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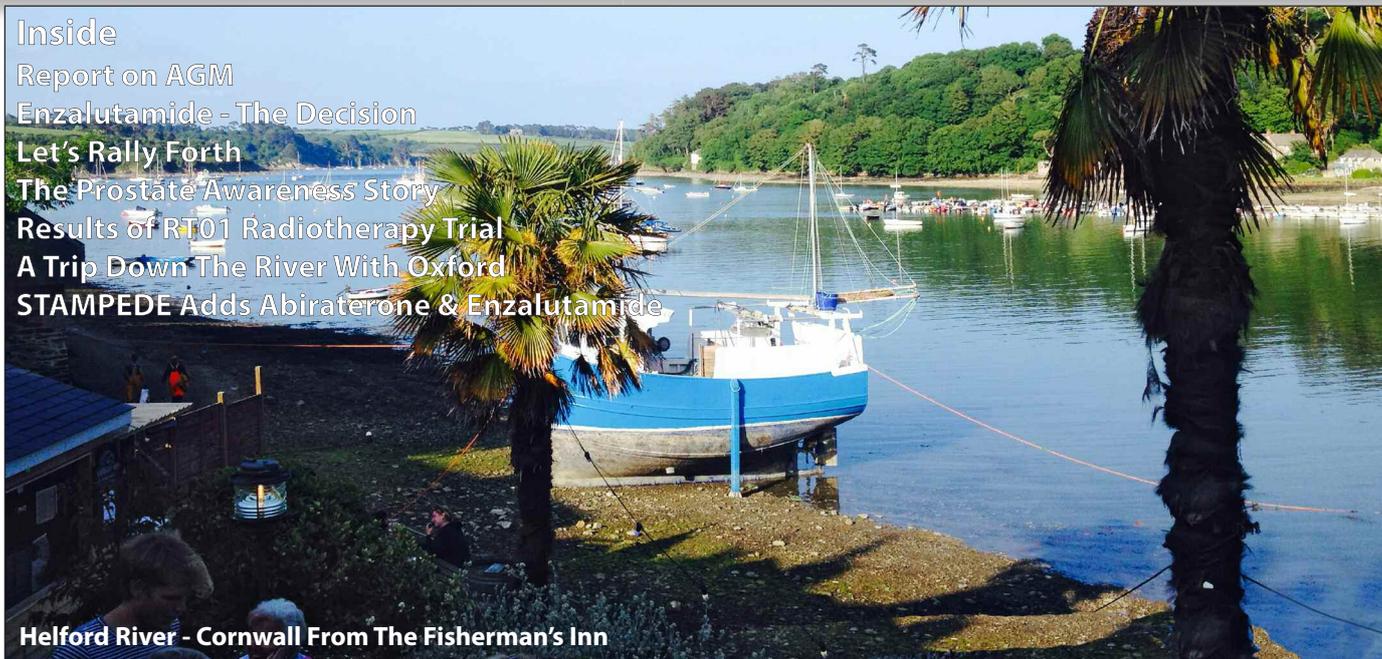
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## Tackle at Twickenham – Prostate Cancer Support Federation AGM

By Terry Garrigan

The conference started with a warm welcome from Sandy Tyndale- Biscoe to the 6th AGM on an equally warm sunny day. There was a brief review of 2013, the actions taken and where money was spent. This was followed by the focus points for 2014:

- Starting an early detection campaign and getting more men tested
- Raising issues facing patients and getting them changed
- Working with groups for a strong vision
- Producing more leaflets for groups
- Helping groups to set up their own websites
- Enabling groups to get preferential insurance rates and for other things they need
- Further development of the "Tackle" brand
- Raising more money to fund all of the above

Elections were held for the Charity's officers and Trustees. For details of the results see p7"

**Roger Wotton**, the regional co-ordinator of groups, explained that regionalisation is necessary to improve communication across the Federation and to achieve better links between grass roots and top table organisations. Also to better support the Federation and be the voice of prostate cancer patients and their families.

### The benefits are:

For the Federation: To improve governance through a strong regional voice and sharper focus on campaign management.

