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

NEWSLETTER
DECEMBER 2016

Dear Members.

Seasonal greetings to you all and thank you for indicating that you wish to remain members of TWWPCaSG. Following the Audit our membership has fallen. A fall was expected; some former members have moved out of the area or are trying to leave their diagnosis behind and move forward. The number may well increase in the next month or so when we add members who wish to remain but omitted to reply to our Membership Audit.

Reminder
Our next Pub Lunch is on
Monday 05 December at 12.00p.m. at the Rose & Crown, Lammas Street, Carmarthen, SA31 3AE

If you wish to join us please contact Gill Lewins, Tel. 01348 873596, or E-mail cglewins@btinternet.com circa. 2 weeks before the event. This is our first lunch after our Membership Audit. This may affect numbers. The Rose and Crown have indicated a **maximum of 50** therefore it is essential that you book in advance.

A new blood test.

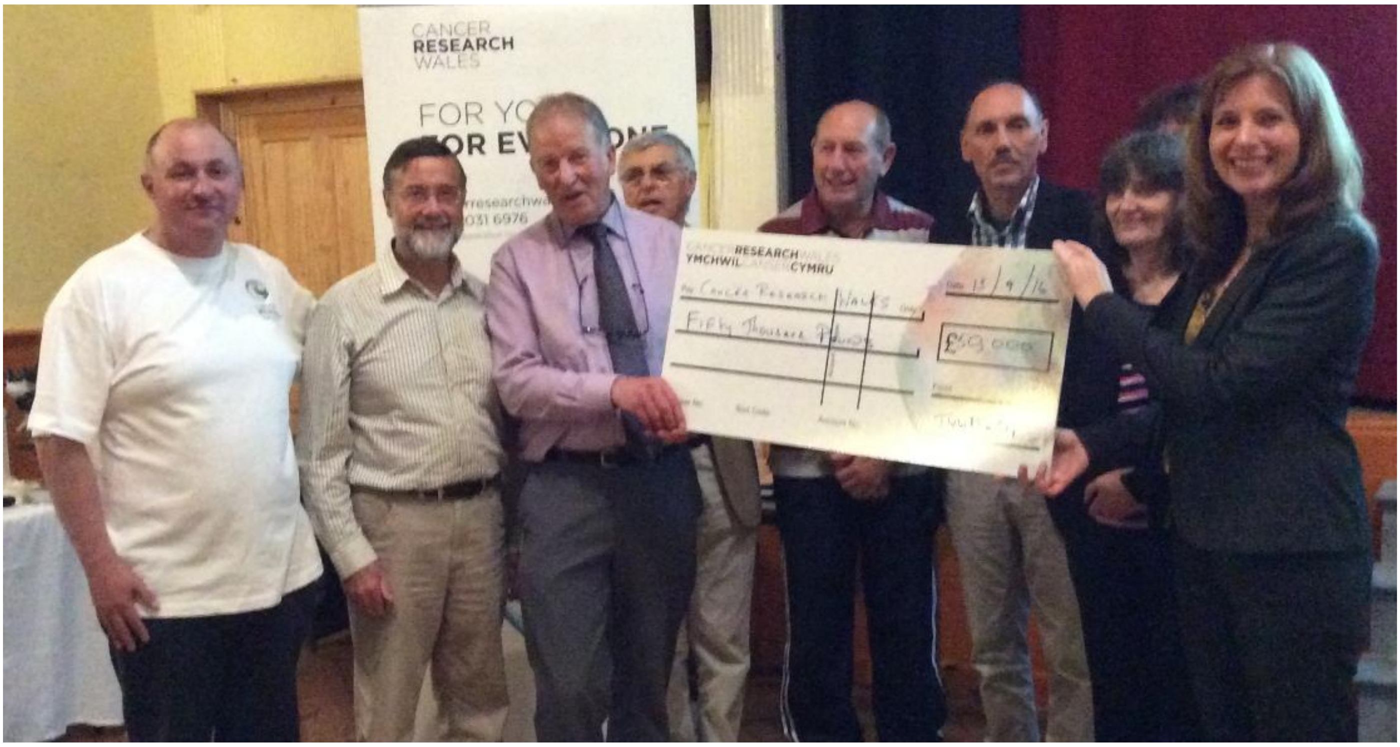
We are all acutely aware of the need to find a new and better blood test or perhaps a urine test which will diagnose prostate cancer. Ideally this should distinguish between the aggressive cancers which need urgent treatment and the less aggressive which can be monitored.

