



Pages 1-3 AGM Report Feedback on PSA Discussions with GPs Tackle Chief Executive Moves On England quiz Cabazitaxel and Firmagon - Tackle Makes A Difference News From Our Groups

St. Mary's - The Isles of Scilly

TACKLE 2016 AGM & ANNUAL CONFERENCE "TROUBLE DOWN BELOW" TUESDAY 21 JUNE 2016
Held at the Royal National Hotel, London

Chairman Roger Wotton welcomed 27 of the 84 groups in the Federation, now titled the "The National Federation Of Prostate Cancer Support Groups". The theme of the day was "Trouble Down Below" and we had three really good presentations on screening, PSA testing and an insight into some latest treatment techniques.

First up was Chris Booth, talking about screening:

Mr Chris Booth MBBS FRCS, Emeritas Consultant Urologist, Colchester To screen or not to screen – that is the only question.

- 47,300 diagnosed with prostate cancer per year with 10,837 deaths as a result
- 84% survivorship at 10 years from diagnosis
- One of the chief preventative measures is to cut down on obesity
- Only 8% of men are being PSA tested
- Although the death rate is decreasing, it is not in the 80+ age group.
- Metastatic prostate cancer is notoriously hard to treat

At this stage there is not enough evidence for a prostate screening programme to be introduced.

The PSA test is freely available to men over 50 who request it. Men concerned about the risk of prostate cancer should receive clear and balanced information about the advantages / disadvantages of the test, biopsy and treatment. This is to help them make an informed decision about whether to have the test or not.

Benefits of controlled screening:

- Raising awareness of prostate cancer
- Raising awareness of risk
- Educating commissioners and providers
- Introduction of baseline testing
- Introduction of risk profiling
- Ensuring imaging before biopsy
- Standardising best practice

Continued on Page 2

The implementation of prostatic assessment clinics is a potential way to go, with nurses backed by GPs and urologists with expertise in this field.

This could result in a 25% benefit in reducing unnecessary biopsies:

Men age 50+:

Current Pathway	
Suspected prostate cancer	
TRUS biopsy in all men	
Cancer any grade or size	No cancer
Treatment	

Proposed pathway	
Suspected prostate cancer	
Multi-parametric MRI in all men	
Reduced number of biopsies	No biopsy required
Biopsy	
Cancer	
Treatment	

Unselected men at age 45:

PSA 1.5	PSA 1.5-2.9	PSA 3+
Check 5 yearly	Check every 2 years	Immediate MRI assisted biopsy
No PSA up to the age of 60 (end of study)		Prostate cancer detected
		Staging therapy follow up

Chris then led a Q & A session and reflected that it would be cost effective to do MRIs before biopsy

The second speaker was Karen Stalbow, head of Policy, Knowledge and Impact at Prostate Cancer UK (PCUK). Karen led a session on the latest PSA guidelines :

Karen Stalbow – PC UK

PSA Consensus and the Prostate Cancer Risk Management Programme (PCRMP)

PC UK aims

- to improve diagnosis with the hope to tame prostate cancer within 10 years
- to commit £2million to cut the problem of inaccurate diagnoses while assessing every mans PCRMP
- to roll out MP MRI before biopsy
- to improve the use of the PSA test

The UK National Screening Committee do not recommend a systematic population screening programme.

PC UK have produced a set of statements, representing the consensus view of hundreds of health professionals, to support primary health care professionals to use the PSA test more effectively for men without symptoms of prostate cancer. The set of thirteen consensus statements, providing additional guidance to Public Health England's Prostate Cancer Risk Management Programme (PCRMP), will drive improvements in the early detection of prostate cancer in men without symptoms whilst aiming to avoid over treatment and reduce variation in practice.

You can read more about the statements, evidence behind them and the methods used to develop the consensus on the PC UK website:

<http://tinyurl.com/z2krbc3>

PC UK PCRMP launch and next steps

- National and trade media coverage
- Information for the public
- Summary leaflet and PSA resource pack
- Journal article submission
- Primary Healthcare Professionals survey in the Autumn
- Tell us about your PSA test experience form, objectives being
 - ⊙ to understand more on the experience of men discussing the PSA test with their GP
 - ⊙ to continue to get men to discuss
 - ⊙ to support and change a delivery team to promote PSA test consensus in areas where men thought their conversations were poor

“How can we work together” to be published in a future newsletter.