For support groups: To allow better networking, a degree of resource sharing to promote best practice.

For individuals: To make it easier for their voice to be heard.

Some of the feedback Roger collated from the regional meetings:• The need to improve the awareness of prostate cancer to GPs at first contact and better publicity at the point of delivery.

- Avoiding the postcode lottery in care pathways and to understand the role of the CCG in primary care, better.
- More help needed for men with advanced disease, improved support and better conversation.
- Attracting newly diagnosed men to existing groups.
- The setting up of new groups in target areas.
- PSA testing, help with local events, choosing the best approach and financial support.
- Relationship with PC UK such as "who does what?"
- The bigger picture including Macmillan.

The next steps are to address the above issues and update the groups.

We broke for lunch, tea and coffee and a chance to socially catch up with everyone.

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**“The Pit Stop Prostate Cancer Health and Wellbeing Initiative”**

*Stephanie Snow, Head of Healthcare at Munro and Forster Communications.*



*Stephanie Snow, Head of Healthcare at Munro and Forster Communications.*

Three sessions took place in the afternoon. A summary of the key points from each is detailed below.

Stephanie works on a steering committee on an oncology programme.

While discussing what a patient can do to keep himself well, the Pit Stop health and wellbeing initiative was born. This was designed for patients to keep themselves well between clinic visits. Many men are reluctant to worry their GP with their concerns which may seem trivial, just a general feeling of not being well. A Pit Stop Log Book folder was designed to give patients a check list to complete to show trends on how they are doing before their next visit to the doctor. This would work like a monthly service record and may also include exercise, diet and lifestyle.

Participants were asked how best to encourage men to help themselves; how Pit Stop could be made useful and more appealing for men to use; the best way to make it accessible and easy to follow; how healthcare professionals could be encouraged to use it; and lastly, the most efficient way to broadcast its existence. One suggestion was a mobile ‘App’. This information would be private for the patient to share with his physician alone and the data logged would not be shared elsewhere. There were mixed reactions to this log which did not include enough information (no reference to erectile dysfunction, symptom guide or emotional state). Food for thought!

**“Surviving Prostate Cancer through a Positive Mental Attitude”**

*Speaker Dr Stéphanie McArdle, John van Geest Cancer Research Centre, Nottingham Trent University.*

Stephanie is a senior research scientist in tumour immunology and has an overview of the work taking place at the JvGCRC.

The Centre is identifying where the research is needed:

1. Cancer picked up ⇒ Will it progress?
  - ⇒ Flow cytometry ⇒ Immune markers ⇒ to identify immune response for aggressive disease
2. High PSA ⇒ TRUS biopsy ⇒ Aggressive cancer found ⇒ Patient not responding to hormonal treatment ⇒ vaccine to treat the disease
3. No cancer picked up ⇒ Further investigation ⇒ Elisa test A TRUS biopsy may not pick up cancer sited at the back of the prostate gland

**The Future:**

- PSA taken - additional marker indicative of cancer
- To clinic for MRI guided biopsy the transperineal route. Only three cores need to be taken under general anaesthetic.

Some cells evolve rapidly others more slowly. At the moment there is only the PSA test and repeat TRUS biopsies. Stéphanie is researching the above.

**Immunology and immunotherapy:**

The research centre is currently working on a vaccine. Although unavailable at the moment it would need to be widely accessible to work effectively. In summary, the aims are to improve diagnosis and to develop a vaccine and immunotherapies to improve survival rates.

**A positive mental attitude:**

Stéphanie analysed Hugh Gunn’s experience. He showed determination and came to terms with the situation with a clear focused mind. He felt useful and valued helping others. With this in mind it is important to remember that the size of the prostate gland increases over time. Men generally die with the disease rather than from it and the majority of cases are diagnosed in men over 65yrs.



*Speaker Dr Stéphanie McArdle, John van Geest Cancer Research Centre, Nottingham Trent University*

Hypothetically, during the working life of a man he may be busy, happy and successful with a diet rich in protein. Stress will keep him alert to achieve his targets. On retirement, relaxation strikes and with no change to his diet he may begin to gain weight. His workload and physical activity reduces.