At the beginning of the month details of a new promising blood test were reported in the media. Scientists from Queen Mary's Barts Cancer Institute (University of London) have conducted a 'preliminary study' of just 80 blood samples taken from men with prostate cancer. Tests on these samples have looked at their genetic make-up by observing minute strands of DNA. The information provided by detailed analysis could enable scientists to closely monitor tumours and observe how cancers mutate and evolve, and gain an insight into how cancer moves around our bodies. Medication could be switched to a more effective drug if the cancer becomes more resistant to current treatment.

At the moment Active Surveillance may in fact be exactly the right treatment choice for some thus avoiding the side effects of invasive treatment. However our current tests and scans cannot guarantee this. A more accurate test could take away the element of chance and introduce more certainty to the process of treatment choice. Leading the study, which now needs to be scaled up, is Dr. Yong-Jie Lu.

Dr Ian Frame (PCUK) observed, *"This research adds to our understanding of what makes cancer cells tick but it's incredibly early days. A blood test which could detect an aggressive cancer and how best to treat it would be the ultimate goal, but a lot more research is needed before we get there."*

Group Donation to Cancer Research Wales. *A report & photograph by David Goddard.*



Cheque presentation to CRW

Pictured at the presentation are from L to R: Dr Lee Campbell (Science Projects and Research Communications Manager – CRW), David Goddard, Phil Burr, Iori Rees, Colin Adams, Martin Peake, Di Bell, (David Parmar-Phillips - hiding!) [all TWWPCaSG] and Liz Andrews (Charity Director – CRW).

A £50,000 cheque from The West Wales Prostate Cancer Support Group was presented to Cancer Research Wales (CRW) at their Science Café evening on the 13th September 2016 held in the Victoria Hall, Lampeter. It was very appropriate that our cheque was for £50K because CRW are celebrating their 50th anniversary and they are funding 50 projects this year. We also learnt that 50 people per day are diagnosed with some form of cancer in Wales. Cancer Research Wales had a display of their current research. There were four talks - an Introduction from Liz Andrews, an Overview from Lee Campbell then two researchers talked about their own projects.

HOW IS OUR RESEACH PROJECT GOING?

Members may have been wondering what has become of the Cancer Research Wales early diagnosis project jointly funded by CRW and TWWPCaSG (see above presentation).

Well, all Cancer Research Wales work must be assessed by outside referees before a research project can be agreed. TWWPCaSG also needs to be certain that the donations from its members, from members of the public and from donor organisations is well spent. The

CRW appraisal takes time as we have discovered and observations from referees must be taken into account. This has now happened enabling the project to move forward.

Professor Richard Neale, Researcher and Primary Care Specialist, now relocated to Derby, will retain an overview of the project, but its day to day running will be supervised by Prof. Clare Wilkinson at Bangor. The next step is to appoint the person who will be funded by the joint grant and until this happens an exact starting date cannot be arranged.

The project will run for two years. I have gone from elation when our offer to support this project to the tune of £50,000 was agreed by CRW, to despair when the independent referees couldn't agree the detail, to elation again now that the project has been fully approved. This is wonderful news. Dr Lee Campbell from CRW has agreed to update Members in the March Newsletter. *Phil*

Phil's Story: Instalment No 5.
Oh for a full night's sleep!

I can recall, with the fondest of memories, those halcyon days (nights!) when I would put my head on the pillow and not stir for 7 hours. What I would give for a full night's sleep now! For the past few years I have become increasingly aware that less than 3 night-time trips to the loo represents a good night for me. This issue has been discussed at follow-up appointments and the view seems to be that in all likelihood my bladder has suffered radio therapy "collateral" damage. It has lost its compliance and no longer has the flexibility it once had – hence it's distinct lack of capacity. This together with the natural aging process and the commonly experienced increase in renal function when resting at night results in disturbed sleep, smaller volumes voided and increased frequency of voiding. Yet another compromise to be accepted!

