Federation launches new website

From this February the Federation launches a new website, www.tackleprostate.org

This new style will have more impact and more information. At the moment it is still being developed, but key features are already in place, including a “latest news” feature (currently headlining NICE’s betrayal of patients over Enzalutamide, see below), and a web version of PCaSO’s acclaimed patients’ booklet, Knowledge Empowers.

In the near future we plan to include video clips, a blog facility and pages on which member groups can put up their own announcements and news. Please visit the site, and if you have comments, send them to: webmaster@prostatecancerfederation.org.uk.

Patients outraged by cruel NICE betrayal

Men with advanced prostate cancer have been betrayed by “Orwellian” manoeuvring by NICE to deny them the life-saving drug, Enzalutamide.

Enzalutamide is one of two drugs used to control the cancer when, as invariably happens, conventional hormone therapy and chemotherapy cease to work. The other is Abiraterone, which was approved by NICE in mid-2012 and many (but not all) men are doing well on it. However, one of its drawbacks is that it can cause liver damage, particularly in patients who have previously had chemotherapy. For such patients, the only hope is Enzalutamide, which has been undergoing the NICE appraisal process for the last 14 months.

All the signs were that that it would be approved. Indeed, the last draft of the consultation document, released in November, approved the use of the drug for any patient who had been given chemotherapy. Based on this a number of clinicians have led those of their patients who are not doing well on Abiraterone to expect imminent approval of Enzalutamide.

Earlier this month however, in a cruel move that dashed these patients’ hopes, NICE issued a final assessment. To patients’ and clinicians’ dismay, with no prior discussion, a caveat had been introduced that use of Enzalutamide was not approved where the patient had previously been given Abiraterone, the very class of patient for whom it might be said that Enzalutamide was developed. We in Tackle immediately sent a strong letter of protest, pointing out that this was an abuse of NICE’s process, and the caveat was not supported by any evidence.

The response from NICE was almost instantaneous. Consultees were asked to pretend the final assessment had never existed. Two weeks later, a step backwards was taken and a revised consultation document issued, but the offending caveat is, of course, still there.

We say: Patients are outraged by this cruel betrayal by NICE. NICE have broken their own appraisal procedures in order to introduce, based on no evidence, a significant change that will be the death knell for many patients. Then, when caught out, they attempted to cover their tracks. They cannot be allowed to get away with it. We call on clinicians, some of whom have reported “spectacular” results with this drug, to put their weight behind a patient’s call for fairness.
In a brief introduction, Sandy Tyndale-Biscoe, Chairman of the Tackle Campaign, spoke of the campaign’s plans for 2014. These include raising funds to make the Federation self-supporting, campaigning for PSA-based early detection, working with PC-UK to improve support for patients’ groups, and hosting the Europa Uomo Annual Assembly in London.

Having been a GP himself he can understand the problems from both sides. In 1998 the “data service” was a lady called Margaret who held pieces of information in a back room at his practice along with everything else. Patient data service for men with disease, can now be accessed online and enables you to both input and take out information.

He thought that roles for a support group could include: buddy support which would need specialist training, website navigation support, which could be possible through Skype, and campaigning for and helping specify a patient data service by which hospital letters and test results could be obtained online. This last is already available in America with radiology units in the State of Georgia putting scans online. He noted that, although a great service with huge potential, information online can be too remote and impersonal. On a visit to a clinic there is often the “door handle” effect, when a patient’s true worry is only be raised as he opens the door to leave with an “Oh, by the way, doctor,...”.

Robert Lester, of the Edinburgh and Lothian PCSG, spoke about implementing a Patient data service by which prostate cancer patients might access their own clinical information on-line.

Dr Mark Newbold, Chief Exec Heart of England NHS Foundation Trust spoke about Working with Clinical Commissioning Groups.

Dr Newbold explained that he trained in medicine before pursuing a career in management. He explained the purchaser/provider split underlying the NHS. The providers include acute hospitals, GPs and community care and should all be Foundation Trusts.

