.

My excellent GP surgery has just got better! I can now:

- order my repeat prescription on line;
- ask my GP, a nurse or administrator a question on line, with a response promised within a working day;
- see a list of my appointments;
- make an appointment on line (although this facility is limited at present).

This new service is a significant help to me as I don't have to wait for the surgery to be open, and must save the surgery time since un-necessary appointments may be avoided and staff need not be interrupted to answer the phone. Thank you to my surgery and NHS Wales!
(Alun, we wish you well and thank you for your update. Improvements to your GP Practice are a real step forward. PB)

Understanding Chemotherapy;
Macmillan Cancer Support.
Our Hywel Dda UHB and ABMUHB Hospitals have Macmillan information stands and either have a Macmillan Information Officer full time or share with another hospital. The information stand at Glangwili is in the Outpatient Foyer. It was here that I picked up a copy of Understanding Chemotherapy; a practical guide to tests and treatment.

It is a weighty booklet, but designed to be easily read. It is not Prostate Cancer specific but is a mine of information on all chemotherapy matters. It begins with an easy to understand explanation - What is cancer? It goes on to describe the nature and function of the lymphatic system which helps to protect us from infection and disease.

Following is a simple description of chemotherapy, how this therapy works and the side effects of treatment and the circumstances in which this treatment is prescribed. A meatier section follows expanding on the subjects touched upon in the introduction. This has information on preparing for chemotherapy, where and how chemotherapy is given and different ways of administering chemotherapy drugs. The booklet explains how to contact your hospital if you have a temperature, feel unwell or need advice on side effects during or after treatment. It gives advice on contacting the hospital 'out of hours' and the importance of keeping hospital numbers to hand. The final pages of the booklet are devoted to keeping a record of drugs, doses, when to take medication, special instructions and possible side effects. Here you will find space for contact details. There is also a page of useful questions to ask your nurse or doctor.

A significant section of the booklet is devoted to possible side effects, changes to treatment plans, the effect of chemotherapy on sex life and fertility and late effects of chemotherapy drugs. The booklet is full of useful hints on how to mitigate some of the side effects. How your diagnosis or treatment can affect holidays and travel insurance is not ignored nor are ways of coping if you feel anxious or depressed. It recommends the keeping of a diary; always a good idea if you are undergoing diagnosis or treatment. There is a section on self-help and recovery and, typical of Macmillan not to have missed anything, a section on work and employment rights, financial help and benefits.
If chemotherapy becomes part of your treatment plan then this book is full of useful information and sound advice. You can get your own copy by ringing Macmillan on 0808 808 0000. PB

Abiraterone Update.
Several members made contact in late march after reading that NICE has approved Abiraterone for use in England at an earlier stage of treatment. On hearing this I contacted the All Wales Medicines Strategy Group (AWMSG) to see if and

when they would add their seal of approval. They responded that, "As soon as NICE publish its final guidance, then this will apply to patients in Wales. This happened on 27 April 2016 putting Abiraterone 'on the same footing' as Enzalutamide.

Referred to with enthusiasm by Prof. Howard Kynaston at our 2015 AGM as 'Super Hormone Therapies,' Abiraterone and Enzalutamide are now available before and in order to postpone chemotherapy To date, two of our members have been prescribed Enzalutamide in a different context i.e. after chemotherapy. The availability of these two drugs for use when more conventional hormone therapy has failed is a welcome step forward. Both have the capacity to extend life and the quality of life. They are described as well tolerated (not too many side effects). They don't work for everyone, but that goes for all treatments.

Radiotherapy Update.

External Beam Radiotherapy and open surgery were the two options available to me in 2007. My research discovered two types, namely 3D conformal radiotherapy (3D-CRT) available at Singleton Hospital or intensity modulated radiotherapy (IMRT), available in Cardiff. The latter permits a variable dose of treatment to different areas and a lower risk of side effects. For this reason I determined to choose IMRT of the radiotherapy options but didn't know how successful an application to a different NHS Trust would be. In the end I came out in favour of surgery going against the advice given to me by the Lead Urology Clinician at the time. I have no regrets. I am also delighted that for those patients with localised cancer the choices are far greater than on offer to me in 2007.

I was pleased to report in the March Newsletter that IMRT technology is in full use at Singleton Hospital. The following month the Western Mail published a useful article on this in its health pages celebrating Singleton's success in this field. Clinical Oncology Lead Dr Delia Pudney used the analogy *"IMRT is to radiotherapy what the smart phone is to the mobile phone."* Dr Simon Ryde, Director of Medical Physics and Clinical Engineering said *"The Implementation Team has risen to the Challenge (of this technology) and we can now offer the benefits of IMRT to several hundred patients a year and treat a range of different cancers. Singleton Hospital achieved a remarkable 68% of radiotherapy patients being treated with IMRT against the national target of 24%. This places Singleton in the top five of UK radiotherapy centres."*