In conclusion, intensive lifestyle changes may affect the progression of early prostate cancer. A positive mental attitude focuses the mind. Changing to a healthier diet together with some form of exercise such as walking may also be helpful. Attending a support group to help others while helping yourself. In short we cannot change our DNA but we have the ability to control our lifestyle to influence us both positively and negatively. "This is what you can do yourself, to make you feel better". You can actually alter your genes by changing your lifestyle, which will in turn influence your immune system.

For those over 65 yrs or if changing your professional activity:

- Change your diet
- Continue with physical activity
- Help yourself by helping others
- Do some mental relaxation (meditation, Yoga, visualisation)

To those under 65 yrs with cancer, do all of the above, talk to people and join a support group, you are not alone!

#### Finally, did you know?

- Afro-Caribbean men get prostate cancer younger, their PSA should be checked from 40yrs and they are more likely to get aggressive disease.
- GP's should recommend those diagnosed a local support group.
- Laughter is a powerful way to tap into positive emotions.
- Each patient carries his own doctor inside him.
- Dying is less important than dying inside, keep your attitude positive.

The holistic health team consists of health consultants (all RGN's), a clinical nutritionist, physiotherapists, osteopaths, an

#### "The Grayshott Spa holistic approach to natural therapy"

*Elaine Williams and Stephanie Moore*

acupuncturist, a psychotherapist (EFT / NLP), massage therapists, a fitness instructor and the ESPA founder Sue Harmswoth.

Nurture and Support consists of a pre arrival telephone consultation, four night accommodation, nutritious menus, one to one nutrition consultation, gentle exercise and relaxation class, health lectures, the use of all the Spa facilities and the choice of five ESPA treatments of up to 340 mins. These treatments may be back, face and scalp massage, facials, body treatments, hand and foot indulgence and body envelopments.

Grayshotts philosophy:

- To encourage healthy, well balanced meals emphasising high quality proteins, natural fats, good fibre and gentle carbohydrates.
- To enforce healthy practice by offering daily lectures on health related subjects, such as stress, fats, carbohydrates – the dieting myth!
- The importance of managing stress – it's about having a balance.

Supporting physical and psychological health. Encouraging small changes over the long term, thus gaining a sense of self control over their own health. The opportunity to have a nutrition consultation to discuss dietary habits and recommendation for change.

Focus on functional foods such as, dark leafy vegetables, brightly coloured veg such as rainbow peppers, turmeric, garlic and onions, flaxseeds, sprouted pulses and seeds, green tea, extra virgin olive oil, sea veg (iodine for glandular cell health), tomato paste (lycopene). Possible supplements such as Vit D, pro-biotics and Omega 3. The jury is out on the use of dairy such as milk, butter, cheese and yoghurt.



*Stephanie Moore - Grayshott Spa*

Foods to limit include: dairy, commercial cooking oils, blackened charred oils, refined sugars, wheat. Remember that chlorine, bromide and fluoride competitively inhibit iodine uptake. It is important to manage blood sugar – Type 2 diabetes is shown to be a factor in prostate cancer due to testosterone.

Lifestyle: manage stress effectively, have good quality and quantity of sleep, do moderate exercise and have some daily "down time".

Grayshott Spa donated £25,000 to the Federation enough for 20 x 4day stays.

#### Overall

It was a very interesting day which seemed to work well with holding the AGM in the morning instead of the afternoon. A date for the diary is 8th September 2014, an on-line auction in aid of "Tackle".



*The Trustees of Tackle, Left to Right: Sandy Tyndale-Biscoe (Chairman), Hugh Gunn (Treasurer), Rob Banner, Rowena Bartlett (Chief Executive), David Smith Secretary, Ken Mastris and Erik Friis Scheel*

## Let's Rally Forth

Rob Banner



"ETE", flashed up with PROSTaid colours,  
Pictured with Rob Banner, in the grounds of Laund Abbey

"Some day Rob I am going to do that MG Owners Club Classic Car Rally in Leicestershire". said Hugh Gunn, he has been saying that, for at least the last six years!! , Hugh, Trustee of PROSTaid has advanced prostate cancer. I was starting to think so why the hell doesn't he do it?? Every time I asked him, well I don't know if the car or I will even make it.

