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Westonbirt National Arboretum

The Jon Rees interview - Reproduced from The Independent

If someone is experiencing urinary symptoms, should they be worried?

Urinary symptoms are caused by lots of different things. It's important for anyone with new, troublesome urinary symptoms to discuss them with their GP to find out the cause — and to get away from the idea that they're simply a part of growing older and something you have to live with.

What is benign prostate disease?

It's enlargement of the prostate and it happens to all men as they get older. A lot of men who have symptoms caused by benign prostate disease are worried about prostate cancer. I would encourage men with symptoms to see their GP so that, hopefully, those fears can be allayed — or, if there is evidence of cancer, a plan can be made for treatment.

What is the PSA test, and how does it help diagnosis?

It stands for Prostate Specific Antigen which is a chemical made only by the prostate. Your PSA level can be checked with a simple blood test. Borderline or mildly raised levels can be difficult to interpret, but the higher the level the more likely it is due to prostate cancer.

What is a 'normal' level for a PSA test?

It depends on how old you are. If you are in your 50s it should be less than three; in your sixties less than four, and in your seventies less than five. But other factors can make your PSA level rise — such as benign enlargement disease, infection or a condition called prostatitis — which is why it can be a difficult test to interpret.



Dr. Jon Rees

Who should have the PSA test?

Men who have urinary symptoms will often be offered a test as part of their assessment. There is no national screening programme using PSA as this has not, as yet, proven to be beneficial. But, men who are at greater risk of prostate cancer are the most likely to benefit from undergoing testing. African-Caribbean men are 3 times more likely to develop prostate cancer as white men in the UK. Men who have a family history of the disease, e.g. if their father or brother have had prostate cancer, should also think about being tested.

If you have a PSA test when you are relatively young — say 50 or 55 — with a level that is roughly above one, then there is growing evidence that you may be at higher risk of prostate cancer in the future.

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These men who should be thinking about having regular PSA tests, so it may be useful to 'get a score on the board' from an early age to understand future risk.

Why are support groups important?

A lot of men with prostate disease and prostate cancer can feel quite isolated. They will receive professional support, of course; but it can be incredibly helpful to speak to other men who are going through the same thing as themselves. If you have treatment for prostate cancer it can have an impact on your sexual function and continence. So a support group enables men to talk about things that they might not be easily able to discuss with health professionals, or with their friends and family. Tackle

Prostate Cancer has a network of over 70 support groups around the country, so their website is a good way to find if there is something in your local area.

Are men better informed about prostate issues these days?

Thankfully, yes. I have been a GP for 10 years and, during that time, I've seen a difference. Men are getting much better at coming forward and asking questions. The message to men is that going to see their GP about urinary symptoms doesn't mean they will end up having treatment or an operation. Lots of men simply get a test to reassure them. It's far better to do that than sit at home worrying.



Know your PSA : Get a Score on the Board

As part of our commitment to Groups who feel men should know their PSA, we have enlisted the help of three sportsmen to raise awareness about why it's important to **Get a Score on the Board**. Jason Leonard, David Gower and Damian Hopley will be speaking to the press about why men at risk should Get a Score on the Board so that any changes can be tracked. The interview in The Independent (reproduced on pages 1 and 2) is also part of our **Get a Score on the Board** campaign. A full report in the next edition



The Friends of Prostate Sufferers (FOPS) Support Group at No.34

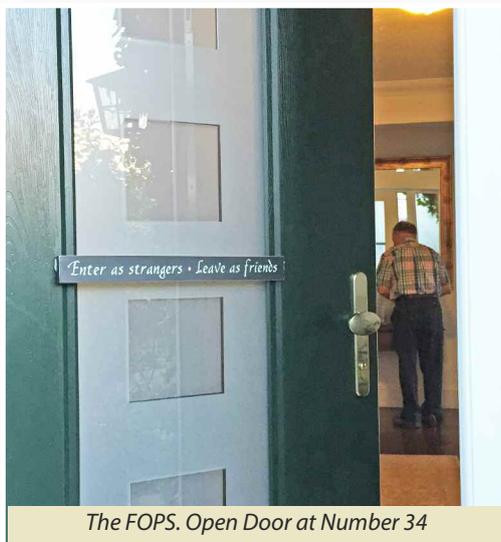
Gabrielle, (co-host of FOPS Support Group)

A can-do attitude to setting up a support group at home has created a growing community in Hertfordshire to share their positive and negative experiences...

