



REG. CHARITY NO.1229395

[www.westwalesprostatecancer.org.uk](http://www.westwalesprostatecancer.org.uk)

Patron: Chris Jones. Radio & Television Presenter.

# NEWSLETTER

## APRIL 2019

Dear Member/Friend

Welcome to this edition of our Group's Newsletter. If anyone has any items they would like to appear in the next or future newsletters please let me know. All contributions or ideas gratefully received. (DG).

We are pleased to confirm that Ray Paul has agreed to be a member of the Committee.

### **2019 AGM**

The Chair and Trustees would like to invite you (and partner) to our 11th AGM:

**TWWPCaSG 2019 AGM**  
**Friday 31st May 2019**  
**The Cothi Suite,**  
**The Halliwell Centre,**  
**University of Wales Trinity Saint David,**  
**Carmarthen,**  
**SA31 3EP**

We will gather from 10am for tea/coffee with the official "business" meeting commencing at 10:45am.

Following the business meeting we have a presentation:

**'Management of advanced disease;  
international trials and the Stampede trial  
present and future'**

Guest Speaker:

**Professor John Staffurth,**  
Director of Radiotherapy Trials,  
Consultant Clinical Oncologist and Clinical  
Reader in Oncology  
Cardiff University School of Medicine.

Professor Staffurth will be happy to take questions after his presentation following which a Buffet Lunch will be available. This is always a great opportunity to chat to and catch up with other members and partners.

Lunch over, our afternoon presentation will be:

**'Results of the Aramis Clinical Trial  
and Other Updates'**

Guest Speaker:

**Mr Yeung Ng,**  
Consultant Urologist,  
Hywel Dda University Health Board.

Mr Ng has spoken at previous AGMs and is a valued contributor to our newsletter.

Again, he will be happy to take questions after his presentation.

**Your attendance at our AGM is very important for the well-being of the group.**

**Let's make our 11<sup>th</sup> AGM a bumper one for attendance!**

Please respond to our AGM invitation letter (enclosed with this Newsletter) without delay and do remember to put the event in your diary - 31 May 2019.

### "Pub" Lunches

#### Newcastle Emlyn RFC 7 April 2019

There were over 30 members, friends and partners at the NCE Rugby Club lunch on the 7<sup>th</sup> April. The food was great and so too was the conversation.



"Pub" lunch attendees at Newcastle Emlyn Rugby Football Club.

Don't miss out on our next lunch:

#### Remaining Pub Lunches for 2019

**8<sup>th</sup> July**

**Tafarn Y Tanerdy,  
Penlanffos Road,  
Carmarthen, SA31 2EY.**

**7<sup>th</sup> October**

**The Cottage Inn,  
Pentrefelin, Llandeilo, SA19 6SD.**

**2<sup>nd</sup> December**

**Nantylfin Hotel, Llandissilio, Clynderwen  
SA66 7SU.**

Please always confirm with Gill Lewins in good time whether you will be attending (see Contact details at end of this newsletter). These get-togethers are always a good chance to catch up with other members and their partners.

We assemble at 12:00hrs for 12:30.

#### Other outreach work

In January Ken spoke on Radio Cymru - he says "... nothing to shout about, they simply wanted my opinion about the use of words like 'brave and courageous battle' when used in connection with cancer sufferers".

Also he gave a talk to the Newcastle Emlyn Patients' Participation Group at Emlyn Surgery,

as a consequence of which, we benefitted from the proceeds of a quiz night held in the Pelican pub, Newcastle Emlyn on 14 February (see later).

### **The Group's Facebook Page.**

We are pleased to announce that David Bunce has now set up a Facebook page for the Group. It is a closed group and you can ask to join by searching for The West Wales Prostate Cancer Support Group. There are clear guidelines and it will enable members to communicate and message each other, provide dates and information and updates. This approach is new to the group and will be monitored.

### **A point of clarification from Phil Battison...**

In the December 2018 edition of the Newsletter we quoted from an article that had appeared in 22/10/18 issue of The Daily Mail. In fact the newspaper report was referring to the results of the STAMPEDE Trial, though the report did not mention this.