Over the last few years I have carried out a number of periods of detailed monitoring of both fluid consumption and voided volumes, including times. All this suggests that there is little correlation between what/how much I drink and my night time voiding. Urology/Cancer Nurse Specialists have offered advice: drink little after 19:00hrs, no fizzy drinks in the evening, avoid alcohol (that's the hardest!!!), avoid caffeine etc. None of this seems to have any consistent benefit. My trials with "DIY" bladder training have not helped matters either. I have tried "holding on" and suffered a number of "close shaves" and a couple of actual "mishaps" as a result and "holding on" at night is simply not an option! I have also tried various medications including diuretics and one specifically aimed at easing enlarged prostate symptoms with, again, little consistent improvement/benefit.

It seems I am destined to sleep for an average of 2 hours at a time with the occasional 3 hour block if I'm lucky. The net result is of course that I am tired most of the time. Tired when I go to bed at night and still tired when I get up, 8 hrs later, for breakfast. My tiredness is compounded by my hormone treatment which has fatigue as a well documented side effect. The monitoring I carry out is now suggesting that the situation is worsening. Recently a course of action has been suggested that might relieve my nocturia - a transurethral resection of the prostate (TURP). I am thinking about this and will discuss it further at my next follow-up in spring 2017. Despite these nocturnal disturbances I still regard myself as a lucky man – I have always acknowledged this. I know there are many PCa patients out there dealing with far worse than disturbed sleep.

Keep carrying on.

I continue to attend Mr Betts' Urology Clinic at Salford Royal Hospital (SRH) though I do not often see the man himself. That's OK – I am, after all, in a near "steady state" situation with a PSA rising only slowly. Mr Betts' time is better spent on patients with greater needs than me. In 2010 the Oncologist at The Christie in whose care I had been since 2001 moved to a teaching role and was replaced by Consultant Clinical Oncologist, Dr Anna Tran. Coincident with this change was a move by The

Christie to establish Follow-up Clinics at other hospitals in the Greater Manchester area. Fortunately for me one such clinic was set up at SRH so I have been attending Dr Tran's Clinic there since 2010.

It is interesting to note that over the past 15 years I have been under the care of only 3 Consultants – 2 Oncologists and 1 Urologist. Of course I do not always see the Consultant at follow-ups but I know they are usually somewhere in the Clinic if I have a specific need to see them. This continuity of care has been a great comfort to Anne and me over the years and it really saddens me to hear of Group Members who have not enjoyed the same continuity in West Wales.

Don't panic Mr Mainwaring!

My PSA is currently (Oct '16) 14.3 reflecting a 3 point rise in only 6 months. This is disappointing. It is the largest 6 month increase since this (my 3rd) round of hormone treatment began in 2006 and obviously indicates that the treatment is losing its effectiveness (as indeed I was told it would do back in 2001). Looking on the brighter side, 14.3 reflects a long term (9 years) rate of increase of only 1.3 units per year and my "time to double" is still about 3 years. Never-the-less, at my SRH follow-up appointment in early November, in the light of this 3 point rise I was put on 4 monthly PSA tests and follow-ups. Watch this space… It is likely that in the not too distant future further staging scans and additional treatment will be required. Until then I'll continue enjoying life but when the time for intervention eventually comes, I'll do what I have done for the past 15 years – trust my Doctors!!!

So that's my story - so far… I hope, indeed believe, there is still a long way to go. I was caught "in the nick of time". My treatment has been more successful than I (and I suspect everyone else including my Consultants) had ever hoped. My care has been second to none, for which I must here record my sincere appreciation: I could not have wished for better treatment from all the staff at Salford Royal and The Christie Hospitals. True, for the past 15 years I've had to deal with issues that I'd hoped would never arise or at least not arise so early in my lifetime. On the other hand I have enjoyed the ongoing love and support of my wife Anne and children Evan and Sian.

Post Script.

Throughout *My Story* I have tried to include only those dates, facts and figures that are essential to the sense of the text. However I know that my PSA record has been a point of interest in conversations with Group Members (and others) over the years. In the light of this and with Phil Burr's permission, I hope to include a copy of my 15 year PSA record chart in the next news letter. Hopefully that issue will also include a brief account of those 15 years from Anne's perspective.

Thank you Phil for this 'almost' final instalment.

Representatives (Clinicians) from the Academy of Medical Royal Colleges (AOMRC) air their views on unnecessary tests and treatments.