### Then he phoned me, Rob I am doing it!

His Classic Car, a Austin Sprite, in fantastic condition, lies resplendent and cosseted in his Garage whilst his other car sits on the drive exposed to the vagaries of the weather. ETE 400J is everyman's dream. A sexy bright red pristine, polished Classic car, Vintage 1971. Lovingly rebuilt by Hugh some years ago, from a rolling chassis and several cardboard boxes full of bits!

Hugh is used to doing things not recommended by oncologists. Running a half marathon, learning to water ski, boogie boarding down rapids, a tandem skydive. All great fun to tick off his bucket list. Especially exciting when forbidden by an earlier oncologist who, almost nine years earlier gloomily told him he had about 18-30 months left and to get all his holidays in now!

The day for the Rally had arrived. A wonderful warm sunny day, we parked at the White Horse, Broughton Astley and munched our bacon sandwich whilst inspecting the car park, which soon filled up with a fabulous array of Classic Cars. Enviously admiring them and talking to their doting owners, who pampered and polished their precious possessions!

Before we knew it we were off, waved off by a steward in the middle of the road with a gigantic union jack.

Ignoring Hugh's comments, "Hope she makes it, how many miles is it, Rob", as the Sprite, flashed up in PROSTaid colours and anxious to get off, roared into action effectively silencing me.

Normally over talkative, I had to shout our staccato spiel of continuous directions. Apart from getting lost and landing up in Cosby in the first ten minutes, we refound the route and roared faultlessly through the remote and pretty lanes and back waters of Leicestershire. After a welcome coffee break at Launde Abbey, we sallied forth again this time through the even remoter lanes of Rutland, to arrive at Burgley House Stamford, in time for a wonderful executive picnic lunch supplied by Hugh's wife Kate and eaten on a blanket on the lawn in front of the House. Lord Cecil would have been impressed!

So if you want to do something, don't sit there, go and do it. None of us know how much more life we will be blessed with, but at least you might, as you make the years tick on, have the opportunity to avenge your oncologist!

## A study concerning the emotional impact of cancer

Department of Psychology, University of Sheffield

Haffiezah An-Nadiah Azlan

### Background

Emotion has a significant impact on the quality of life in patients with cancer. Cancer patients typically experience many types of emotions as they have to endure many challenges, experience changes to their appearance and bodily function, and need to confront many physical and psychological adjustments. Moreover, they also have to cope with the demands of treatment. Most cancer treatments have an impact on body image, particularly when body integrity is breached or body function is altered as a result of medical intervention. It is likely that these changes in body image and function play a role in the genesis of reduced psychological well-being in cancer patients, and it is hypothesised that emotion plays an important role in linking the two. Therefore we are conducting research into how people of any age with any type of cancer feel about themselves and the consequences those feelings might have for mental health. Our work to date in the general population suggests that how people feel about themselves (their emotions towards their 'self' image and behaviour) affects their quality of life, and can directly lead to secondary mental health problems, such as depression. Using these findings, we have begun to explore methods of tackling negative feeling states people have towards themselves, with an aim to reduce depressive symptoms and improve quality of life. We would like to evaluate whether the same causal links occur between feeling states and mental well-being in people with cancer (with a view to ultimately help them to have an improved quality of life). Examining the role of emotion in cancer patients has important implications for understanding the emotional processes that affect their well-being and how these can be treated clinically.

### Aim

The aim is to examine the role of emotion in the development of depression among cancer patients.

### Study design

This quantitative study uses an online survey methodology with five measures administered, covering emotion, anxiety and depression.

### What does the study involve?

The study involves filling out a series of short questionnaires and will take approximately 15 minutes with possible follow-ups 6 months later. All responses are anonymous and will be treated confidentially. A full debrief will be available following participation and we will give participants feedback on the results at the end of the study.