The NHS is driven by many factors, many of them non-medical, e.g. media storms, usually negative (e.g. the Mid Staff hospital scandal), public and political opinion, serious health issues in local areas, and protecting NHS budgets (i.e. cuts elsewhere). His view was that the NHS, although very good at acute illness, is poor at chronic illness. There is a need to maintain health and to listen to the patient. There is an independent funding review for new treatments.

Asked about the legal position of a GP who refuses to do a
PSA test, he said that the GP takes that decision on himself. Some problems are so complex that one has to be highly intelligent and well informed, just to be undecided about them! A patient can opt to go anywhere for the right treatment, even abroad. It’s probably best to travel to where the expertise is.

The afternoon session began with a brief update from David Smith on the “Riskman” project which arose from “The Great PSA Debate” in 2009.

There had been difficulty in getting the £1M funding required for Phase 3, but Owen Sharp from PCUK confirmed his backing and the team are confident the money will be found. The DRE (digital rectal examination) will be replaced by a biomarker or genetic marker which would cost approx £500 a test. The project has been kept afloat by legacy of £50,000 from The Bailey Will Trust.

Roger Wotton of the Vale of Aylesbury PCG spoke on Engaging with local sports organisations.

His theme was what the members of the Federation could do through the agency of sport, to raise awareness and “tackle” prostate cancer. Could anything be done nationally? Was there a single big idea? During 2014 the hopes are to target The Open (golf), the Tour de France and Black cab drivers (LTDA London Taxi Drivers Assoc).

The day ended with members asking for more regional meetings which would be easier to get to, to share ideas and implement good practice.

Researchers are trying to stimulate the body’s immune system to target cancer cells using immunotherapy.

The PROSPECT Study is testing a vaccine-based immunotherapy for prostate cancer. The vaccine – given by a series of seven injections over five months – is designed to train the body’s immune system to destroy prostate cancer cells. The trial is for men with prostate cancer that has spread to other parts of the body and is no longer responding to hormone therapy.

It is currently running in Bristol, Birmingham, Cardiff, Glasgow, Guildford, Leeds, St. Mary’s, Royal Marsden, St Bart’s, Manchester, Plymouth, Southampton and Clatterbridge Hospitals. For more information, please contact one of the centres listed above.

Telephone numbers and addresses can be found on the Tackle website: www.tackleprostate.org/get-on-a-trial.php
Our Federation is the voice of people with Prostate Cancer. It is underpinned by a network of support groups across the country, but the Federation would like to improve the connection with and between these support groups. To help achieve this, an initiative is underway to establish a number of regions made, bringing together groups to help improve communication and share experiences, without individual groups losing their local identity.

With such a regional structure the Federation will find it easier to establish consensus policies, to stay in touch with emerging local issues and to focus on the right patient priorities. At the moment it is difficult to identify and share best practice as there is no mechanism to promote good ideas emerging from support groups. Of course, it goes without saying the proposal for such a regional structure should not add any overhead to the organisation, have any material effect on costs and must be self-sustainable with benefits clearly outweighing any issues arising.

When we talk of benefits, we are thinking about real opportunities for networking, in addition to the national workshops held each year. Having a simple regional structure in place should encourage and facilitate some resource sharing across groups. Examples might be having a key speaker talk to a larger audience, arranging a joint visit to discuss or view new clinical developments, or two or more groups combining at a key public event to maximise the impact in raising awareness. We could also look to having regional reports in each edition of this newsletter.

This proposal will also benefit prostate cancer patients by making it easier to have their voice heard at the top of the Federation. At this level it also provides a sharper focus on campaign management, where a regional implementation can be more easily managed and followed through.