In May 2015 the AOMRC launched 'Choosing Wisely,' an initiative to promote conversations between doctors and patients about the value to patients of a range of tests and treatments. It would have been hard to miss news of this initiative which was featured in the press and on television at the end of October. The Academy has published a list of treatments, procedures and tests which it claims should be reconsidered, being of little or no benefit to the patient.

I found the best report on this story was by Natasha Clark, former Times journalist. She describes herself as a political journalist and currently works for City A.M. Ltd, London's first free daily business newspaper. Natasha reported that the Academy will eventually publish a list of up to 150 procedures, but she claims to have been sent only 38 saying, "*We have 'reached out' to the Academy for clarification.*"

I too 'reached out' to the Academy, having been alarmed by the press coverage. I sought access to the Academy's own release to the press, but was simply referred to the Academy website which I found hard work; no easy to follow list here! My phone calls and e-mails did discover a Welsh Academy with identical aims and almost identical websites yet claiming to be independent. I did establish that the Welsh Academy launched its own proposals last year. This 'sister' organisation is contenting itself at the moment with examining 20 procedures and releasing its recommendations in stages.

AOMRC describes the aim of its recent initiative as the promotion of conversations between doctors and patients i.e. to help patients and clinicians choose care that is:
Supported by evidence
Not duplicative of other tests and procedures already received
Free from harm
Truly necessary
Consistent with patients' values

All are very laudable. The idea of a full and proper conversation between patient and clinician is excellent and surely goes without saying. However on purely practical considerations the usual 10 minute appointment precludes lengthy debate.

I have selected four procedures of consequence to men with prostate cancer or awaiting diagnosis which AOMRC hints may be of no benefit.

1."Back pain is not likely to need an x-ray."
We know that metastatic PCa in the bone can cause otherwise unexplained lower back pain and this must be thoroughly investigated. For some men this may be their first indication of advanced prostate cancer. I am aware of a number of men who have been given painkillers without proper investigation of the real cause of their pain.

2."Chemotherapy in the final months of life for cancer patients can do more harm than good."
Chemotherapy is offered to prostate cancer patients when hormone therapy is failing. This treatment is now available at an earlier stage of advanced cancer and buys time. The side effects can be more than a little unpleasant and will affect patients differently. Sometimes chemotherapy opens the door to other treatments, but thankfully the 'super-hormone' therapy drugs Abiraterone and Enzalutamide have recently become available to men **before** chemotherapy. Some patients can struggle to complete a full course of chemotherapy due to adverse side effects but the option to try chemotherapy must remain. No patient takes this step without listening to his Consultant and hopefully family and friends. The desire to extend life can be very strong. One of our members passed away recently having chosen not to try chemotherapy. I admire his decision. Both options must remain.

3."If you are receiving palliative chemotherapy or radiotherapy, post-treatment CT scans and MRI scans are unlikely to be of benefit."
We know these scans are used by clinicians under these circumstances to inform and advise both themselves and patients. I am unsure how widely they are used.

4."Unless you are at risk of prostate cancer due to family history, screening does not lead to a longer life."
I will direct my remarks to the PSA test, below.
Statement from Royal Medical Colleges on value of PSA test.
"Unless you are at risk of prostate cancer because of race or family history, screening for a specific protein produced by the prostate (Prostate Specific Antigen-PSA) does not lead to a longer life.
There is a misperception that early testing of PSA is of benefit in detecting prostate cancer in its early stages. There are important trade-offs between the potential benefits and harms involved with either screening or not screening for prostate cancer and a lack of evidence on screening outcomes. Potential benefits include

earlier diagnosis of prostate cancer but potential harms include additional hospital visits, tests, anxiety and over diagnosis (the identification of prostate cancer that would never have caused symptoms in the patient's lifetime, leading to unnecessary treatment and associated adverse effects). It is particularly important that patients make informed decisions about the value of having the test."

I did advise AOMRC that there is no screening for prostate cancer! It is, of course, referring to the PSA test as a diagnostic tool. (PSA testing to monitor patients after treatment is a very accurate tool and there is no suggestion from AOMRC that this is unnecessary or harmful. In this respect I think the Academy failed to make this clear and press coverage was unduly alarming). The Academy maintains that the PSA test as a diagnostic tool does not lead to a longer life. I believe that recent data does suggest that if PSA screening was introduced, thousands of men would need to be tested to save just a few lives. However, we should be considering not just saving lives but extending lives and improving the quality of those lives.