At my routine follow-up appointment with Mr Ng (Cons. Urologist, HDUHB) in December, he pointed out that the item, as presented in the Newsletter, may give rise to "false hope" amongst our members and that anyone wishing to know more precise details should consult the source material ie. The Lancet Vol. 392 1 December 2018.

There may be some benefit to some patients but as reported on p2353 of the above Lancet:

***"Radiotherapy to the prostate did not improve overall survival for unselected patients with newly diagnosed metastatic prostate cancer."***

Anyone wishing to read the full Lancet article (and, having read it, good luck to you!!!) can access it using this link:

[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)32486-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)32486-3/fulltext)

It has never been our intention to raise unfounded expectations amongst our membership and we sincerely apologise if anyone feels they have been misled on this occasion. Thank you Mr Ng for raising this issue.

### **Future collection dates:**

Dates have been arranged for collections:- Sunday 26<sup>th</sup> May and 1<sup>st</sup> September at the Carmarthen "Flea" Markets.

David Parmar-Phillips would appreciate offers of help from anyone who feels able to "man" our stand. Please see the Contacts list at the end of this newsletter.

We would also appreciate some help with our store collections. If anyone has ideas for future places we could "collect" from or if you feel you can help in any way please get in touch with Ken or any of the Davids, or chat to us at the next pub lunch.

It's not about the money but the opportunity to be seen in the community and get our existence known. It's a chance to interact with the general public and answer their queries where possible or point them in the right direction.

### **Upcoming events:**

**Science Café in Carmarthen (St Peter's Civic Hall) - Friday May 3rd 7-9pm**

(from Lee Campbell - Cancer Research Wales)  
*"Just wanted to let The West Wales Prostate Cancer Support Group know that we will be holding a science café in Carmarthen on May 3rd.*

*Similar to the one we held in Lampeter a couple of years ago, we will have a series of speakers on the night as well as some interactive displays.*

*Lisa Formby from Wrexham has agreed to come and speak about our funded project - Diagnostic Journeys in Prostate Cancer.*

*Lisa has taken over from Tania Searle, who you remember was working on the project. Tania left to go to a new job for a cancer charity in North Wales. Lisa has got quickly up to speed and will seek to finish the work which we hope will result in the development of some evidence-based recommendations and guidelines."*

### **Donations received with our thanks:**

Newcastle Emlyn Patients' Participation Group's quiz night held in the Pelican pub, Newcastle Emlyn on 14 February raised

£225.51 for our group.

Ken has received a cheque for £50.00 via Gill Lewins from V R Coleman.

A donation of £75 has been received from David Murray.

Ken recently collected a cheque for £2,100 from the Derilys Court Golf Club Seniors. The presentation was made by John Phillip Jones - the Seniors Captain.



**Chairman Ken receiving the cheque from John Phillip Jones - the Seniors Captain.**

Member Duncan McNally has a group of friends who are due to carry out a sponsored walk in Santiago de Compostela - funds raised will be donated to our group. We wish them all the best with their efforts.

**We thank all of these people and groups for their generosity.**

### **Patients' Stories: Jeff Thomas 2018 PCa update/treatment diary**

.... continued from last edition....

And so we get to 2018, and whilst Daniel Craig couldn't "be me" for the sequel. Danny De Vito did offer, but as he's taller than me I turned him down!

Started the new-year feeling ok with my first foray back into the treatment area on the 22/01/18 when I had my bloods taken for my 3 monthly Prostag/3 injection on the 29th. All ok with injection given in tummy area as usual.

I then had my regular pre booked meeting with Dr. Phan on the 05/02/18, wherein she

informed me that as my PSA was back up to 322 I would be restarting chemo, (Cabazitaxel), in early March, and that she would be holding off on Enzalutamide to see if the chemo plus steroids reduces my PSA.

Actually then had my 1st appointment from Glangwili booked for 26/02/18, but had to postpone this due to a sickness/diarrhoea bug which took hold on the 23rd. So 1st infusion of Cabazitaxel was rescheduled for wed 07/03/18.

