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2014 Annual Conference and AGM – "Tackle at Twickenham"

Twickenham Stadium, 12th June, 2014

The 2014 Annual Conference and AGM of the Prostate Cancer Support Federation will be held on 12th June at South Stand, Door A, Rugby House, Twickenham Stadium. The event is sponsored by Janssen and Prostate Cancer UK, and will be co-located with the Annual Assembly of Europa Uomo, which occurs the next day.

The morning session, which commences at 11:00 am sharp, will comprise a short Annual General Meeting, including election of Officers and Trustees, and then an extended open forum at which members can discuss the charity's progress and future direction.

The afternoon, Conference session, in which we will be joined by Europa Uomo delegates, is focusing on well-being and life-style aspects of living with prostate cancer. Topics include Jansen's "Pit-Stop" programme for managing your life-style with cancer, Prostate Cancer UK's new campaign on erectile dysfunction, Stéphanie McArdle on well-being, and news from Grayshot Spa who have donated £25,000 worth of stays and treatments as prizes to Federation members.

As usual, attendance is free to representatives of Member Groups. In addition, thanks to the generosity of our sponsors, we are in a position to offer travel expense refunds for up to two representatives from each Member. These will be paid direct to the Member Group who can then distribute the funds as they wish amongst their members.

To book places, please email the following information to: bookings@prostatecancerfederation.org.uk

Name(s) of participant(s)

Support Group Name

Any dietary requirements

Contact telephone number and email address

Please indicate which participant will be the Group's Delegate for AGM voting

For details of the Twickenham site and how to get there, please see the Tackle website, www.tackleprostate.org.

A Progress report from Chief Executive

by Rowena Bartlett

What's been happening....

Continuing with the plan that the focus this year would be on Fundraising & Communications, there has been a great deal of activity and much has been achieved. So far this year we have had national press coverage, raised over £20k, secured a new Ambassador and new partnerships, finished the website, set up Twitter and Facebook and set up a TextGiving facility. And, thanks to Roger Wotton, we now have a regionalised structure.

Fundraising 2014

Funds raised so far this year total £20,500, comprising £13.5k from Astellas, £5k anonymous donation (likely to be as a result of articles in the national press), £1,500 from Thorold Dewling Recruitment. We have also received a £50,000 legacy donation for Riskman.

For our Awareness Event, The Winning Tackle (details below), we have so far received prizes of a two-night stay at Grayshott Spa, a signed English Rugby Shirt and PowerTravellers as prizes. Once again, the Think Tank have supported us by billing us for only part of the work that they do.

In addition to Astellas, we have secured other new long-term partners: Power Traveller, Thorold Dewling Recruitment, The Rugby Players Association and Grayshott Spa.

We now have TextGiving facility and Tackle-branded collecting tins, buckets, pens, bibs, T-shirts, caps and wristbands.

Communications and PR

We have had good press coverage including two articles in the broadsheets on the Enzalutamide campaign, and increasing recognition of Tackle as the voice of prostate cancer patients. Illustrative of this is that we have been asked to provide the chairman for a working group to inform the development of a NICE Quality Standard for prostate cancer. Recent activity during Prostate Cancer Awareness Month was focused on Riskman. During May we will be promoting awareness of Tackle and the importance of Early Detection.

The new website (www.tackleprostate.org) is now fully running, although of course we will continue to improve and develop it. We now have Twitter and Facebook accounts.

Annual Conference and AGM

Tackle at Twickenham will take place on Thursday 12th June with a focus on well-being and will include a presentation of PitStop, a Janssen project to encourage healthy living for prostate cancer patients. The conference will be funded by PC-UK and Janssen and, this year, we can offer travel costs to representatives from Member organisations.

Regionalisation

Thanks to some excellent work by Roger Wotton, we now have a regional structure and have had our first meeting of regional coordinators. We will be hearing from our Regional Representatives at the Conference in June when they will present their findings from a Questionnaire about what the priorities are for Groups. In this way we are improving our role as "The Voice of the Patient". There are already signs that Regionalisation will lead to increased membership, better support for patients and greater campaigning strength.