The ABMUHB Cancer Lead, Dr Martin Rolles, reported that *"The pace of radiotherapy technology development in improving cancer treatments in the last 10 years has been breathtaking and shows no sign of slowing."* However just as Singleton 'plays catch-up' I discover that Velindre Cancer Hospital in Cardiff is forging ahead and is in the middle of an ambitious programme of implementing several advanced radiotherapy techniques aimed also at increasing cure rates and reducing side effects. Of these **Stereotactic Radiotherapy** or Stereotactic Ablative Body Radiotherapy (SABR) is of special interest. Sometimes referred to as Cyberknife, the therapy is delivered in 3-7 treatments compared to 4-7 weeks of 'standard radiotherapy.' Velindre Hospital reports that, in some instances, it allows them to treat patients who could not have been treated with conventional radiotherapy.

Of particular interest is the news that Velindre has joined the PACE Trial and will be comparing results achieved with SABR against results achieved with standard radiotherapy. This is part of a wider trial coordinated by the Royal Marsden Hospital, London. (Velindre also reports that they are leading the development of a trial comparing the combination of MRI-guided implanted radiotherapy (brachytherapy) with external beam radiotherapy in more advanced cases). Patients with an interest in receiving stereotactic radiotherapy need to contact their consultant. Please note, a successful application doesn't guarantee Cyberknife therapy but offers a 50:50 chance that you will receive either this therapy or standard radiotherapy. The treatment is described in more detail below with the permission of and thanks to the Birmingham Prostate Clinic which also has Cyberknife technology.

Stereotactic or 'Cyberknife' Radiotherapy.

The Cyberknife is a type of radiotherapy which is ground-breaking in terms of the treatment programme. By delivering a much higher dose, using highly accurate technology, the Cyberknife reduces the number of treatment sessions required from 37 down to just five. There is no knife, no incisions and it is not a form of surgery.

The Cyberknife system is composed of several parts – treatment is delivered by a linear accelerator (Linac). The Linac is mounted on a robotic arm, which is able to move freely around the patient and deliver treatment from all angles. The patient lies on a couch which itself can be programmed and adjusted to allow the beams to reach the tumour from many angles and in an optimal way. The system also includes two x-ray machines located above the patient. These machines take images of the patient every 15 seconds and by doing so, can detect tiny movements. This is very important for prostate cancer patients, because the prostate itself can move, even though this may not be evident externally. If movement exceeds tiny margins, the robot and Linac automatically stops and treatment is re-started to exactly match the changed location of the prostate.

What is different about the Cyberknife? The key difference is the degree of accuracy achieved by the Cyberknife, as a result of x-rays being taken every 15 seconds. For prostate cancer patients, this is important because the prostate moves internally, even when the patient remains absolutely still. "The imaging we have from treatment so far has shown exactly how much the prostate can move without any external signs of movement, such as when gas passes through the rectum or as the bladder fills," says Dr. El-Modir. When using traditional radiotherapy (even the most advanced Linac machines), oncologists plan treatments using margins of 5–15mm, to allow for natural movement and slight inaccuracy. The margins with Cyberknife are much smaller: just 0–2mm. Because of this confidence in accuracy the Cyberknife can safely deliver much higher doses of radiotherapy in each session. This very high dose, delivered with such precision, is known medically as stereotactic therapy. With the Cyberknife the number of treatment sessions is just five, compared with 37 required for standard prostate cancer radiotherapy. Who is suitable for treatment with the Cyberknife? Cyberknife is suitable for the following patients with prostate cancer: Localised prostate cancer (T1 or T2). Gleason score up to 7 and PSA less than 20. No severe urinary symptoms or previous TURP (you will need to be able to manage without going to the toilet for 30 minutes to one hour during treatment). Cyberknife is not suitable if you have artificial hips on both sides, but may be possible if on one side only. Nor is it suitable if you have any medical condition or an implant that prohibits having MRI scans.

What does Cyberknife treatment involve for a patient? The first step is to implant gold markers, known as Fiducial Markers, into your prostate. These markers are made of gold and are the size of a grain of rice. They are implanted using a needle under ultrasound guidance via the perineum or rectum. You may experience a little discomfort, but this is normally mild. There follows a wait of seven to ten days for any minor swelling to settle down and any movement to settle. In pre-treatment planning, before your treatment, you will have CT and MRI scans. CT scans are always used for radiotherapy planning and this is combined with MRI, because MRI provides a better definition of the outline of the prostate. The two are then fused together, along with the location of the markers which have been implanted into your prostate. The markers work on the same principle as the 'lock on' process used by airline pilots to ensure they are following a route. X-rays taken every 15 seconds during treatment will check whether the actual location of the gold markers matches their location in your pre-treatment treatment mapping. So any changes, even very small ones, are quickly identified and if there is movement the robot will stop treatment and correct for the movement.