The plan is to allocate support groups to regions. The proposed regions are shown below:

Each regional organisation will operate as a network, meeting a minimum of twice a year, with one meeting scheduled immediately prior to any national Federation meeting. The way that individual support groups form a network within their region will vary. It could be a meeting of committee members (or steering group members) from each support group, or could be open to all members of all support groups in the region.

Each regional group will be organised and administered by one of the existing local support groups. A nominee from each regional group, essentially a regional “focal point” will be appointed to represent regional group interests at the national level. It is hoped each region in turn might host key meetings of the Federation.

<table>
<thead>
<tr>
<th>Region</th>
<th>Support Groups</th>
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<tbody>
<tr>
<td>Scotland</td>
<td>Edinburgh &amp; Lothian PCSG</td>
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<tr>
<td>North West</td>
<td>Bolton PCSG; Bury/Heywood PCSG; East Lancs PCSG (Burnley); Furness PCSG; Leigh Lancashire PCiG (Crewe); Oldham PCS; Salford PCS; Stockport PCS; North Cumbia (Carlisle); The Men’s Group (Liverpool); Liverpool; South Liverpool Cancer Support Centre; Prostate; The Key PCSG (Lancaster); Wirral &amp; N. Cheshire PCS; The Walnut Group ( Preston); High Peak PCSG (Sheffield); N. Staffordshire PCSG; Shropshire PCSG</td>
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<tr>
<td>North East</td>
<td>Leeds PCSG; Teesside PCSG; Northern Region PCSG (Newcastle); York &amp; Selby PCSG</td>
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<td>Heart of England</td>
<td>Cancer Support Dudley; Leics &amp; Rutland PCiG; Central England PCiG (Leics); Practise (Leics); City &amp; Sandwell PCSG; Radnorshire PCSG; South Warwickshire PCSG</td>
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<tr>
<td>Wales</td>
<td>Progress PCiG (Newport); Cardiff PCiG; West Wales PCiG (Cardigan)</td>
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<td>Midshires</td>
<td>Aylesbury Vale PCSG; Chiltern PCSG; FOPPS (Wafford); Oxfordshire PCiG; Reading PCiG; Cotswold PCSG</td>
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<tr>
<td>Eastern Counties</td>
<td>Cambridgeshire PCiG; East Suffolk PCiG; Norfolk &amp; Waveney PCiG; PHASE (Essex)</td>
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<tr>
<td>London</td>
<td>APPLE; Cancer Black Care; Greater London PCiG; Guys &amp; St. Thomas’</td>
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<tr>
<td>South East</td>
<td>PCiG South Brighton; PCiG Oxford; Chichester; PCiG Hampshire; PCiG East Sussex; PCiG Eastbourne; PCiG Cambridgeshire (Kent); PSA; Midstatute; PSA Orpington; PSA Canterbury; PSA Tunbridge Wells; SS Cancer Care (Surrey); The Prostate Project (Surrey)</td>
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<tr>
<td>Western Counties</td>
<td>Cornwall PCiG; Devonford PCiG; N &amp; E Devon PSA; Prospect PCiG (Bristol); Somerset PSA; Torbay PCiG; PCiG Dorset</td>
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</table>

At the moment of writing we are identifying individuals who might wish to take on the role of regional focal point to help take this initiative further, and we are working up the details of how this proposal can be implemented. Watch this space for further news on this initiative!

Of course, if you would like to volunteer to be a coordinator, please get in touch with me, rwortton@btconnect.com.
Sorting out ED - a symptom of confusion?
Bob Melling

To back this up with your voice, last summer I asked Groups for help with a survey of ED as experienced before diagnosis, to explore its relevance. Without asking direct questions the evidence lies hidden, and I have found no other source - by NICE's own admission "...on the assessment of patients presenting... with symptoms... evidence in this area was so limited that some [other] reviews have been included, to enable cautious extrapolation...". Personally, I would rather trust my life to something more solid than "cautious extrapolation", and the survey has made a start.