We were fortunate enough to have a third speaker, Dr Manit Arya, from University College London Hospital (UCLH) and PAH who shared with us some of the latest treatment techniques :

Transforming the pathway in Prostate Cancer

Diagnosis:

TRUS biopsy misses 1 in 4 prostate cancers and leads to systemic sepsis in a large number of men

Transperineal biopsy is another route and the ideal way forward. This particular biopsy picks up 70-90% of significant cancer but still misses 1 in 10. This is still much improved on the TRUS biopsy which misses 33%.

Current diagnostic pathway

Elevated PSA	
Multipractic MRI	
Positive	Negative
Targeted transperineal biopsy – LA/sedation	Back on AS (active surveillance)
AS (active surveillance) or treatment	

Manit posed the question “Can we treat just the target?” as opposed to complete removal. With breast cancer a lumpectomy may suffice or in kidney cancer partial removal of the kidney. Similarly, with prostate cancer, if the aggressive cancer can be located, the tools are there to treat just that part and not the whole gland.

HIFU/Cryotherapy (Freezing)

Both these focal therapies avoid the cavernosa vesicles

protecting the nerve endings. They are intended to decrease incontinence and impotency and reduce rectal injury.

Cryotherapy: These machines have been modified and work by inserting freezing needles via the perineum. Fusing of the cancer image onto the ultrasound image helps to maintain continence and erections.

HIFU: This treatment thermally ablates the prostate cancer cells, virtually boiling them. The focal lens size can be changed, to help preserve erections. NICE guidelines advise that focal treatment if available must be part of a randomised trial or database. It is not suitable for all and definitely not for a high risk patient. Nor is it suitable for men with locally advanced cancer. After 4 to 5 years some men will need further treatment or prostatectomy. If cancer returns after radiotherapy it can prove to be particularly problematic.

Elevated PSA					
Multipractic MRI					
Targeted transperineal biopsy					
Localised cancer			No cancer		
Decision making					
AS	Surgery	Radiotherapy			
		Failure			
	Watchful waiting	Hormone Therapy (HT)	HIFU/ Cryo (Salvage)		

After the presentations we had a very interesting Q&A Panel Session with Chris Booth, Manit Arya and Rob Cornes, an Orchid Male Cancer Information Nurse. Here is a small selection of questions put to the panel.....

Q: *How does the panel view the decision to discharge patients into the local community?*

A: *There is a danger if the GP isn't knowledgeable or hasn't enough expertise. CNS nurses may offer a follow up service either 6 monthly or annually*

Q: *Views on super sensitive PSAs 0.1 0.2 0.3*

A: *There may well be slight fluctuations in PSA tests. After 3 small rises it would be deemed as recurrence. RADICALS is a trial to see the best time to administer radiotherapy after a radical prostatectomy*

Q: *A member with PSA below 0.1 who has had 20 sessions of radiotherapy so far and 3 HT injections (to be continued for 3 years) asked "has the cancer gone?"*

A: *Not necessarily. Remember the radiotherapy will go on working for 2 years after cessation of treatment. 1 in 3 men start to get a rising PSA after 8-9 years*

You can view the conference on YouTube at <http://tinyurl.com/jphnuej>

Tackle is very grateful to Terry Garrigan, Purley Prostate Cancer Support Group (SEHC) for producing this comprehensive report of the AGM

Feedback on PSA Discussions with GPs

Roger Wotton

You will have seen in the previous issue of Prostate Matters an article calling for men to share experiences of the PSA test. Prostate Cancer UK is spearheading an initiative to collect feedback on discussions men may have had with their GP over the last few years. Tackle Prostate Cancer has offered to help by publicising this initiative. You will find a form in this edition of Prostate Matters, which you can use to record feedback on any discussion you have had with your GP about a PSA Test during the past few years. A pre-paid envelope is also included. We know experiences are varied across the country so trying to identify any problems related to these discussions would be really helpful.

You can also find this form online. Just enter bit.ly/psa-survey in your browser.