It is difficult to believe that it is over three years since the first support group meeting at our home, No. 34. What started with five or six of us has grown to 120-150. We have always said, "Come when you can and go when you like" which seems to work very well around people's health and states of mind.

Almost 40 attend each meeting, and half of these come with their partners or other family member - but we manage to find a seat for everyone; due, perhaps, to the small number who never leave the kitchen and would rather stand naked in the garden than ask our 'resident' urologists a question! Nevertheless, we respect the variety within the group.

Most of those attending are here by word-of-mouth, although we deliver invitation leaflets to all the surrounding hospitals. There is, we believe, a woeful need for more support groups nationwide as many more men are now being diagnosed with prostate cancer and have little or no access to a support group. Our experience of Prostate Cancer Support Groups is how difficult it is to persuade men to even consider the notion of attending such a meeting. Somehow we need to put the message out that we are here, when men are first diagnosed with prostate cancer. We need to rectify the preconceived idea that such events are for those unable to cope, as opposed to those who are determined to cope and, when possible, to help others.



The FOPS. Open Door at Number 34

With support from Roger Wotton, a member of Aylesbury Vale Support Group and Chair of Tackle Prostate Cancer, we have successfully applied to Macmillan for a grant to video one of our group meetings. We will distribute this film through Tackle and through Macmillan. Seeing how simple our format is might just encourage someone else to start up a group in their area. I think we can show how easy and enjoyable our evenings together can be. In our three years together we have seen great courage and can only hope having someone to talk to "that knows exactly what you are going through" has helped the men who attend. Two

of our members, Max and John, (both late diagnoses) came to us in the final months of their lives and we hope they found some comfort at our meetings. One of our founder members, our lovely Terry, passed away recently.

Apart from being able to ask the urologists questions, the men who come here like to chat amongst themselves about specific procedures they are undergoing or particular medication they are being treated with. For some of our members, this is the only time in the month that they will speak about their health and how they are coping. Some have had distressing encounters with brusque consultants, others have been more fortunate in being treated by those more reassuring and considerate.

So as we start our next year of gatherings here at No.34, I would suggest (on behalf of all our members) that any claim of success in our support group is primarily because we stand on the shoulders of giants — our local urologists Alvan Pope and Julian Shah.

Patients Demand The Implementation of The STAMPEDE Results Hugh Gunn

At the 2015 Tackle AGM held in Birmingham earlier this year, one of the Keynote Speakers was Professor Nick James, who gave us the initial results of the STAMPEDE Trial. This is an ongoing trial into finding better ways of treating advanced prostate cancer. It has included over 5000 men and has shown up some staggering, groundbreaking results.

The Trial showed that if newly diagnosed men with **advanced prostate cancer** are given six doses of docetaxel based chemotherapy, it adds twenty two months to their overall survival.



Professor Nick James

At the moment, the official pathway is to give ten doses of docetaxel based chemotherapy towards the end of the treatment journey, when first line hormone treatment has failed, with the body already weakened and the results uncertain

Docetaxel is an inexpensive treatment, having come off patent and so there should be no overall increase in cost in implementing this trial. In fact, in the long run it will save money, because only six doses, not ten will be given. This is also much kinder to the patient, as I know personally, it is the last four that are difficult and produce problems

So, why on earth is this treatment not being adopted. It certainly is in Birmingham and other centres where the trial was carried out and also in Scotland where the Scottish Medical Consortium has passed it. However, most Heath Authorities are saying no. Indeed, there is at least one Health Authority who has told patients that "Yes it is a good idea to have docetaxel based chemotherapy when first diagnosed, but it is not funded. You can have but it will cost you between £18,000 - £20,000".