And in the pipeline.....

Tackle Launch/Awareness Event : The Winning Tackle

This is taking place in May. We will be promoting awareness of the disease and the importance of early detection. We are targeting morning commuters for two days at Waterloo Station (footfall 27,000 each morning between 6.30am and 9.30am) and two days at Victoria Station. Commuters will be encouraged to log-on to the Tackle Website to find out more about prostate cancer and the chance to win a prize. This will also raise Tackle's profile and result in a considerable number of hits on our website. The newly reprinted It's a Man Thing will be distributed.

Project with Grayshott Spa and Zandra Rhodes

Grayshott Spa in Surrey are offering a new complementary treatment to cancer patients. They have donated £25,000 worth of stays and treatments to Tackle for us to gift to our members. They are also developing a fundraising project for us with a press call likely to be in October with Zandra Rhodes and possibly Boris Johnson.

We are now beginning to reap the rewards of the groundwork we have done over the last couple of years and, given our limited resources, we are achieving a great deal and making good progress with our aims to raise our profile and to become financially self-sufficient.

SCREENING - FURTHER THOUGHTS

David Baxter-Smith

I have recently heard two interesting clinical histories which I would like to present to you:-

Case History 1:- A man of 58 had a routine test as he was anxious about possible carcinoma. The test was positive as a result of which he underwent biopsies but unfortunately this process led to complications as a result of which he needed further extensive treatment and was in hospital for ten days. Fortunately the biopsies all proved negative.

Was he over treated?

Case History 2:- A man of 67 had a routine test as he was anxious about possible carcinoma. The test was positive and he was advised to undergo radical surgery. This left him incontinent and with erectile dysfunction but he has been cured of the carcinoma.

Was it worth it ?

Answers to these clinical problems:-

Both men were advised to undergo screening for bowel carcinoma.

Case History 1:- The result of his test was a false positive - blood was found in his motions possibly as a result of bleeding gums when he brushed his teeth. The biopsies of suspicious looking areas in his bowel when examined at colonoscopy produced a bowel perforation for which he needed major surgery to repair the defect.

Case History 2:- This man was found to have a low carcinoma of the rectum for which he had an anterior resection leaving him with an end colostomy which is incontinent of faeces and the pelvic surgery damaged nerves needed for an adequate erection.

Was it worth it ?

The Government promote screening for bowel cancer and yet this may lead to over treatment, incontinence and erectile dysfunction.

The Government objects to screening for prostate cancer which may lead to over treatment, incontinence and erectile dysfunction!

Norfolk and Waveney PCSG Helps The Norfolk and Norwich University Hospitals NHS Foundation

David Paull



The Targeted Radiotherapy Appeal Fund Raising Team

The Norfolk and Norwich University Hospitals NHS Foundation Trust launched a new fundraising appeal to raise £600,000 in late 2013 called Targeted Radiotherapy Appeal. The aim is to treat more cancer patients with a type of radiotherapy which reduces treatment times and also means some patients can be treated closer to home.

The money raised will be used to reconfigure some of the existing rooms and to buy equipment in the Colney Centre, to provide state-of-the-art facilities for people undergoing internal radiotherapy, known as high dose rate (HDR) brachytherapy. The new facilities will allow more patients to benefit from this treatment.

Standard radiotherapy uses radiation directed at the tumour from outside the body so that the radiation travels through normal tissue to get to the tumour. This means that some normal tissue could be damaged, although modern techniques aim to keep this to a minimum. Brachytherapy involves placing radioactive sources inside or near a tumour. As the radiation is delivered internally it does not have to pass through so much normal tissue, which reduces the long-term side effects. It also means the dose that tumours can receive is significantly higher, which in turn can improve cure rates and reduce treatment times.