What did we find? Thank you to 126 members who completed questionnaires – obviously the more the better, but this was a fair if modest sample. It showed that:-

- 28% have experienced ED before diagnosis
- 54% of them reported it to their GP, and 60% of those had a PSA test.

This left 40% who did not - and these were twice as likely to be dissatisfied with the GP’s explanation as those tested, suggesting an "unexplained" number who should have been tested.

- those tested were more likely to be diagnosed with PC in the following 3 years than those untested, with some evidence that diagnosis was at an earlier stage.

These findings deserve to be taken seriously – and important questions demand answers. Shouldn’t men be openly encouraged to report ED to their GP? Why so many untested and unsatisfied when they do? - this suggests arbitrary treatment. Isn’t ED a valuable factor in risk-based screening? Does the general toleration of an age trend for ED cover up the similar trend for prostate cancer?

And what else are we ignoring...? Onward...

Editors Note:
Bob’s article above makes the important point that men who suffer unexplained erection problems should seek medical attention as it might be an indication of prostate cancer. It may also be a pre-cursor of a heart attack. A recent article in Trends in Urology states that, on average, ED precedes a cardiac event by between 2 and 5 years. You can see Prof Mike Kirby discussing the link between erectile dysfunction and cardiovascular disease by going to:
http://www.trendsinurology.com/view/0/videos.html

Next to cancer itself, the prospect of erectile dysfunction (ED) sends a chill to the hearts and parts of men, threatening our self-esteem, relationships, and identity. When young we needn’t think the unthinkable, but in our maturity we must – ED is a life-damaging but acknowledged side effect of many prostate cancer treatments, but just as importantly it can be a symptom, and in a world where diagnosis is chancy, and screening not fully up to the challenge, every indicator of risk matters.

Generally, men need to be more alert to signs that all is not right with them. If that leads to earlier prostate diagnosis, more lives have a chance. And doctors need more information about less common signs. We are told that “...prostate cancer is frequently asymptomatic...” but is that because we and GPs are too focussed on “headline” symptoms, particularly urinary which are usually the first mentioned and reported? ED is one of a range of other non-specific symptoms – West Wales Group has researched a list of 21 - but unlike say, “lower back pain”, by its nature it rings more strident alarm bells, and should spur us to action.

Equally alarming, there are contradictions for GPs when ED is presented to them. Recently the Federation made representations to NICE to address this in their current review of Guideline CG27 on Referral for Cancer Testing, where ED tops the list of symptoms requiring PSA tests “if unexplained [at primary examination]”. Yet the NICE website also points to other guidance which says “tests... only if there are other symptoms”. (Anyway, how can ED be “explained” without all the evidence?) And there are other confusing sources. Alarming indeed.
Leighton Hospital Prostate Cancer Support Group Goes to ASDA

Gary Steele

SHoppers in Winsford were given the offer of a lifetime, courtesy of a royally-recognised cancer testing pioneer.

For the first time ever in the UK, men had the chance to get a lifesaving prostate specific antigen (PSA) test carried out for free while they picked up their weekly groceries.

The Leighton Hospital Prostate Cancer Support Group (LHPCSG) has tested 1,210 men this year alone – successfully treating 38 men for cancer.

The charity’s chairman, Gary Steele, was awarded the MBE this year for his lifesaving work and his tireless campaign to get the Government to roll out these techniques across the NHS.

“It’s gone very, very well and there has been a great turnout,” said Gary, of the event on Monday, October 7th.

“Men are coming along, sitting down, and putting their test into the machine. That’s him finished then and he can go shopping with his misses.

Ten minutes later, he can come back and he’s got his result. It’s completely revolutionised how we can operate.”

The supermarket-based event allowed Gary to target men who might not have found time to attend one of the dedicated testing events he runs throughout the year.

Tony Vine, 68, was visiting his Winsford partner from his home in Rossett in North Wales when he dropped into ASDA.

In less than 10 minutes he was able to get a PSA test and put his mind at rest.