We know that PCa often has no symptoms. Without the option of a PSA test, cancer will continue to be diagnosed too late for curative treatment. I was alarmed by the AOMRC's suggestion that the PSA test does not extend lives and I am pleased to say that Prof. Chris Eden, Consultant Urologist, Royal Surrey County Hospital, agrees. In the Mail, he commented, *"There is no scientific evidence to back this up. In fact the opposite is true."* Many patients would agree with Prof. Eden!

How did the Academy arrive at its list of 'dubious' procedures?

AOMRC says *"All Colleges and Faculties were asked to identify five tests or procedures commonly used in their speciality, whose necessity should be questioned and therefore discussed with patients. These will form the core recommendations of the Choosing Wisely programme."..."To facilitate a Choosing Wisely conversation around the recommendations, shared decision making must be in place. We are currently developing tools, decision aids and patient information to help support conversations between doctors and patients around each of the recommendations."*

When I questioned AOMRC further I learned that of the 22 Colleges which were invited to take part in this exercise, only 11 did! Assuming each college came up with a different list of 5 procedures, then the Academy would have a total of 55 to consider before drawing up their list. It is highly likely that some of these procedures will have been duplicated and it is perfectly possible that only one College, for example, supported the inclusion of unnecessary/harmful PSA tests as a diagnostic tool. This is hardly representative of clinical opinion, not very scientific and may well represent a minority view. We know that a few clinicians do disapprove of the PSA test, but there already is a well established 'Prostate Cancer Risk Management Programme' (PCRMP) which entitles 'concerned men' without symptoms to have a PSA test from age 50 after a discussion of the pros and cons. There is therefore no need for diagnostic PSA testing to be on the AOMRC list at all; 'Choosing Wisely' already happens. This ground is already covered! What would be useful would be for the Academy to ensure that GPs are aware of the PCRMP. We still hear of GPs who refuse men a PSA test or discourage them from having one: hardly a proper discussion.

TWWPCaSG does write to all West and South West Wales GPs every two years to raise awareness of the Prostate Cancer Risk Management Programme and the right of men to have a PSA test. In 2012 we were successful in bringing Prostate Action, now part of Prostate Cancer UK to Carmarthen to run a 'Prostate Cancer Masterclass for Primary Care Professionals.' At the conclusion of this Masterclass, attendees, mostly GPs and Practice Nurses were very much pro PSA testing.

TWWPCaSG Chair Ken Jones has requested another 'Prostate Cancer Masterclass' again aimed at Primary Care Professionals. This is planned to take place in West Wales next

March. It will be jointly funded by our support group and Prostate Cancer UK.

My overall concern about the AOMRC 'Choosing Wisely' initiative is that it may have given men the impression that the PSA test either as a follow up test or diagnostic test won't be available in the future. This is not the case. PB.

Hywel Dda UHB Update.
TWWPCaSG has campaigned for over 6 years for all Prostate Cancer Patients to be given their next appointment as they leave clinic.

We were eventually offered this – and more - by the former Hywel Dda UHB CEO, Trevor Purt, with a promise that the change would be implemented over a period of 2 years. That period came to an end earlier this year. During this time we have drawn to the attention of the Health Board a number of cases where patients have clearly slipped off the radar or waited far too long for a follow up appointment.

On behalf of TWWPCaSG, Ken Jones our Chair and I have continued to campaign for a level playing field so that PCa patients are treated the same as other cancer patients e.g. oncology patients, breast cancer patients etc. The two of us have held a number of meetings with and written to the Health Board on this and on other issues. We have not given up!

Ken Jones and I together with New Trustee, Ken Davies, met the New Deputy CEO, Joe Teape, on 15 August at Bronglais Hospital to discuss the single issue of follow up appointments. We have since been assured that there is no reason why ***all cancer patients*** (incl. prostate) cannot be given their next appointment in outpatients before they leave clinic.

We have to accept that there are staffing shortages (particularly at Bronglais), therefore "ordinary" urology patients (i.e. non-cancer cases) are excluded from this promise.

The Health Board has undertaken to remind clinicians that they are to inform 'cancer monitoring' patients and nurses that a follow up appointment is required so that 'a do not cancel' can be placed on the system - this to be clearly conveyed to the nursing/reception staff for implementation.