HDR brachytherapy is mostly used to treat cervical cancer patients at NNUH. The new facilities will mean NNUH will become one of just a handful of hospital Trusts in the country offering HDR prostate brachytherapy. The new service lead, Dr Jenny Nobes says "this will reduce travel for this group of patients who currently have to travel to London for HDR brachytherapy".

Dr Tom Roques, NNUH Consultant Oncologist, said: "The new brachytherapy service will make a real difference for patients with some types of cancer. It will allow us to focus radiotherapy more accurately, particularly for some prostate cancer patients. This should lead to higher cure rates, less damage to surrounding organs and fewer repeat visits to hospital for treatment."

Following the launch of the appeal senior figures have signed a pledge to support the cancer fundraising campaign. Those signing the TRA pledge were the Right Reverend Graham James, Lord Bishop of Norwich; Philip Blanchflower, Chairman of Big C; Daniel Williams, Chief Executive of Big C; Simon Bailey, Temporary Chief Constable of Norfolk; Noel Warner, Chair of

Norfolk and Waveney Prostate Cancer Support Group, Provincial Grand Mason John Rushmer and Wendy Adams, Vice Chairman of the Norfolk Federation of WIs. The group was joined by Martin Bell OBE, the broadcaster and former MP, who is also supporting the campaign in his role as patron of the Norfolk and Waveney Prostate Cancer Support Group.

The Lord Lieutenant of Norfolk Richard Jewson and the Right Reverend Alan Hopes, Bishop of East Anglia have also committed to signing the TRA pledge although they were not able to be at the event.

The Right Reverend Graham James, Lord Bishop of Norwich, says: "I am pleased to endorse the appeal which will have such significant benefit for local cancer patients. By bringing together public figures I hope we will encourage others to raise money for the appeal and to get the message out to a wider audience."

Health Minister Norman Lamb MP spoke in support of the campaign although he was unable to be at the event. He said: "The Norfolk and Norwich University Hospital is the only hospital providing radiotherapy for cancer patients in Norfolk. It is incredibly important to ensure that people have access to good quality modern medical facilities and, where possible, for treatments to be available locally."

Daniel Williams, Chief Executive of Big C says: "Big C is very pleased to have pledged £50k towards this appeal. As Norfolk's cancer charity we are very pleased to be supporting the development of new specialist treatment and expertise which will improve the lives of local people."

Anna Dugdale, Chief Executive of the Norfolk and Norwich University Hospital, says: "We are very grateful for this pledge of support by leaders within our community for the Targeted Radiotherapy Appeal campaign which will make a huge difference to the lives of local people and their families."

Enzalutamide - The Decision

NICE have finally made their decision on enzalutamide. It is now recommended for use with advanced prostate cancer patients who have undergone one round of docetaxel based chemotherapy.

The caveat that we complained about so bitterly 3 months ago, which banned the drug's use after abiraterone, has been removed. Instead, the guidance specifically states that the use of enzalutamide for treating prostate cancer previously treated with abiraterone is NOT covered. What does that mean?

In their guidance notes NICE now agree that enzalutamide can be beneficial if given after abiraterone.

We would like to believe that this means that the decision on treatment pathways will be left to clinicians. We would have preferred it if NICE had followed Wittgenstein's advice remained silent about that on which they felt they should not speak, but the main objective has been achieved and we should be grateful for that. Our task, as patient-led support groups, is to ensure that the individual oncologists and local commissioners are aware of the potential effectiveness of enzalutamide after abiraterone, particularly when the patient has been taken off the latter drug because of its toxicity.

Tackle has been working extremely hard on this and it is gratifying that our arguments, presented forcefully to the appraisal committee, have been listened to. It is a success, albeit only a partial one. A big thank you to all of you who have taken the trouble to sign the petition, which was set up by PC-UK, which has 12,000 names on

Reflections from the Front Line: The Walnut Programme in a Nutshell

Sarah Russell, Director of Education and Research, Peace Hospice Care and the Hospice of St Francis, and Doctoral Research Student



Often hospice care is seen to be just about dying. But it is not. It is also about living and being with our community. The Walnut programme is exactly about that. Supporting people to live and helping them in the way that matters most to them.