### Who can enter this study?

You can enter this study if you  
-are diagnosed as having cancer  
-are at least 18 years old

### Referral to this study

If you think you are eligible and are interested in taking part in the research, please use the following link to access the study pages, find out more information and to take part:

<http://goo.gl/N8aqqV>

The study is password-protected and you will need the following password to log in: myemotion

If you need further details about what is involved in this study, please contact: Haffiezah An-Nadiah Azlan, postgraduate student for Prof. Paul G. Overton, Head of Department in Department of Psychology, University of Sheffield.

Tel: +44 (0) 114 222 6624 Email: haazlan1@sheffield.ac.uk



# Results Of Trial Testing Higher Doses Of Radiotherapy To Treat Prostate Cancer

Annabelle South



Results of trial testing higher doses of radiotherapy to treat prostate cancer

Earlier this year the long-term results of the RT01 trial were published. RT01 tested whether standard or higher doses of radiotherapy were best for treating localised and locally-advanced prostate cancer. It compared a 7.5 week course of radiotherapy (the higher dose) with a 6.5 week course (the standard dose).

843 men took part in the trial, and their health was monitored by doctors for around 10 years. The results showed that, 10 years after treatment, men who had received the higher dose were less likely to have signs of their cancer coming back or getting worse. They were also less likely to need to start long-term hormone therapy.

However, there was no difference in how long the two groups of men lived. Men in both groups lived much longer than expected and almost three quarters were still alive after 10 years.

Men who received the higher dose were more likely to have side-effects such as diarrhoea or rectal bleeding. But most of the side-effects were mild or moderate.

Participants joined RT01 and were treated between 1998 and 2001. Since then newer radiotherapy techniques have been developed, such as intensity-modulated radiotherapy (IMRT), which allow even higher doses to be given with fewer side-effects.

Professor David Dearnaley, of The Institute of Cancer Research and The Royal Marsden NHS Foundation Trust, who lead the trial, said: "Our trial has proved that treating men with localised prostate cancer using higher doses of radiotherapy is more effective than a less intensive regime. The dose-escalated regime is safe in the long term, and reduces the chances that a cancer will return and men will require further hormone-deprivation treatment. These benefits outweigh the increase in

side-effects we saw. Overall our study has shown men are probably better off after having the escalated regime, which is now the norm in the UK.

"Another key finding is that radiotherapy in general is both a safe and an effective treatment for localised prostate cancer. Almost three quarters of men treated with either the more or less intensive radiotherapy regimes are still alive after 10 years, and of the men who have died, less than half actually died from prostate cancer."

The RT01 trial has already changed how men with localised prostate cancer are treated. The current NICE guidelines recommend the use of the higher dose of radiotherapy, based on the five-year results of RT01. The trial also helped to develop guidelines on how to limit the radiation that organs near the tumour receive.

Information from RT01 is now contributing to biological studies to help better understand the disease and the side-effects of radiotherapy.

If you would like to read the full results of RT01, The Lancet Oncology paper can be found <http://bit.ly/RT01results>

## Please Check Your Details

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

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

<http://tinyurl.com/429ee7f>

and the contact web page:

[www.tackleprostate.org/member-organisations.php](http://www.tackleprostate.org/member-organisations.php)

If there are any alterations, please contact:

Sandy Tyndale-Biscoe

Email [webmaster@prostatecancerfederation.org.uk](mailto:webmaster@prostatecancerfederation.org.uk)

## Oxfordshire Prostate Cancer Support Group Recent events.



At 2.30 pm on Sunday 29th July, 95 members and friends set sail aboard a steamer on an epic journey along the river Thames. The boat had previously taken part in such events as rescuing troops at Dunkirk and delivering on D-day. Our journey was not as adventurous, but very enjoyable. We successfully navigated the second deepest lock on the river, saw a good variety of wildlife and the music from the jazz band entertained us, and the public on the riverside. The bar was well used and sustenance catered for by way of a cream tea. A poignant moment for me was, when having a conversation with two members, one simply said "my GP saved my life". We had our Group Name banners on the side of the boat to show people that there is life after PCa. The sun shone, fellowship was good and we made a successful landing at 4.30 - unfortunately, no duty free goods were available.