The other consequence of giving chemotherapy when first diagnosed, is that docetaxel based chemotherapy is the rubicon the patient has to cross before any of the late stage advanced cancer drugs can be given. This of course, would conveniently circumnavigate this hurdle.

As patients we should demand that this low cost, highly effective treatment should be implemented as soon as possible. There is no clinical nor financial reason why it should not be.

Screening for Prostate Cancer

Tackle's contribution Roger Wotton

UK National Screening Committee (NSC) recently asked a number of stakeholders for their views on screening for prostate cancer – something close to many of our hearts. Our Federation was one such stakeholder. More specifically, NSC asked for views on a paper they produced last year which recommended against population-wide prostate cancer screening. Their reasons for not recommending screening included a view that the current PSA test is not effective enough, there is over-diagnosis leading to overtreatment and there are a significant number of impotence, incontinence and rectal problems arising from the treatments.



Our submission to the NSC took issue with a number of their views, assumptions and conclusions in the report. We put together a small team comprising Dr. Chris Booth, Keith Cass MBE, Sandy Tyndale-Biscoe and Roger Wotton to come up with a consensus view, which was endorsed by Prof. Frank Chinegwundoh MBE in whose name we made the submission. Our thanks go particularly to Chris Booth who led much of the submission work.



UK National Screening Committee

In summary we responded with a similar view to that shared by the British Association of Urological Surgeons (BAUS). PSA testing needs to be part of a shared decision making process with the patient. It may not be a perfect test but it is the only one we have today. It's about intelligent use of PSA testing and identifying those who are potentially at risk of developing the disease. A baseline PSA value at around 50 years of age (or maybe even 45) may predict the risk of disease and inform actions thereafter. These can include little or no further action for some time, repeat testing at certain intervals, or immediate further treatment. Such baseline testing would be a significant step forward. Men should be assessed on an individual basis but particular "at-risk" groups include men with one or more affected first-degree relatives or those of African or Caribbean descent. Targeting these men using public awareness campaigns should be considered. Men should be able to request and receive counselling, followed by prompt PSA testing if desired and further investigation when necessary.

We also provided many sources of research which echoed these views, and particularly examples of where the PSA test is currently used inappropriately, too late, or not at all.

We now have to wait until November to see what, if any, changes are made to the current NSC screening advice. We will report any outcomes in a future edition of Prostate Matters.

Tackle Welcomes Two New Trustees

Mike Harrison, Chairman Prostate Cancer Support - North West

I was diagnosed with Prostate Cancer in 2007 and had a radical prostatectomy in June of that year followed by radiation treatment in 2012. I am currently in good health.

I joined the Prostate Cancer Support - North West Executive in 2009, established High Peak group in September 2010 and became Chairman of Prostate Cancer Support - North West in 2012.

As Federation North West regional co-ordinator, I am committed to developing the North West network, and to working with all agencies and organisations to raise awareness of prostate cancer and support the needs of patients and their families.

I am frustrated when hearing about new 'breakthrough' treatments because I feel little has changed over the past 10 years. Whilst research into new treatments is vital we need to work with what we have now.

I remember the feeling of being completely alone when I was first diagnosed and want to do everything I can to prevent others from feeling the same.

I am currently working with PC-UK on a project to raise GPs' awareness of Prostate Cancer to improve the standard of care provided, particularly on first presentation.

We need to continue to raise awareness and get men taking as keen an interest in their own health as women.



Mike Harrison

In the absence of a national screening programme we need to encourage more men to 'get a score on the board'.

We need earlier diagnosis, a standard package of information for the newly diagnosed and a common diagnostic pathway everywhere in the country.

I am pleased to be a trustee, helping the Federation to achieve these goals.