I then attended at Glangwili chemo unit on the 07/03/18 and commenced my Cabazitaxel chemo treatment. This consisted of a different regime to my previous Docetaxel infusions in that it started with a saline drip, followed by an antihistamine infusion, steroid infusion, Cabazitaxel infusion then finally a saline drip. All ok with treatment taking approximately 3 hours. I was then informed that I would have weekly bloods for the next 3 weeks prior to the next scheduled chemo infusion on the 26/03/18.

Following on from this treatment I had a pain in the top of my right arm and a cough/cold for approximately 2 weeks.

At my next infusion I was informed that my PSA had gone up to 717, but as a "spike" in PSA is a well-known side effect of Cabazitaxel my medical staff were not too concerned and would monitor same at next infusion.

Sure enough at my next infusion, (No 3), on the 18/04/18, my PSA had come down to 587 with my ALP (Alkaline Phosphate bone marker), down to 211. (Normal range 30-130). Following this infusion I had no ill effects with my next infusion booked for 09/05/18.

Sometime in late April I also read an article on the Budwig Protocol, and decided to supplement my treatment with this concoction, which consisted of a daily portion of Quark, (vegetarian cottage cheese), mixed with flaxseed oil. I took this for the next 6 months



with no ill effects.

My next treatment was a regular 3 monthly Prostate/3 injection on the 23/04/18.

I then had bloods taken for chemo on the 09/05/18 with infusion on the same day!!  
PSA down to 580 with a marker put on my file to possibly see Dr Phan before next infusion.

Bloods on 29/05/18 for infusion No 5 on 30/05/18 indicated that my PSA had gone back up to 626 but that my ALP had reduced a further 20 points to 191.

Cabazitaxel Infusion No 5 on 30th all ok. However Glangwili nurses to check with Dr Phan re additional treatments and scans. All ok carry on as planned.

My bloods on the 19/06/18 for infusion No 6 indicated a drop in PSA to 588 with ALP down to 160. Cabazitaxel infusion No 6 on 20/06/18, no issues with CT scan booked for 29/06/18.

A meeting was also arranged with Dr Phan for 09/07/18 to review scan and have a chat about "way ahead", eg possible infusion No 7?

I then had a Diabetes clinic appointment on the 27/06/18 which indicated that my HA1b diabetes marker was 42 with normal being less than 48, so all ok there with just advice to try to get it down to <40. Blood pressure also fine at 115/76 with next appointment booked for 6 months.

29/06/18-CT scan.

9/7/18- Met with Dr Phan, all stable, so push on for possible 10 infusions of Cabazitaxel. Then consider Radium 223 in Bristol.

11/7/18-Chemo 2/7. PSA down 15 to 543. ALP down 2 to 158. All ok during infusion. (3 hours).

19/7/18-Phone call from Bristol Royal Infirmary, please attend oncology clinic on 23/7/18 for meeting with Dr Kirk re Radium 223 treatment. 23/7/18- Met with Dr Hannah Kirk in Bristol, who outlined Radium 223

treatment plan and possible side effects. However she also stated that as I looked reasonably fit she didn't anticipate any issues. She stated that she was looking to start treatment on 10/8/18 but would need to liaise with Dr Phan re cancellation of Chemo treatments, and cessation of steroids. Also told not to get too hung up on PSA no's. As a better marker for Radium treatment is a lowering of ALP no's. Also before leaving I had blood tests and was weighed (95.2kg).

25/7/18- oncology nurses phoned from Bristol to ask if I had any queries prior to commencing treatment on 10/8/18.

26/7/18-chemotherapy unit in Glangwili phoned to confirm that chemo suspended and to be superseded by Radium 223 in Bristol. Also informed that normally I would have to go to Bristol approx 1 week before each treatment to be weighed, have blood taken and be generally assessed for future infusions. However it had been arranged that all of this process would be done in Glangwili including a video conference with the staff in Bristol to ensure I was ok to progress. This arrangement continued for the next 6 months which meant I only had to travel to Bristol once a month. (So, once again, thanks to the NHS for facilitating this).

27/7/18-via oncology unit Bristol all booked and confirmed for 1st Radium 223 treatment on 10/8/18.

10/8/18-attended at Bristol Royal Infirmary for 1st treatment of Radium 223. All ok. With regime consisting of saline infusion, Radium infusion, saline infusion. Also informed of possible side effects, diarrhoea, constipation, temperature issues, nausea. PSA 588. ALP 135. Blue card issued outlining treatment plan.