The next day, we attended a rather different event where we were handing out information literature. The small village of Cassington, just outside of Oxford, was holding its annual "Bike Night". The number of motor-cycles this year was slightly up on last year when approximately 10,500 (yes, ten thousand five hundred) attended. The age range was well within our target group and we had many interesting conversations. We gave out over 2,000 leaflets, it was difficult not to approach the same person twice as the majority wore the standard leather outfits, sunglasses and were carrying a pint of beer! Again, an enjoyable event which we hope will have helped many people.

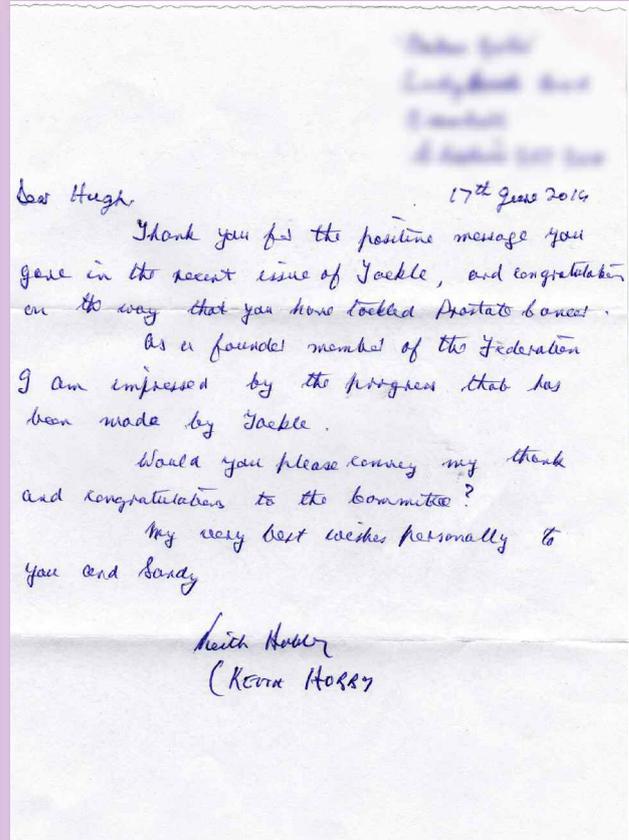
### Europa Uomo

We are proud to announce that the new Chairman of Europa Uomo is one of our Trustees of Tackle, Ken Mastris. This is an important role and it will be very good to have Tackle involved in this high profile organisation.

### AGM Election Results

We were blessed with a total of six very well qualified candidates who offered themselves as Trustees. The Constitution allows for only four to join the Board as elected members and in the election the following received the most votes from the Members: Rob Banner, Dr Frank Chingwundoh MBE, Ken Mastris and Roger Wotton. Tackle cannot afford to turn away skilled and experienced volunteers however, and the two unsuccessful candidates, Gary Steele MBE and Allan Higgin, will be invited to work with the Board in suitable roles.

We have received the letter below, from Keith Hobby, who was one of the founder member Trustees of the Federation. Thank you Keith, it is really good to know that we are getting things right!



### Gift Aid

**Did you know, if your group is a registered charity, you can claim GiftAid from HMRC on personal donations given to the charity. This will increase their value by 25% at no cost to the charity or the donor. To register or to find out more, go to:**

[www.hmrc.gov.uk/charities/gift-aid-toolkit.htm](http://www.hmrc.gov.uk/charities/gift-aid-toolkit.htm)

### Follow us on Social Media



[www.facebook.com/tackleprostate](http://www.facebook.com/tackleprostate)



Tackle @TackleProstate



Text Giving - Text:  
TACK13 £

## Prostate Cancer Support Federation

Action for prostate cancer patients and their families

16 Kirby Street  
London EC1N 8TS

[www.tackleprostate.org](http://www.tackleprostate.org)