What is the Walnut Programme?

A communication skills workshop funded by Prostate Cancer UK and part of 'Back in the Driving Seat' programme provided by the Hospice of St Francis and Peace Hospice Care in Hertfordshire.

Why bother?

What men tell us and published research confirms, is that men and their families can sometimes find conversations about living with prostate cancer tricky! This could be with each other, doctors and nurses or when talking and supporting each other. How often do you get a chance to safely try out different ways to have these conversations?

How does it work?

I act as the facilitator for the Walnut programme. I will discuss and agree with the men (and their families) what would be most helpful in a short workshop. The workshop includes two volunteer actors role playing scenarios chosen by the group. The group then decides what and how to have the conversations so that they can try out ideas and thoughts for tricky conversations.

What do the men think?

The Hospice of St Francis, Peace Hospice Care and the Aylesbury Vale Prostate Cancer Support Group have worked together on the first Walnut Programme workshop. The group as its name suggests, exists to support men that have been diagnosed as having prostate cancer and, just as importantly, it supports their wives, partners and families. The group covers an area stretching from Thame to Berkhamsted.

Roger and Jeremy tell us:

In our first workshop we planned with Sarah the type of conversations that we found tricky. We wanted to be able to support newly diagnosed men and their families as best as possible. The aim was to try out difficult conversations and discuss different strategies, as well as see and hear the impact of our words in the scenarios. In the workshop we played out two types of conversations, tried out different wording, had feedback from the actors and reflected together. This was felt to be a very valuable exercise.

"These workshops are having a really positive impact on my work – it is helping me to help others see their problems clearly and find solutions to those problems."

As a result of the partnership we hope to be able to offer a link between prostate cancer patients, the hospices and existing members of the support group. Talking to each other does seem to reap benefits! This also applies to wives and partners of prostate cancer sufferers. Early feedback suggests that this could develop to be a successful and valuable collaboration.

PS Why 'Walnut Programme'?.....because the prostate gland is about the size of a walnut.

And finally:

Prostate Cancer will affect one in eight of all men in the UK (one in four if they're of African/Caribbean descent). This means that every hour one man in the UK will die of prostate cancer. Prostate cancer is a treatable condition if diagnosed soon enough. In the past months a number of celebrities have publicly admitted that they have prostate cancer and Bill Bailey has appeared in TV ads, urging men to look after themselves by having the simple blood test that could identify the disease early and save their lives. This publicity is a breakthrough. Together we can help each other, as prostate cancer has been a taboo subject among most men and many find it difficult to discuss the topic.

A survival Guide to Advanced Prostate Cancer

Hugh Gunn

The bomb shell burst in 2005 at the age of 59. I had advanced prostate cancer, a PSA of 760 and extensive bone metastases. I was given 18-30 months to live with a rapidly decreasing quality of life. The outlook couldn't be more bleak. The following few weeks passed in a haze of numbness. Nine years ago, there were no helplines for what I had (none that I could find anyway), I was on hormone treatment and flying blind.

How on earth how am I still here? I fill in forms and put the date as 2014 and I still have to pinch myself that it's real. I didn't expect to see the Olympics, but oh how I enjoyed it when I did.

I soon realised that I had to make some serious lifestyle decisions and with the support of my wife and family, I retired from my business and then promptly wondered what I was going to do with the rest of my life. After a couple of months, I got over feeling sorry for myself and began to look for a new direction. At the time, the newly formed prostate cancer support group in Leicester had a series of articles in the local newspaper and I decided to give it a go. I remember, at the time anger setting in. How dare anybody write me off so easily! Never having run before, I decided to run the Nottingham Half Marathon, just to prove that I had a lot more life in me than had been predicted. The running training was brutal. Although I trained with a group, I was so much slower than my colleagues that I was virtually running on my own and this gave me the opportunity to think about my situation. My trainer, John Pinches, a fellow prostate cancer patient, was so supportive and gave me the confidence to believe that I could complete my goal. On the day, the atmosphere was electric and helped to carry me along. My time was 2 hours 49 minutes. Not brilliant, but I had done it!