24/8/18-Bloods taken for next Radium session. PSA 412 & ALP 188.

But all ok for 2nd treatment on the 7/9/18 as Radium does sometimes cause a PSA/ALP spike. Then met with Dr Phan who confirmed

everything ok for 2nd treatment.

7/9/18-attended Bristol for Radium 223/2. All ok, treatment approx 20 mins. So home by 3 pm.

24/9/18-Met with Dr Phan for pre-treatment chat/video conference. All ok. PSA 403. ALP 133. Also discussed possibilities of another new treatment Lutetium 177. (Which has been credited with fantastic results for advanced PCa in several countries, Germany, Finland, South Africa and Australia). At the moment this is only available privately, but may be available as part of a trial in UK in 2019.

25/9/18-Bloods for Radium/3 all ok.

5/10/18-Radium223/3 treatment in Bristol, went in for appointment 1/2 hour earlier than usual so back in Carmarthen by 1pm.

8/10/18- HT (hormone therapy) injection in Doctor's surgery. Also had Flu Jab at the same time!!

Next bloods due 19/10/18. Bloods ok. PSA down to 367. ALP down to 112.

22/10/18- Met with Dr Phan all ok. But future treatments in Bristol moved from Fridays to Thursdays. With next one due 1/11/18. Weight 93.5kg.

1/11/18- attended Bristol Royal Infirmary, all ok infusion done by new nurse.

15/11/18-Met with Dr Phan for video conf. etc. PSA 335. ALP 95. Continue with current treatment plan and review way ahead in Feb/19. (Immunotherapy/trials etc.)

19/11/18- spoke with nurses in Bristol. All ok for next treatment but next appointment with Dr Phan needs to be brought forward in order for Radium to be ordered from Norway in advance of Xmas rush!

29/11/18- Radium 223/5 infusion all ok.

13/12/18- Bloods ok. PSA 358. ALP 82.

17/12/18- Met with Dr Phan. All ok for Radium 223/6 (last infusion) on 27/12/18. Then possible 3 month treatment holiday with just bloods and a chat in Feb/19. With scan to be booked for end of March/19.

Queried normal survival times after successful Radium treatments which are quoted at 12-36 months. However told that everyone is individual so difficult to predict anything and it's more important as to how you feel after it.

27/12/18-attended Bristol for last Radium treatment, (No 6). All ok. Sad to say goodbye to oncology staff who've been brilliant but may be back there for trials in the new- year?? So watch this space.

31/12/18 HT (hormone therapy injection). With annual diabetes check-up booked for 16/1/19.

And so we get to the end of yet another eventful year. To date I've now had regular Hormone Injections, (Degaralix and Prostag/3).

Steroids, (prednisolone).

6 x Docetaxel chemotherapy infusions.

7 x Cabazitaxel chemotherapy infusions.

6x Radium 223 infusions. And look forward to whatever else the NHS or the private sector can throw at me in 2019.

I've managed to continue playing golf (off a 15 handicap) for the bulk of the year. Although I now avoid playing in the rain and use a buggy whenever possible as walking 18 holes is now very tiring.

Other than some minor set-backs and general aches and pains, I feel that I've come through it quite well. Obviously there are "down days" but these are offset by many more "up days". And I'm a genuine believer in PMA (positive mental attitude) because if you dwell on PCa too much then it will bring you down, and this is amply identified in the fact that two of the "boys" that I've had various treatments with

over the last two years have died during 2018, a sad loss to us all.

Finally, for this instalment of my journey, I can tell you that I've already booked another golfing holiday in Portugal in January/19. And look forward to my meetings with Dr Phan in Feb/March 19 to plan the way ahead.

PS. If you'd like further details of my journey I've got a blog running on the Prostate Cancer UK website under the name of "Valleyboy" which to date has over 30k hits!!

Keep the Faith - Jeff Thomas.

Thank you Geoff for this update.

### **Update on Amit Bahl's project**

As reported in last June's newsletter we had previously received a proposal from Dr. Amit Bahl, who is carrying out research to determine whether non-cancer drugs can be re-purposed to use as adjuvant therapy in prostate cancer treatment. At the 2018 AGM it was confirmed that the committee had agreed that we should fund this project in total at a cost of £27,000.