(The above update came too late to be printed in the September Newsletter but was e-mailed to members.)

Please play your part and politely request your follow up appointment from your Nurse/Consultant and be sure not to leave without it. This should take a lot of worry out of booking your next follow up appointment.

Wales Cancer Delivery Plan.
Too late for this Newsletter, I understand that the Welsh Assembly Government will shortly publish its updated Cancer Delivery Plan. Meanwhile Macmillan Cancer Support has announced that it has invested £20,000,000 to provide cancer services in Wales. It aims to offer people with cancer and their loved ones the support they need during their treatment and afterwards in line with the Welsh Government's plan.

More than £4,000,000 will enable the appointment of Macmillan Clinical Nurse Specialists. Macmillan also plans to fund allied health professionals including physiotherapists and dieticians. Hywel Dda UHB has recently benefited from the appointment of two Macmillan Clinical Nurse Specialists. They are:

Lisa O'Malley CNS.
Lisa is one of two Macmillan Funded Urology Nurse Specialists recently appointed to the Hywel Dda UHB Urology Department.

Lisa introduces herself to our Readers:

Lisa O'Malley

"I have been in the NHS for twenty years. I had my first job in Prince Philip Hospital Theatres from being a student nurse at Morriston Hospital. It was my first nursing job interview; I was offered the job, and twenty years on I was still there! I experienced remarkable things, from major vascular procedures to all the urology procedures you can think of. I was very fortunate.

So why change you say, well, the NHS is an ever changing entity. So that means we as health care professionals should change with it and continue to develop and grow in the best interests of our patients. I look forward to developing my new role as the Macmillan Clinical Nurse Specialist in Urology and working closely with The West Wales Prostate Cancer Support Group, in providing the best possible outcomes for our prostate cancer patients.

In my spare time, I enjoy spending time with the family. I also have recently taken up Yoga and am thoroughly enjoying it, Namaste!" L.O.

Ceri Thomas CNS

The second Macmillan funded appointment is Ceri Thomas CNS.

Ceri introduces himself to our readers:

Ceri Thomas

"I have been qualified since 1995 and initially worked within two acute care areas: Intensive Care Units and (primarily) Accident & Emergency Departments. Prior to my children being born I started working in the Outpatients Department at Glangwili General Hospital. Here I often worked as the Lead Out-Patient Nurse within the Urology Clinic. It was from this experience I realised I had a great enthusiasm for Urology Care; therefore attaining a position as a Macmillan Clinical Nurse Specialist in Urology is literally a dream coming to fruition.

Similarly to my colleague Lisa O'Malley, I am looking forward to developing my new role with Macmillan and working closely with The West Wales Prostate Cancer Support Group and others, to provide patients with the best care and support possible.

I am married with three children and am a keen motorcyclist. I also enjoy exercising and going to the cinema." C.T.

I met Lisa recently when I delivered some TWWPCaSG leaflets to Derwen Ward, Glangwili Hospital and I have recently spoken to Ceri on the 'phone. I was impressed by their enthusiasm. We wish them well in their new appointments.

ABM UHB Follow-up Appointments.

We came to an arrangement with the Informatics Department (ABM UHB) several years ago for PCa patients attending follow-up clinics in Swansea, Neath Port Talbot and Bridgend. It was agreed that as they left clinic these patients would be given a target follow-up date with a promise that a final date, to be received later, would be within a week of that target. Much has happened at Morriston Hospital since then, including the opening of a new Outpatients Department. We would be interested to hear if the 'target date' letter is still being offered to patients there and at other ABM UHB Hospitals.

A message from Natalie Lloyd:

"Hi - I'm the Clinical Services Officer at Prostate Cancer UK and I just wanted to let you know we recently launched a translation service, so people affected by prostate cancer or prostate concerns can speak to our Specialist Nurses in their own language - including Welsh. The service can be accessed on 0800 074 8383 and callers should simply say, in English, the language they wish to use and they'll be connected with an interpreter.

You can find more information here: http://prostatecanceruk.org/get-support/our-specialist-nurses/specialist-nurse-telephone-translation-service.