### Patrons:

Dr. Thomas Stuttaford OBE  
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David Smith

### Treasurer:

Hugh Gunn

### Federation Trustees

Rob Banner

Dr. Frank Chinegwundoh MBE

Ken Mastris

Roger Wotton

Shaun Madle

Erik Friis Scheel

### To View other roles carried out by volunteers, please visit:

<http://tinyurl.com/lzmkfwc>

Prostate Matters is published four times a year, providing news, information, personal memoir and opinion about prostate cancer. It also reports, quotes and cites published medical views and research findings about prostate problems.

The Federation does not promote any treatments or dietary, drug, exercise or lifestyle change intended to prevent or treat a specific disease or condition. Anyone who wishes to embark on any such treatments should first consult with and seek clearance from a qualified health care professional on any treatment or lifestyle changes



## STAMPEDE trial adds new arm investigating combination of abiraterone and enzalutamide

Annabelle South

STAMPEDE trial adds new arm investigating combination of abiraterone and enzalutamide.

The STAMPEDE trial is opening a new arm to assess whether adding both enzalutamide (Xtandi) and abiraterone (Zytiga) to standard treatment improves survival. The researchers will compare this combination of drugs to standard treatment alone.

Previous research has suggested that enzalutamide and abiraterone can have a complementary effect in reducing the levels of male hormones, slowing down the growth of prostate cancer. But it has only been tested in men whose hormone therapy has already failed. STAMPEDE will test whether the combination of drugs can improve survival if given earlier, when men are first starting long-term hormone therapy. STAMPEDE will assess if the combination is both effective and safe for these men.

How will the STAMPEDE trial test this new combination of drugs?

The STAMPEDE trial is hoping to recruit 1,800 new participants from across the UK and Switzerland to this part of the trial. These participants will be men with prostate cancer who are starting long-term hormone therapy for the first time. It will include men with:

- high-risk disease that has not yet spread beyond the prostate,
- newly-diagnosed disease that has already spread,
- patients who have already been treated for prostate cancer, but are about to start long-term hormone therapy for the first time as their disease has got worse.

The clinical and research team will follow-up all the participants closely. They will do regular blood tests to ensure potential side-effects are managed appropriately. They will also monitor the quality of life of participants through

questionnaires.

This new comparison opened in July 2014, and the results will become available in around 6 to 7 years. If the combination of enzalutamide and abiraterone improves survival, it may change how men with prostate cancer are treated.

### About the STAMPEDE trial

STAMPEDE is the largest trial ever of how to treat prostate cancer. Since 2005 more than 5,500 men have joined the trial.

STAMPEDE uses an innovative design called "multi-arm, multi-stage design". The design allows several new treatments to be assessed at the same time. Each new treatment is compared to the control arm which is the usual standard-of-care. Recruitment will stop early to arms that look unlikely to improve survival.

And the trial can also adapt to include new research arms. The first of these, abiraterone (Zytiga), was seamlessly introduced in November 2011. It took 9 months less than expected to the required number of patients. The trial introduced a second new research arm in January 2013, assessing radiotherapy to the prostate in men whose disease had already spread elsewhere. Men joining STAMPEDE in the near future may be approached about this comparison too.

This new research arm is made possible through the support of doctors from 130 NHS hospitals in the UK. Cancer Research UK has approved the underpinning scientific rationale for this comparison. Astellas and Janssen are providing free-of-charge drugs to trial participants. Astellas and the Medical Research Council have also provided further financial support to the team managing STAMPEDE at the MRC CTU at UCL.

More information on the STAMPEDE trial can be found on the trial website ([www.stampedetrial.org](http://www.stampedetrial.org))

As you have seen from the article sent on by Graham Fulford, Prostate Awareness is a fantastic way of raising awareness of prostate cancer. We all owe Colin Peach a huge thank you for his innovative campaign!! I think we all enjoy watching his progress and well done on achieving a third place at Musselburgh

[Watch this space](#)