“It was an absolute piece of cake, no problems whatsoever.

“I’ve been saying I’d get it done for several years but never got round to it.

It was fantastic walking in today and being able to get it done so quickly.”

If the PSA test result shows a risk of developing cancer, the charity’s urologist, Dr David Baxter-Smith, conducts another simple test that avoids the need for an invasive biopsy procedure.

The sample is then boxed and sent to experts in Cambridge, costing the charity £200.

LHPCSG’s lifesaving work has cost in excess of £40,000 this year alone – all of which has to be raised by charitable donations.

“It’s a lot of money, but what price do you put on a man’s life?” said Gary.

For videos illustrating the simplicity of the procedure, visit www.winsfordguardian.co.uk

To get in touch for a PSA test or for fundraising forms, call: 01606 553097 or email coll.hubbatt@tiscali.co.uk

For more on prostate cancer, visit www.tackleprostate.org

The UK falls well behind the rest of Europe and America, in PSA testing.

Gary’s work massively expands the current treatments available on the NHS – offering PSA testing to a wider age range, with the offer of further expert testing if required.

In the rest of Europe and throughout many countries elsewhere in the world, all men of 50 are required to undergo a test and Gary wants to see the UK follow the example, as well as wider use of the new life-extending prostate cancer drugs which are now becoming available.

LHPSSG has detected 51 cancers this year alone, of which 38 have been successfully treated – that’s 38 lives saved.

The remainder are on active surveillance, whereby Gary’s charity keeps tabs on the patient, offering further testing and continued support.

80 per cent of men diagnosed with prostate cancer don’t have any symptoms.

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/429eef7f

and the contact web page:

www.tackleprostate.org/member-organisations.php

If there are any alterations, please contact:

Sandy Tyndale-Biscoe

Email webmaster@prostatecancerfederation.org.uk
Integration

Peter Hosking  Torbay Prostate Support Association

In November I attended the Hospital formal AGM. After the usual business issues, there was a talk explaining Integration and new government initiatives. After the talk, I asked the question, why were GPs not included in this and they were unable to answer. I commented that perhaps there was a lack of understanding by a minority of GPs although most are excellent. A better understanding of symptoms and treatments would not go amiss and the need to give PSA blood tests early where requested, as authorised by the Ministry of Health. Thereby getting treatment early as opposed to treatment when it is too late?

My arguments were well received by the Chairman and all of the members present.

To my surprise, the following morning, I received an invitation to attend a meeting at the offices of the local Clinical Medical Commissioning Group with their Managing Director and Area GPs’ Chair.

I was very courteously received and the outcome of meeting was highly satisfactory. I was invited to assist in the preparation of guidance notes for GPs and to assist them in dealing with prospective prostate cancer Patients and relatives. I was delighted to accept.

Formal sessions I understand are already in progress in the North of England and have also begun in South Devon, as is perhaps happening elsewhere. These sessions I understand are being well received by the GPs and their participation is splendid.

The Benefits of Aromatherapy

Kate Gunn

Hospitals are usually noisy, very busy and sometimes frightening places, but as soon as we entered LOROS, our local hospice, we were met by smiling faces and an atmosphere that was bright, warm and calm.

After seven years of battling my husband Hugh’s advanced prostate cancer, we were feeling ragged and starting to fear that we were getting to a state of complete exhaustion. It was suggested that we might benefit from a course of aromatherapy and so we attended with an open mind. Our therapist/nurse, Shindy, greeted us with a serene smile and showed us to a lovely warm room with low lighting and gentle music playing. There was a soft waft of lavender and her hands started their magic of what felt like gentle ripples, gradually turning to waves of relaxation. You feel all the tension falling away and afterwards my mind and body felt light. Hugh felt exactly the same and luckily we were able to have another five sessions over the summer.

LOROS gave us a peaceful haven that allowed us to reconnect with ourselves and feel recharged to deal with our challenges.