The treatment; some patients have their five sessions within one week, others on alternative days across two weeks. Each session takes 30 minutes to an hour. Patients lie on the couch while the robotic arm moves around them, delivering treatment. You are not enclosed within the machine, as is necessary during an MRI scan, so there is no difficulty with claustrophobia. However, staff will help the patient to prepare for the experience of the robot moving around them, often getting quite close. The advantage of the constant process of imaging during treatment is that if you do move, or need to take a short break, this can be accommodated.

How effective is the Cyberknife and what are the possible side-effects and complications? Several clinical studies have shown that Cyberknife is as effective as standard radiotherapy. Cyberknife is one of the recommended treatment options for the treatment of localised prostate cancer by the American Society of Radiation Oncology (ASTRO). Possible side effects during treatment are mild to moderate urinary problems and mild fatigue for 1–2 months; about 1% of patients need catheterization for urinary retention. Patients resume normal activity immediately after treatment. Possible long-term side effects; despite receiving high doses of radiation, long-term urinary effects are not common and rectal injury is rare; 20–30% patients develop erectile dysfunction.

See more at:
Birmingham Prostate Clinic.
Website:
www.birminghamprostateclinic.co.uk

HIFU Update.

HIFU or High Intensity Focused Ultrasound is a relatively new treatment for men with localised prostate cancer. It can be used as a Primary Treatment or Second Line or Salvage treatment. It has been embraced by some clinicians, but treated with great caution by others. In Wales it was available at Wrexham Maelor Hospital as a primary treatment under trial conditions and is now available, at the same hospital, as a salvage treatment for patients with localised cancer who have been failed by external beam radiotherapy, brachytherapy or first treatment HIFU.

Patients looking at HIFU as a primary treatment need to undergo an MRI scan and a template biopsy prior to treatment. The results will indicate if the patient is a suitable candidate for HIFU and will be used to help direct the ultrasound beam to those areas of the prostate where the cancer is most aggressive. Slower growing cancers are not usually treated. The aim: to treat only those areas of greatest concern and therefore avoid unnecessary collateral damage.

So what is new? NHS Consultants at St. Mary's Hospital (Imperial College Healthcare NHS Trust), London are conducting a trial using a **new machine** which enables them to use MRI technology to guide the beam **during the procedure itself**. Clinicians hope this will lead to even greater accuracy; a greater success rate with fewer side effects. St. Mary's is currently recruiting patients to this trial now (Ref. PCa006 Study. MRI Guided HIFU). I have been in touch with Ramandeep Kaur, Research Nurse at Imperial College Healthcare NHS Trust. Raman *says "This study is actively recruiting and is an NHS funded study i.e. funded for everyone."* The advice given is to seek the help of your Consultant with the referral process. The criteria for referral are strict. As with standard HIFU participants must have an approved MRI and template biopsy and a Gleason score of seven (3+4 or 4+3) and the cancer should be confined to one side of the prostate. To be considered for this trial, St Mary's will need access to your diagnostic test results. (I am happy to pass the detailed criteria to any interested member. For Clinicians, the Fax referral number at the hospital is 0203 313 0161).

Cabazitaxel.

Not so much an update is the news that chemotherapy drug **Cabazitaxel** has now been approved by NICE for use in England and Wales. This drug has a chequered history having been refused some years ago by NICE. It then became available as part of the Cancer Drugs Fund (England only) but was briefly removed before being returned on appeal by the Manufacturer. It has now been reappraised in the light of new data and a reduced price from the maker. Prostate Cancer UK says *"Nice has shown flexibility in its procedures in order to make this decision. This flexibility has been crucial and we hope that it is a sign of what we can expect to see under the new appraisal system for cancer treatments due to start in July 2016."* The drug should become routinely available in 3 months time for patients with advanced cancer. This story slipped through my radar and I am grateful to Alun who writes his quarterly diary in the Newsletter for bringing it to my attention.

Pub lunch reminder.
Our next pub lunches are:
Monday 01 August at 12.00p.m.
Nant-y-Ffin Hotel, Llandissilio,
Clunderwen, Pembs,
SA66 7SU***
Monday 03 October at 12.00p.m.
Red Lion, Sway Road, Morriston,
Swansea, SA6 6JA

*****This represents a change to our provisional programme published in our 'Pull out & Keep' sheet from our December 2015 Newsletter**

(Many of you have given us your e-mail contact addresses over the years. We are then able to send pub lunch reminders and details of research questionnaires etc. I use 'Blind Carbon Copy' (BCC) to send these e-mails to maintain your confidentiality. Some of these come back undelivered, possibly because you have subsequently changed your e-mail address. If you haven't had an e-mail pub lunch reminder recently and have changed your e-mail address but not notified us, please let me have your new e-mail address. If you have never given us your e-mail address but would like to receive e-mails please let us know.)
A short report on our 8th AGM will be included in the September Newsletter.

Best Wishes from Phil Burr on behalf
of the Chair and Trustees of
TWWPCaSG.

Phil

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