Keith S. Cass MBE Chairman of the Red Sock Campaign

I thank you all for electing me to serve on the board of trustees of Tackle for the next 3 years at a time when I believe that we will see massive changes in the diagnosis and treatment of prostate cancer.

I have lived in Cardiff since I was 21 working in the coal and steel industry.



Keith Cass MBE

After selling my railway engineering business in 1999 I settled down to what I had hoped would be a life of fun and leisure.

2006. That was all shattered when in Feb and still in my 50s I was diagnosed with metastatic PCa (PSA 125, Gleason 9) with hormone therapy offered as treatment.

2007 I founded the Red Sock Campaign.

2008 I joined the committee of the Cardiff support group (formerly known as PROCARE).

2013 was a memorable year. I was awarded the MBE for my Red Sock Campaign work. The medal was an achievement I have dedicated to all men with prostate cancer and their carers.

As well as representing Tackle on the Prostate Cancer Advisory Group I am a patient representative on both the AWMSG in Cardiff and the PLG at Velindre Cancer Centre.

My mission and vision for Tackle is to continue raising the awareness of prostate cancer and seeking the best and most timely treatment for all men worldwide.

My greatest achievement in the last 10 years has been, in the words of the Bee Gees -

"STAYIN' ALIVE!"

Living The Dream With Advanced Prostate Cancer

Jim & Elizabeth Lidgate - Somerset PCSG

Jim, aged 78, was diagnosed with an aggressive prostate cancer in 2005. He had a Radical Prostatectomy, two years later radiotherapy, a year after that hormone therapy and last August started Enzalutamide because he had developed a small metastasis, with no side effects so far.



Jim Lidgate, pictured with a member of the Huli Tribe

All his life he has been a bird watcher and had always dreamt of seeing Birds of Paradise. Throughout all Jim's treatment we had travelled far and wide in different continents and understood the difficulties involved. We saw a company had come up with a bird watching trip to Papua New Guinea and another to Bali, Java, Flores and Komodo. These were back to back trips and as this was a good excuse to see both Birds of Paradise and Komodo Dragons. **We asked our Oncologist if this trip was a good idea? His words were "go for it!"**

We had to find travel insurance, which was a nightmare. However MacMillan came up with phone numbers and advice, as did Prostate Cancer UK and we found a very supportive (though expensive) company. The length of time we were away and the metastatic cancer put up the price up from £100s to Thousands!



Jim with the Mud Men, complete with mask

We didn't do any preparation for this holiday until the final payment was made, in case Jim hit a problem. However, he was very excited and read his bird books cover to cover!

When Jim goes anywhere he always takes extra washable urinary incontinence pads and his faithful 'drizzle stops', so this was no different from our other trips. We made sure that our travel injections and Malaria cover were up to date.

We flew to Singapore on 17th July and on to Port Moresby, Papua New Guinea. We had to fly to all the lodges because they were inaccessible by road. David Attenborough never had this luxury! Our plane was a nine seater that bumped down on a strip of fairly level grass. We saw the Raggiana Birds of Paradise fairly early on. they have their own territories and were very vocal.

Jim did find scrambling around in forest very hard work, but used a walking stick of mine and the others in the group helped him climb and scramble! We had two weeks in Papua New Guinea, visiting many birding sites and a local Huli tribe, who wear Bird of Paradise feathers as adornment, Mudmen who wear 16 kilo clay masks and Wigmen who have grown their hair for about 18 months for other tribes to wear!



The Frightening Komodo Dragon

From Papua New Guinea we flew to Bali and birded in venues in the north, we 'popped' over to Java for two nights and saw the magnificent Green Peacock, bigger than its Blue cousin in India. Back to Bali and on to Flores where we birded in the mountains and then a four hour boat trip to Komodo to see the Dragons. Quite a frightening but impressive beast!

Our holiday comprised of eleven plane flights which was very tiring. It was very hot and humid most of the time but cold in the mountains at night. Sometimes no electricity in Papua New Guinea, nor hot water. BUT we have some wonderful memories and Photos. AND we fulfilled dreams that neither of us thought would happen.