This was one of the most important and best decisions I have ever made. Through this, I became involved with PROSTaid, made lots of new friends and met people in the same position as myself. I was not alone anymore. Over the years, I have done things I could never have dreamed about. I became treasurer of PROSTaid, and helped organise and take part in many fundraising events, including Dragon Boat racing and most exciting of all, a Sky Dive!



Through PROSTaid, I became involved with the Prostate Cancer Support Federation and once again had the privilege of becoming Hon. Treasurer. Through this role, I have got to know people from all over the country and I take my turn on the help line. Something that I dearly could have done with when I was diagnosed. I also

produce the newsletter, Prostate Matters. One of the more important roles I have played, together with David Smith, is to represent the Fed, (or Tackle as it now) on NICE appraisal committees for new drugs.



So, what happened to the 18-30 months prognosis? Most importantly, I very soon realised that nothing was going to change for me locally. My consultant told me to get my affairs in order and get all of my holidays in now.

I decided go down the trial route and went to see Prof. James at QE Birmingham. The first thing he did was to put me onto intermittent hormone therapy. Something very new at the time, but it enabled Zoladex to last for 5½ years. This time scale was important because when it failed (which it always will if metastasised), treatments had moved on and instead of being an end of life issue, it meant an alteration in treatment. I went onto the TRAPEZE Trial, which for me meant 6 months of chemotherapy and in addition Zoladronic Acid for bone health, which I am still receiving. The benefits of chemotherapy, lasted for about 2 months and after a battle with the East Midland SHA, I was one of the first men to be given Abiraterone. This worked very well for my cancer, but after a time I had to come off it because of liver problems. At the time, Astellas, the manufacturer of Enzalutamide was giving it away, free of charge, to failed Abiraterone patients. That was 18 months ago and my PSA seems to be constant a 0.7. I consider myself very fortunate indeed as this avenue has now been closed by NICE. Both Tackle and myself personally have been very very active in fighting this wholly unjust decision, but the jury is still out and we will have to wait and see what the result will be.

Having been through nearly all of the treatments for advanced prostatic cancer, my advice to men in my position would be:

- Keep positive and as active as you possibly can. Do not give up hope.
- If you are not happy with your treatment, get a second opinion.
- Investigate the trial route earlier rather than the later. It is much easier to keep someone well, than try to pull the coals out of the fire when it's too late.
- Get involved with your local support group.
- Learn about your illness and what new treatments are up and coming.

Face the fact that current treatment will fail and be prepared for the next round.

Through all of this, I have been fortunate to have the unstinting help and support of my wife Kate and this is a journey we are going through together.

Norfolk and Waveney PCSG, is celebrating its tenth birthday.

David Paull



David Haines - Chairman Norfolk & Waveney PCSG

One of the country's oldest and most active support groups, the Norfolk and Waveney, is celebrating its tenth birthday.

It all began when an open meeting organised by specialist urology nurses and urology consultants was held at the Norfolk and Norwich University Hospital in 2004. Prostate cancer patients and their partners were invited to discuss the need for such a group and assess the level of interest and support.

There was obviously felt to be a need and on April 26 a group of 17 volunteers met with two of the specialist nurses, Sallie Jermy and Claire Fullalove, and launched the new group.

The founder chairman was David Haines, now the group's president, who recalls: "We were fortunate to have as members of that first committee a dedicated team who laid the foundations for the success and development of the group we see today. Three of them are still serving.

"Over the years, we have lost many of our former friends and colleagues but other equally motivated people have come forward and made great contributions in achieving our key aims, and our present committee remains strong and committed under the energetic leadership of our chairman, Noel Warner, our vice-chairman and former chairman, Ray Cossey, and their hard-working team.