It would be great if you could help us spread the word about this service to your network in some way please? If you need anything further, please get in touch with me directly at natalie.lloyd@prostatecanceruk.org. Many thanks." Consider it done Natalie! (PB).

Good news for men with advanced prostate cancer.

In September NICE recommended Radium-223. It was previously only available as a Cancer Drugs Fund treatment (England) for prostate cancer, not for routine NHS use.

More prostate cancer patients will receive Radium-223 after NICE (the National Institute for Health and Care Excellence) approved it for routine NHS use.

The NICE guidance is:-

"Radium-233 dichloride (Xofigo) is recommended as a possible treatment for hormone-relapsed prostate cancer in adults who:

*have bone metastases with symptoms but no other metastases **and***

have already had docetaxel (an anticancer drug)

or who cannot have docetaxel because it is not suitable for them".

Professor Carole Longson, Director of the Centre for Health Technology Evaluation at NICE, said: *"I am pleased we have been able to broaden our recommendations for radium-223. Patients with prostate cancer will surely benefit from this drug being available for routine NHS use. I hope we'll see more drugs like this move into routine NHS use after companies have been able to better demonstrate cost-effectiveness."*

The guidance was finalised in September and NHS organisations now have three months to make funding available for routine use. The Welsh Assembly Minister for Health and Social Services has issued directions to the NHS in Wales on implementing NICE technology appraisal guidance. When a NICE technology appraisal recommends the use of a drug or treatment, or other technology, the NHS in Wales must usually provide funding and resources for it within 3 months of the guidance being published.

Radium-223 is a mildly radioactive form of the metal radium which is taken up by bone to specifically target tumours there. It is given as an infusion into the bloodstream every month for up to six months. Radium-223 is the first alpha-particle emitting radioactive therapeutic agent recommended for use for the treatment (NHS) of adult men with metastatic hormone relapsed prostate cancer. Bone metastases are a significant cause of mortality in these patients and the availability of radium-223 on the NHS will enable doctors and physicians to better manage the disease.

Professor Paul Workman, Chief Executive of The Institute of Cancer Research (ICR), said: *"It is fantastic news that NICE has reversed its previous decision on Radium-223 so that men who are too frail to be given chemotherapy can now benefit from the treatment on the NHS in England and Wales. Today's (2nd September) announcement brings us in line with Scotland, where Radium-223 is already an option for men with advanced prostate cancer that has spread to the bone, and expands the still limited number of treatment options available to patients.*

This is an exciting and innovative example of a smarter, kinder treatment – specifically targeting bone metastasis and prolonging survival, while reducing the pain and discomfort brought about by bone tumours and improving quality of life." Report by David Goddard.

(Thank you David for your report. I have been keeping an eye on this story, following an enquiry from a member about 2 years ago. It really is excellent news that Radium-223 will soon be available more widely for men whose cancer has spread to the bone.)

Flu Inoculation Day 12th October 2016 at the Tysul Hall, Llandysul. Report by David Goddard.

David and Jeannie Goddard with Ken Jones on the right.

We had a stand at this event, kindly set up by Phil Burr, and "manned" by Jeannie and me for the morning session, Ken Jones and Di Bell for the afternoon. We were positioned by the door and lots of people stopped to chat and take information either on the way in or out and sometimes both (maybe those of the latter had had a chance to think about things whilst "recovering" from the flu jab). D.G.

Alun's Voyage. Month 69.

First, a reminder that I have advanced prostate cancer which has spread to the lymph nodes, I am very fortunate that it is not in the bones or organs.

I have now been on Enzalutamide for over 2 years resulting in my PSA falling from 100 to 18 and but it is now back up to 62.

I have had two sessions of radiotherapy and the need for these, together with my PSA results, indicate that Enzalutamide may have stopped working for me. My Consultant advises that I am "on the cusp" of deciding whether to continue with Enzalutamide.

The dilemma is that the next stage needs to be delayed as long as possible, but without the cancer spreading. Another CT scan will help to inform this decision, but my options are limited. I will then proceed on the next tack of my voyage into the unknown, which is likely to be Cabazitaxel chemotherapy.

I am in regular phone/email contact with my local Macmillan palliative care nurse. I have told her that there is no need to visit me again at present because my condition is stable.
Thanks Alun.