Advanced prostate cancer is an awful disease to come to terms with, but if your dreams are strong enough, it is possible to fulfil them and enjoy life to the full.

STOP PRESS

Tackle is pleased to report that 'The Scottish Medical Consortium' has passed Abiraterone for use in Scotland for pre-chemotherapy patients.

The Cancer Drugs Fund : The story continues

Roger Wotton



You will be aware of the Cancer Drugs Fund (CDF) set up by the government to provide innovative but expensive new drugs to cancer patients – drugs that are currently not on the approved NHS drug list.

As well as fighting on your behalf to keep existing prostate cancer drug treatments on the CDF, Tackle has joined with a coalition of 13 other cancer charities to lobby for a better delivery model for the CDF – one that better reflects patient needs and, in many cases, offers a lifeline to some patients for whom there is no other treatment available.

Tackle has been instrumental in getting Cabazitaxel back on the approved CDF list, after it was removed earlier this year. This is a great achievement, considering the problems other cancer charities are experiencing trying to have their important drugs reinstated after some 23 treatments were withdrawn from the CDF. Another prostate cancer treatment, Radium-223, used to target bone cancer cells is being withdrawn from the CDF in November 2015. However, due to intense lobbying by Tackle, PCUK and leading clinicians this treatment is likely to be available through mainstream NHS channels from January 2016. We will continue to follow progress and monitor developments to ensure our campaigning efforts bear fruit on behalf of all prostate cancer patients.

At the time of writing we are waiting for a new consultative paper to emerge from the NHS, outlining how we can be involved in developing a new model for the CDF. Watch this space!

New Name, Same Aim

Roger Wotton

Those of you who attended the AGM in June will recall the members' agreement for the Federation to move to a 'Charitable Company limited by Guarantee', in other words to become incorporated like many other charities. I am pleased to say the Charity Commissioners have agreed to this change and so from January 2016 we will operate as The National Federation of Prostate Cancer Support Groups, as opposed to our current name of The Prostate Cancer Support Federation. To become incorporated we had to apply for a new charity number and we took the opportunity to make a small name change. This better reflects the fact we are National and we only exist by virtue of having a strong support group structure. We will continue to use the 'Tackle' name as our public face.



What does this change mean?

Nothing as far as our aims and strategy are concerned – it is business as usual. Being incorporated though does have several implications and advantages:

- We are still a charity but now with limited personal liabilities for Trustees and with a more manageable degree of financial risk;
- We have a more secure structure for the future;
- We are in a better position to attract funding from PLCs and Charitable Trusts;
- We now have a more democratic and accountable set-up with Articles of Association rather than a constitution, and there will be proxy voting which will ensure every group has a vote, whether or not they can attend general meetings.

Making this change does not mean any less responsibility on the part of Trustees. As in the past, the Trustees will still be required to run the Federation responsibly. Our new Articles of Association and Rules have the same fundamental content as our current constitution in terms of membership, trustees, meetings, accounts and changes to the articles, with the addition of proxy voting and indemnities. We believe this change brings our governance up to date and is aligned with our plans for growth.

Thoughts for future editions of Prostate Matters

Hugh Gunn - Editor

We are always looking for ways to make Prostate Matters more personal and relevant to our readers and groups.

I would like to introduce a letters Page and possibly a column listing all of the group's up and coming meetings or events

Please let me have any letters you would like publishing, events or suggestions at:

hugh.gunn@tackleprostate.org

tackle

Welcomes New Members

It with great pleasure we welcome the following groups to Tackle:

Compass Prostate Cancer Support Group (East Berkshire)

Contact: Stephen Molloy Email: stephen429@btinternet.com

Peter Seaton, Chairman of 'The Prostate Project' told us that his group has been running it's own Helpline at a cost of £200 pa for many years.

Now, they have decided to use the Tackle Helpline by replacing the number on all of their literature.