"We have found friendship, interest and motivation, and without doubt have made a difference in understanding and dealing with prostate cancer. However, we cannot stop the clock and, with

several long-serving members now in their eighties, the need is for new active volunteers to share the load."

David says that the situation today is very different from that prevailing in 2004. From little public access to information in those days, there is now probably an information overload from the myriad sources on the internet; more media speculation (and hype); and an increase in the number of charities now involved with prostate cancer.

"It is sometimes difficult to sort the wheat from the chaff, particularly when faced with opposing reports, and one of our tasks is to offer patients reliable sources of information, and to arrange a programme of credible speakers to keep us up to date on new diagnostic and treatment developments.

The group also holds regular "Meet and Chat" events with nurses and surviving patients on hand to offer information and reassurance to men (and their partners) who have recently "joined the club".

Although the group has made much headway in increasing local awareness, there is a new generation joining the ranks of those at risk who need to be informed, and the group is this year widening its programme of contact and talks with organisations across Norfolk and Waveney.

David says that over these ten years there have been some great advances in survival rates and the outlook now is that, within the foreseeable future, the disease will become more a chronic treatment condition that will allow most people to carry on with their lives, in much the same way as those living with diabetes.

The group, with the help of supporters and donors, has raised over £100,000 to fund new treatment trials, such as Cryotherapy, and to provide essential items of equipment for the NNUH's pathology and radiology departments, all for the benefit of prostate cancer patients.

The group is also supporting the hospital's £600,000 Targeted Radiotherapy (Brachytherapy) appeal and has already pledged more than £20,000 towards the cost of equipment.

For the future, says David, "We have some way to travel before everyone is aware. We must continue to spread the word."

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 20% 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

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

If there are any alterations, please contact:

Sandy Tyndale-Biscoe

Email webmaster@prostatecancerfederation.org.uk

A view through the keyhole

By Richard Hill

When someone tells you that you have cancer the shock is almost physical to the point you don't take in much more detail at the time. The only thing I remember apart from the diagnosis was the need for a scan which would determine what options I had. The two weeks between initial diagnosis and scan results were the longest of my life, particularly as the biopsy had shown cancer in almost every sample taken.

I was fortunate. The scan seemed to indicate that the cancer had not spread beyond the prostate and so I was informed of my options: radical prostatectomy; radiotherapy; brachytherapy or watchful surveillance. Like all cancer patients, no one would be prescriptive on the way forward – it was my choice. Incredibly difficult even with a great deal of information available. My consultant specialised in the surgical option and explained in easy, sympathetic detail what was entailed. I also had consultations with specialists in radiotherapy and brachytherapy, each of whom were reassuring and confident of a positive outcome. Prostate Cancer UK and Prostaaid provided excellent support, particularly in putting me in contact with men who had been through each of the options available. In many ways, this made the choice even more difficult as all were very reassuring in spite of the legacy effects of treatment.



Richard Hill

In the event I opted for laparoscopic surgery for a number of reasons. First, I had had symptoms which may have been exacerbated by radiotherapy and brachytherapy. Second, I wanted to take action which would be quick and maybe take some of the longer-term emotion out of my situation. Thirdly, I wanted an option which gave me a second course of action if necessary. And finally, I had built up a relationship of trust with my own consultant in which his guidance and support was a key factor. The watchful surveillance option simply felt too nerve-racking as the condition clearly wasn't going to go away.

I was fortunate to be covered by a company medical insurance plan and so was able to proceed fairly quickly, even though I was informed that I had no need to panic. (Easy to say if you haven't got cancer). I was admitted around 7.30 on the Saturday morning of the late May bank holiday 2013 and was immediately prepped for surgery. My consultant was soon on the scene to explain what was going to happen and reassured me that there would be no chronic pain following surgery. I found the consent form mildly distressing as it mentioned the possibility of various types of collateral damage but, frankly, I had gone past caring at that stage.

The anaesthetist then dropped in to see me and was equally reassuring,

talking me through the procedure and singing the praises of my consultant's expertise. Apparently, they performed as a regular duo and had done the same operation earlier that week. It helped a lot knowing that.