Tackle Chief Executive Moves On



Rowena Bartlett, Tackle's CEO, is moving on. After four and a half years at the helm Rowena has decided to spend more time with her family while she considers her next challenge. Rowena said "I feel now is the right time to make a move, having helped develop Tackle to a position where it is now more professionally set-up, better governed and widely recognised as a key player in pursuing the interests of patients. I am proud of what I have achieved at Tackle and wish the organisation every success going forward".

Roger Wotton, Chairman of trustees had this to say. "We owe a debt of gratitude to Rowena for her hard work and determination to build Tackle's reputation, get us punching above our weight and representing the interests of prostate cancer patients and their families in an effective way. We wish Rowena every success in whatever direction she decides to take. The Trustees are now working on finding a suitable successor to continue the work Rowena has started".

Summer's here at Last - Put another prawn on the barbie!

Roger Wotton



Jack Maggot's Ceilidh Band

Aylesbury Vale held their annual summer fun BBQ last month and had a great time, along with guests from the neighbouring Milton Keynes group. 44 members and partners enjoyed a tasty treat put on by Thame Football Partnership and we had music from Jack Maggot's Band, a superb Ceilidh band run by David Rogers, one of our members. As well as a free draw for a bottle of champagne (won of course by the band!) we had a fun quiz on England (see elsewhere in this edition of PM). To top it off we had outdoor games of Boules for those who voted to remain and Quoits for those who voted to leave!



A brace of wives waiting for a dance!



We need you!

Raise vital funds for free when you shop online with **easyfundraising**.org.uk

It costs you nothing to raise money for Tackle - sign up to Easy Fundraising now!

Turn your online shopping into donations for Tackle Prostate Cancer

Do you shop online? Did you know that every time you buy something you could be raising money for Tackle Prostate Cancer?

That's right, over 2,700 well known retailers, including Amazon, John Lewis, eBay and Tesco will donate a small percentage of what you spend to Tackle Prostate Cancer to say thank you for shopping with them.

Just visit: <http://tinyurl.com/qaxl9ny> and follow the simple steps to sign up.

Easyfundraising has already raised over £7 million for over 55,000 good causes across the UK. So what are you waiting for? Head to: <http://tinyurl.com/qaxl9ny> now.

Already registered? Spread the word to family and friends to let them know just how easy it is!

12 year old Alexander Shows How Its Done

12 year old Alexander Holyland's Grand Father, Richard has advanced prostate cancer and he wanted to try to do something to help.

Single handedly, Alexander arranged a 7.5 mile charity run for the Leicester prostate cancer group, PROStaid. He planned the course, produced the sponsorship forms and chased up runners to participate without any help! The event, held on Saturday 23rd April raised a whopping £600 for PROStaid.

Everybody is amazed at Alexander's tenacity and initiative, what an achievement.

Very well done Alexander, everybody who knows you are very proud of you, especially Grand Father, Richard



Alexander is holding the collecting bucket!

Here is an easy England quiz. Feel free to have a go, irrespective of whether you voted to leave or remain!



- 1. Which Shakespearian king said “Cry God for Harry!, England and St. George!”?**

Henry IV Henry V Henry VI Henry VIII
- 2. Which English city has an annual goose fair?**

Nottingham Gloucester Coventry Salisbury
- 3. What is the most southerly tip of mainland England ?**

Land’s End Beachy Head Portland Bill Lizard Point
- 4. Which denomination banknote did the Bank of England introduce in 1752 and withdraw in 1945?**

£100 £200 £500 £1000
- 5. Which English poet wrote the first line “I wandered lonely as a cloud” ?**

Coleridge Tennyson Longfellow Wordsworth
- 6. Aquae Sulis was the latin name for which English city?**

Chester Bath Colchester Oxford
- 7. Where in England was legendary King Arthur reputedly born?**

Tintagel Camelot Glastonbury Boscastle
- 8. When is England’s national day - St. George’s Day?**

March 13th March 23rd April 13th April 23rd
- 9. Which English fortification did William the Conqueror build in 1078?**

Windsor Castle Warwick Castle Tower of London
Dover Castle
- 10. Which of these is not a Classic in English Horseracing?**

The Derby The Newmarket Stakes
The 2,000 Guineas The Oaks

The answers will be posted on the website <http://www.tackleprostate.org>

The Bay Prostate Cancer Support Group attended a Health Mela Den Bray

Members of The Bay Prostate Cancer Support Group attended a Health Mela in Carnforth on 25th June. What's a Mela you ask? Fair comment, we had not heard of before ten days ago.