Triptorelin update

A few weeks ago the All Wales Medicine Strategy Group (AWMSG) informed TWWPCaSG that it would be appraising the hormone therapy drug, Triptorelin (Decapeptyl). They invited patients and patient representatives for their comments. The drug works in much the same way as Zoladex and Prostap by reducing testosterone levels, thereby stopping the cancer from growing. AWMSG is keen to listen to the opinion of patients when medicines are reviewed, and I have always felt it important that organisations like TWWPCaSG should respond.

Triptorelin is manufactured by the pharmaceutical company IPSEN, is NICE approved and already used in England. My first task was to e-mail members inviting individual responses and to e-mail Prostate Cancer UK (PCUK) in London urging them also to respond. Regrettably PCUK, Cardiff closed its Cardiff office recently and has retreated to London. I am determined that given its UK title, it must still keep abreast of what is happening in Wales and work hard for men with prostate cancer on this side of the border. I also informed the Federation of Prostate Cancer Support Groups (Tackle), hoping that that organisation would also respond to the AWMSG invitation.

My next task was to approach IPSEN for more information and trawl the internet looking for reliable sources for the same purpose.

Macmillan, on its website offered:
"Triptorelin can be used on its own or with other types of treatment. It may be used before or after surgery or radiotherapy. It may also be used to control prostate cancer that has spread to other parts of the body (advanced or metastatic prostate cancer). Triptorelin can be given for months or years depending on your situation. Some men with advanced prostate cancer may have intermittent therapy with Triptorelin. This involves having treatment for a few months until the cancer is at a very low level. You can then have a break from treatment and restart Triptorelin when it is needed."

Triptorelin is thus very similar to other hormone therapy drugs and is administered in exactly the same way, by injection into the muscle. Its side effects are very similar too.

At the moment patients in Wales are more likely to be prescribed Zoladex or Prostap. Here in West Wales Zoladex was widely used until a few years ago. Prostap then was introduced on grounds of cost, though I still hear of some new patients being prescribed Zoladex. A small number of Zoladex patients found that Prostap did not suit them and requested a return to Zoladex. Some patients were granted their request.

If Triptorelin is approved by the AWMSG, and IPSEN makes it more cost effective then history might repeat itself and Health Boards, eager to save money might encourage the prescription of this 'new to Wales' drug.

In its favour, Triptorelin can be prescribed in one, three and six month intervals. It could be to the advantage of some men with a stable PSA score to visit their GP every six months (I don't think this is an option with Prostap or Zoladex), but for men with rising PSA scores who may need a change of medication or for men choosing intermittent hormone therapy the six month option would seem inappropriate.

I would like Triptorelin to be approved on the grounds that an additional drug, even if similar to existing drugs, would give more options to both patients and clinicians. Medication which suits one patient may not suit another. A patient may tolerate one drug but not another.

Many patients are not given the Patient Information Leaflet (PIL) when the injection of HT is administered; Practice Nurses often discard this. I was impressed by the IPSEN PIL; the guide far exceeds the normal leaflet. Instead, it takes the form of a substantial patient-friendly booklet with space for information on the nature of the drug, how it is used, and its side effects. It has useful tips on leading an active life and on diet and plenty of space for patient records.

I did liaise with Phillip Anderson from PCUK, London who put together the Prostate Cancer UK response. Our responses were not dissimilar though PCUK seemed to think that the 6 month injection was more significant. It has always been my personal view that patients new to hormone therapy should first be offered a single monthly injection in case of adverse reaction.

It will take a while for the AWMSG to compete its appraisal. PB

Reminder.

We are currently able to offer grants to members to help with transport needs (for journeys outside the remit of Hospital Transport) or, for example, complementary therapy or counselling. The offer comes with a cap of £250.00. If you think such a grant may help you, please contact Andrea Prince, Treasurer

(Contact details can be found on the pull-out Information/Contacts Sheet accompanying this Newsletter).

Lymphoedema Update Contact details:
Gill Shepherd Tel 10974 202897
E-mail lymphoedemamidwales@btinternet.com
(In our September Newsletter I mentioned the valuable work Gill undertakes to support patients with this condition).
Thank you Gill for supplying your contact details.

Thank you to all our Clinicians and Administrative Staff for all your work with prostate cancer patients.

Best wishes to everyone for Christmas and the New Year from Phil Burr on behalf of the Chair and Trustees of TWWPCaSG

Phil