New Treatments for Advanced Prostate Cancer

There have been exciting developments in late 2013 in the treatment of advanced prostate cancer, with new treatments becoming available.

Enzalutamide is about to be passed be NICE, but with the caveat of not being available if Abiraterone has been given first. Enzalutamide is currently available under the CDF. ‘Tackle ‘is doing all it can to make NICE remove this caveat. See page 1.

Radium 223 is now available under the CDF. Radium is very similar to calcium. Like calcium it is taken up by active bone cells. This makes it a good way of targeting bone cancer cells. Cancer cells are more active than bone cells and so more likely to pick up the Radium 223.

Radium 223 treatment uses a type of radiation called alpha particles to kill cancer cells. Radium 223 is injected into your blood and it circulates to your bones. The cancer cells in the bone take it up. The radiation only travels a short distance, between 2 and 10 cells deep. This is much less than a millimetre. So it means that the cancer cells receive a high dose of radiation, but healthy cells receive only a low dose or no radiation. So this treatment causes fewer side effects and is more successful than some other types of radiotherapy

Abiraterone is now available from the CDF for patients who have not yet had chemotherapy. This is very welcome news indeed, as it not only avoids men having to go through the rigors of six months of chemotherapy, but the body will be not have been weakened and be much better placed to accept this very successful treatment.
Prostate Cancer Support Federation
Action for prostate cancer patients and their families
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Mr. David Baxter-Smith

To View other roles carried out by volunteers, please visit:
http://tinyurl.com/lzmfws

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.

Droylsden Group - Awareness and Fund Raising Night
John Coleman

A charity awareness and fundraising evening in aid of Prostate Cancer Support took place on the 12th June 2013 in Hyde, Cheshire. Over 100 people attended the ticketed event and a great night was had by all. The night included a raffle together with an auction. Lots in the auction included family ticket tours for Manchester United and Manchester City, a pair of golden tickets for a tour round Robinson’s Brewery, a signed original cartoon by local cartoonist Tony Husband and a hospitality prize for four at Hyde Football Club. Many more prizes that were donated by local businesses, friends and family were included in the raffle.

Music performances were a great crowd pleaser. The night was opened by local musician/guitarist Darren Smith who played a storming solo acoustic set followed later on in the evening by headline act Greg and Mikey of local band Bauer who played a selection of their songs including new material and a cover of eighties hit ‘Feels Like Heaven’ by Fiction Factory.

The event was also attended by urology consultant surgeons Richard Brough and Steve Bromage and four of the Specialist Urology Nurses from Tameside and Stepping Hill Hospitals.

Organiser Jenny Thornley, whose father has had prostate cancer, was thrilled with how well the night went: ‘I can’t believe what a night we had! There was such a good atmosphere on the night itself and I’ve received such positive feedback from people since. It’s the first time I’ve ever organised anything like this and I can’t say that it was easy but the amount of money we have managed to make more than makes up for it. I couldn’t have hoped for a better result.’

Up to now Jenny has managed to raise almost £2,400 for Prostate Cancer Support from this event. All money raised will go towards funding a robotic arm to assist the urology surgeons carry out more accurate prostate operations at Stepping Hill hospital.

The event was made possible by a grant of £400 from the Prostate Cancer Support Federation

It is planned that a PSA testing session be held in the same venue in the next few months.

Racehorse Prostate Awareness Progress Report

Having been gelded in November 2013 (a condition not unknown to many of us), Colin Peach’s racehorse, Prostate Awareness, is having a well earned rest. He continues to grow and has now reached the height of 16.3 hands. He is a big horse indeed. He will start racing again in April 2014

His stable, ‘Middlam Stables’ in North Yorkshire, are having an open day on April 18th (Good Friday) and Graham Fulford will be holding PSA testing sessions all day.

It is planned that Prostate Awareness will make a series of guest appearances at racecourses all over the country to help raise awareness of prostate cancer. Watch this space.