It is in broad terms an awareness campaign. Because it was held local to our area we attended, not quite knowing what to expect. The venue was Carnforth High School Sports Hall.

I arrived at 0830 to set up our zip up banner posters and loads of literature looking at a long day ahead.

My first thoughts were this is a large hall will anybody come along from the town, how many exhibitors will there be to create interest? My fears proved groundless the hall contained at least 60 stalls. NHS professionals, charities associated with health issues through heart, dementia, obesity, MS society, Galloway's Society all helpful to our



community.

Our team, Michael, Richard and myself were kept busy trying to answer peoples questions about the prostate, very often from ladies who we gathered had partners with some sort of prostate issues.

It was evident that a lot of people were unclear as to what or where the prostate was, what was and its function. Hopefully we were able to enlighten them.

Once again, as we have found at other awareness events we had a proportion of Blokes who had the Ostrich gene and didn't wish to engage in any information gathering. We can only try. So apart from the contact with the public, we made some good contacts with the other stall holders and so we felt it was a really worthwhile exercise that we should try to repeat.



East Lancashire Prostate Cancer Support Group Crosses The Atlantic!

Whilst over in Los Angeles at the end of May, I visited two Prostate Cancer Support Groups. I was made very welcome at the L.A.P.D. group and given a commemorative medallion.

The photo shows Sergeant Don Provencio myself Dave Riley (East Lancashire Prostate Support Group Chairman) along with Officer Jim Rahm. in receipt of a Men United t-shirt.

A Walk Through Oxfordshire John Grundy
Chairman, Oxfordshire Prostate Cancer Support Group

I have many memories of great walking holidays in Europe and beyond. After my initial surgery for prostate cancer in 2010 it seemed that resulting incontinence would put an end to long walks, but with patience and help from the marvellous team at the Churchill Hospital, that problem has been resolved. After follow-up radiotherapy last year I am now walking again for pleasure, but also because I want to show men that there need be no limit to what you can do after cancer treatment.

I'm not sure any more exactly when I had the idea of a walk from Oxford where I live now to North Perrott in Somerset where I grew up, about 130 miles. I think it came to me when I was walking somewhere in north Oxfordshire and came across markers for a long distance path which, had I followed it, would have taken me to Somerset. It seemed like a good idea, but it was one that had to be put behind the ear to await its time. This summer a looming 70th birthday and an increasingly arthritic hip which threatened one day to limit the walking combined to tell me that the time had come. Out came the maps and guide books. Measuring distances and calculating that the legs could still cope with an average of 15 miles a day, I reckoned that I could complete the walk in nine days. The most favourable route went via Wantage, the Ridgeway, Marlborough, Devizes, Westbury, Mere, past Wincanton, then south of Yeovil to home territory and North Perrott. Much of the way was on the chalk uplands, where even in overcrowded Britain you can often walk all day and meet only a handful of people. There were some long distance paths to follow, which makes navigation easier because they have good waymarks and the map can generally stay in the pocket for long periods. And the internet (how did 19th century travellers plan their accommodation?) revealed that there were sufficient pubs, hotels and B&Bs as well as friends along the way to make overnight camping in hedgerows unnecessary. I'm too old for that!



John Grundy on the last day of the walk. The sign seems to say it all



On Sunday 3 July I reached my destination and spent a happy afternoon at North Perrott Cricket Club enjoying the remains of the previous day's beer and cider festival. Along the way I had been soaked beside the Kennet and Avon Canal, thrilled by the distant views on the Downs, attacked by three or four dogs that wanted to take a souvenir from my trousers, surrounded by inquisitive bullocks in a field in Somerset, and delighted by the support I had from sponsors. The walk has raised over £900 for the support group I chair, OPCSG, and proved to me that there is life in the old dog yet. Donations can still be made at:

<https://mydonate.bt.com/fundraisers/johngrundy1>.

Cabazitaxel and Firmagon - Tackle Makes A Difference

Hugh Gunn

A year last February, Cabazitaxel was taken off the CDF and put onto the 'Static List'. This meant that a very valuable late stage advanced prostate cancer treatment, which had been used very successfully in the clinical setting for about nine years was no longer available. A crushing blow to those patients who have had all of the various hormone treatments, including Abiraterone and Enzalutamide fail. This decision left all of these patients with nowhere to go and a very bleak future indeed.