Dr Claire Perks (Reader in Tumour Cell Biology, Translational Health Sciences, Bristol Medical School) reports as follows:

*"We employed a part-time research technician (50 %) on this project who started on the 20<sup>th</sup> October 2018.*

**Question 1:** *Recently a number of established non-cancer drugs have been repurposed for use as potential adjuvants for established cancer therapies and their efficacy in terms of adjuvant therapy to potentiate taxane treatment in relation to ARV-7 (ED androgen receptor variant) positivity is not yet known.*

**In progress:** *We are currently assessing the effects of physiological doses of aspirin in the presence or absence of cabazitaxol in VCaP (ARV-7 positive) and LNCaP (ARV-7 negative cells) prostate cancer cells.*

**Next step:** *We shall repeat these experiments using docetaxel.*

**Question 2:** *Long term culture of ARV-7 negative LNCaP cells in androgen-depleted*

*conditions (charcoal-stripped serum) leads to anti-androgen resistance and the emergence of ARV-7 (after 6 months of culture) and mimics the development of anti-androgen resistance in vivo.*

*To complement the aspirin work in question 1, we have started these long-term cultures in the presence or absence of physiological doses of aspirin (0.25 & 0.5 mM) to determine if androgen-independent growth and the emergence of ARV-7 is reduced and or delayed. We are collecting whole cell lysates and cell supernatants for protein analysis and extracts for RNA analysis. We shall also take photographs of the cells as a record of any morphological changes that we observe. We will stagger the set-up of these long-term experiments to also assess the impact of statins and metformin.*

**Additional Data:** *whilst assessing the response of the LNCaP and VCaP cells to DHT, we made the novel observation that the response of the cells is altered in response to hyperglycaemic conditions. The VCaP cells are unresponsive, whereas the LNCaP cells are very responsive and become more sensitive to DHT with higher levels of glucose. We are currently investigating if this is linked to the ARV-7 status of the cells. This is a novel observation that may be one reason why patients with PCa who present with type 2 diabetes have a worse prognosis. We anticipate this can be written up as a manuscript in the next few months."*

Thank you for this update Clare.

### **Low Residue Diet – Recipe ideas**

In our June 2017 newsletter Gill Shepherd told how, when her husband, David, was put on the Low Residue Diet before undergoing Radiotherapy treatment, she decided to compile a selection of recipes that complied with the Dietary Advice sheet but were nutritious and visually appealing. She has shared some of these recipes with us over the last two years. If anyone would like more information please contact Gill at:

[lymphoedemamidwales@btinternet.com](mailto:lymphoedemamidwales@btinternet.com)

Thank you Gill.

## Membership Database

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. Please be assured that Ken uses the 'Blind Carbon Copy' (BCC) facility to maintain members' confidentiality when distributing these e-mails.

However some emails come back undelivered, possibly because members have changed their

e-mail address.

If you haven't had an e-mail pub lunch reminder recently or if you have changed your e-mail address but not notified us, please let Ken have your new e-mail address. This also applies to any changes to your postal address or contact telephone numbers. If you have never given us your e-mail address but would like to receive e-mails please let us know.

So, with your best interests at heart, an appeal from the Trustees to all members:

### **The importance of our Membership Database.**

It is vitally important to the efficient management of the Group that our Membership Database is accurate and up to date.

The letter accompanying this Newsletter is yet another attempt by the Trustees to ensure that the membership information we hold (in accordance with the GPDA 2018) is accurate.

The letter asks a number of questions regarding contact information and AGM attendance.

### **EVERY member needs to respond to this letter.**

Even if there are no contact detail changes the Trustees need to know accurate numbers attending the AGM for seating and catering purposes.

Respond to the letter enclosed with this Newsletter, without delay.

It will help us to continue helping you!

Best wishes from David Goddard on behalf of the Chair and Trustees of TWWPCaSG.  
We hope to see you all at our AGM on the 31<sup>st</sup> of May.

## TWWPCaSG CONTACTS

### HELPLINES

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### GROUP OFFICIALS

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