I was taken to the pre-op room where the anaesthetic was administered. I remember the clock showing 8.50 and then had a vague recollection of seeing it again at 2pm. The operation had taken around four hours.

The consultant was right, although in some discomfort there was no sharp pain. I was probably back in my room by 3pm and was sat up in a chair by 7pm ready to watch the Test Match highlights. In a nutshell, I was able to walk down the ward the next day and walk up and down steps. By Monday, I was ready to go home and, once my consultant had paid me a visit with the words "It couldn't have gone better", I was allowed to leave. I was particularly pleased to hear that there was no restriction on food or drink so celebrated with a glass of red wine that evening.

As I write this, it is now just over six months since I had the operation. Looking back, I think the worst part of the hospital experience was the discomfort of having the catheter (two weeks in my case). No pain, just awkward and tiresome. It was a real relief to have that removed which then began a period of predicted leakage. I was told that each man responded differently to the operation but that a high percentage of men were content with their condition after a year and around 98% of men content after two years. I was mentally prepared for a lengthy period of pad support. Again, I have been fortunate and was pad-free within four months with no real issues within those four months.

Physically I feel really well now. I was very tired for several weeks after the operation and didn't get back to feeling well for around six weeks. But progressively longer walks helped me get back to normal.

The operation itself has left no legacy twinges. Of the five small insertions to perform the operation, three scars are barely visible spots, one scar is around half an inch and the longest around three-quarters of an each – all discretely hidden from view even when wearing beachwear!

I can now understand how my peer advisers could be so reassuring about keyhole (laparoscopic) surgery. The prospect is not pleasant but the aftermath is far less daunting than I imagined it would be.

There is one very positive outcome in all this for me – it has prompted me to take early retirement from work and do more of those things I really enjoy doing. I shall certainly be back on the cricket field next season, although I suspect my chances of playing for England are as remote as ever despite the new lease of life.

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Prostate Cancer Support Federation

Action for prostate cancer patients and their families

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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

NAILSEA & DISTRICT PROSTATE GROUP

Gordon Hayton



Two foundermembers of N&DPG - Gordon Hayton on the right and Peter Harrowell on the left

This recently affiliated group, based in North Somerset, was formed in April 2012, and has gathered momentum from just 6 members to its current membership of 21. It was felt by two local sufferers that there was a need to bring help and information to others with prostate concerns, not necessarily only cancer, and a small committee was formed to formulate policy and rules.

The Group's aims include raising public awareness of prostate conditions and associated problems, inviting medical experts to give up-to-date advice and information, as a group to assist in pressurising the NHS for early prostate screening, to keep abreast of advances and developments in treatments, to push for a uniform process to allow for more informed choices of treatment, and giving sufferers a local voice,

The group meets regularly on a bi-monthly basis at a local medical centre, to provide a forum for anyone with worries

about prostate health to discuss their concerns, and to meet with others with similar conditions and experiences. Their aim to increase membership is met by advertising through local press, posters and banners.

The group's first speakers meeting, by Dr. Jon Rees, a local GP and a prominent figure in the national forum of urology and prostate problems, was well attended and well received by those who attended. The group is looking for more suitable speakers from the area, and would welcome any help in this direction.

The group has a good working relationship with local medical practises, pharmacies and the local town council. Financial support has come through Waitrose and the town council.

Further information, including details of the group's officers and dates of forthcoming meetings can be found on the group's website - www.nadpg.org.uk.



Racehorse Prostate Awareness Progress Report

Having rested over the winter, 'Prostate Awareness' will make his first appearance of the season on Saturday May 17th at Thirsk.

His stable, 'Middlam Stables' in North Yorkshire, had an open day on April 18th (Good Friday) and Graham Fulford held PSA testing sessions all day. Now, 107 more men know their PSA. The message is getting across.

It is hoped that many more racecourses will be holding PSA testing sessions when Colin's horse runs.

[Watch this space](#)