Tackle was joined by the leading oncologists in the country to appeal this ruling. There was lots of letter writing to the Department of Health, meetings to attend and much hard work to have this decision revisited. The appeal took the form that Cabazitaxel has performed much better in the Clinical setting than in trials. Fortunately, common sense prevailed and in May 2014 Cabazitaxel reappeared on the CDF list.

In September 2015 NICE held another S.T.A. (Single Technology Appraisal) for Cabazitaxel and Tackle was joined by Alan Higgin, representing PCaSO as another patient representative.

After a lengthy meeting, which covered all of the latest information on Cabazitaxel, the public session was closed and NICE was left to make a new FAD (Final Appraisal Determination). Finally, on 25th May 2016, Cabazitaxel was passed for general use within the NHS in England.

This is a considerable achievement for patient power and for Tackle in particular. It is worth noting, that the only organisations representing prostate cancer patients to be involved in overturning this ruling were Tackle Prostate Cancer and PCaSO. Without their intervention and that of very senior oncologists, Cabazitaxel would no longer be available.

Firmagon (Degarelix) has also reached a satisfactory conclusion. It has finally been passed for use in patients who present with Spinal Metastases. This is very different from the previous FAD which said that Firmagon could only be used on patients showing signs or symptoms of spinal compression. This is a case which has been dragging on for literally years and one in which Tackle has been heavily involved. This included an appeal about the previous FAD and Tackle was an 'Appellant' at the hearing. Once again, much hard work, many letters and meetings in London, but a good result in the end.

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prostate cancer

www.tackleprostate.org

The National Federation Of Prostate Cancer
Support Groups

Tackle Prostate Cancer is the campaign name of
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The Editor would like to thank
everybody who has contributed to
Prostate Matters.

Without you, we would not exist. Please
keep the contributions coming.

East Lancashire Support Group Hold a PSA Testing Event

East Lancashire Prostate Support
Group held a PSA blood testing event
on Saturday 31st January 2016

The event took place at Burnley FC,
Turf Moor during the morning, 9am till
12 noon. The testing was carried by
Gary Steele and his 'team' including
eight Phlebotomists. The response
was beyond our wildest expectations,
273 men turned up during the three
hours!

They started arriving 8-40am and by 9
we had to ask the Football Club if we
could use an extra adjacent room.
Men came from all parts of East
Lancashire and continued arriving
right up to 12 noon!

**Out of the 273 tested - 14 were Red,
15 were Amber, rest were green
(ok). Two of the Red were, one at
PAS 268, one at 800!**

To have a successful event like this
does in fact need a lot of promoting
and advertising, via Local newspapers,
pubs, clubs, health centres, leafleting
around town, local radio stations, in
fact Stuart Marshall was interviewed
on Radio Lancashire at 7-20am on the
morning just prior to the event.

Quite a number of men had then
heard it on the half hour news
bulletins throughout the morning.

The East Lancashire Prostate Support
Group would like to thank all of those
who helped to make this such a
success, especially Burnley Football
Club's Catering Department, Football
in the Community Department, their
Media Department and of course the
eight Phlebotomists.

Over the course of nine events held,
1,140 men were tested

Stuart Marshall



Pictured left o right Stuart Marshall, Gordon Birtwistle,
(Burnley MP), Julie White

Please Check Your Details
Unless otherwise requested, your
details will appear on the list of
groups on our website.
We are asking all affiliated groups to check their
details on the Tackle website. The information
has been updated to include meeting times and
places.
See the map at: <http://tinyurl.com/omp6y5e>
If there are any corrections required please
contact Simon Lanyon by email:
simon.lanyon@tackleprostate.org.

tackle
Welcomes New Members
It with great pleasure we welcome the
following group to Tackle:
**North Hampshire
Prostate Cancer Support Group**
Catchment Area:
North Hampshire
Contact: Alan Instone
alan@eldamar.co.uk

 Follow us on Social Media
<http://tinyurl.com/o2blofo>
 Tackle @TackleProstate
 Text Giving - Text:

**Don't forget, the
National Help Line
is now Free of
charge:
0800 035 5302**



Phlebotomist Win Bond