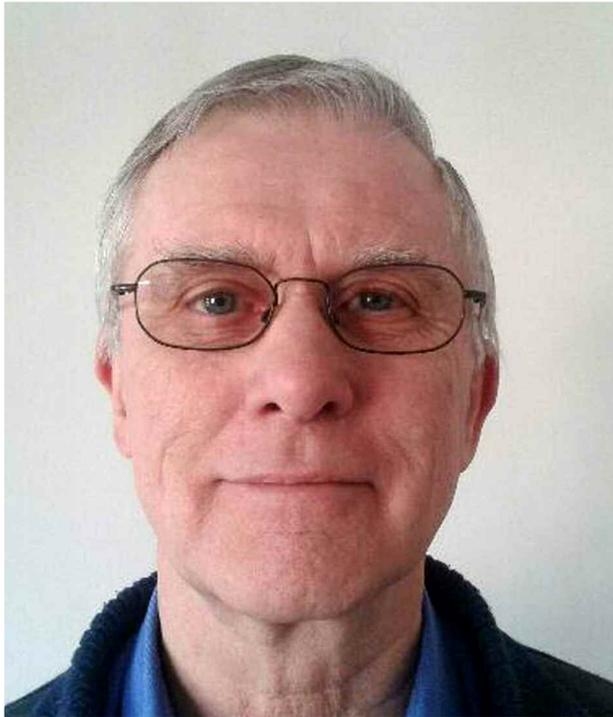
Tackle's Helpliners, all of whom are extremely experienced, put callers in touch with a local group in their area as well as with patient experts who have undergone similar treatment.

We all want better testing for prostate cancer. Elsewhere in this edition you will see an article calling for earlier and more consistent PSA testing for men. One of our members has started a petition for national screening and already has 50,000 signatures. If you feel as an individual you would like to support this call for screening you can find the petition at <http://tinyurl.com/nj7n49k>

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

POST-RADIOTHERAPY TREATMENT - Part Two

Roy Sowersby



Roy Sowersby

In my previous article I explained how the Royal Marsden Hospital would be willing to look into my pelvic radiation disease. At my first appointment I was given an endoscopy and a breath test to check levels of hydrogen and/or methane that might cause gastric problems. The results showed that everything was normal. My second appointment was to undergo a colonoscopy. This concluded that that all was normal in the rectum, colon and ileum but that I had 'mild radiation proctopathy with grade I telangiectasia in the anus'. This is an apparently common symptom of radiotherapy for prostate and other cancers in that area.

At my next appointment I saw a nurse specialist who said I had no undue problems, but wanted to regulate my bowel habits. She also sent me for a stomach x-ray, which showed my stomach was full of air.

She said I could eat what I liked, but suggested that I take stomach powder (Normacol) for a month to see if that eased the air in my stomach. This involves taking ½ a sachet a day for a week, seeing whether this has worked, and, if not, increasing the dose to one packet a day.

Thus, I feel extremely lucky and privileged to have had a complete MOT that has confirmed that I am generally fit and well, and can carry on enjoying a normal life. I was advised to have another review later in the year and will be contacted when appropriate.

I do hope that this has helped you to learn more about a little-known problem and that you get the same result as me if you choose to have the procedures. I am happy to be contacted to discuss individual issues.

Roy Sowersby
07973 667770

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/429ee7f>

And the contact details at: <http://tinyurl.com/omp6y5e>

If there are any corrections required please contact Simon Lanyon by email: simon.lanyon@tackleprostate.org.

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



We need you!

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

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!

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Text Giving - Text: TACK13 £

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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.

It's a Man Thing, Music Event, Claverdon

Hugh Gunn Editor Prostate Matters

Oncologists are busy people and it's understandable that once their working day is done, they would want to relax and switch off. Not so Professor Nick James of Queen Elizabeth Hospital Birmingham. He has completed cycle rides and organised musical events to raise the profile of prostate cancer and to raise funds to help patients.



Professor Nick James, announces the winners of the raffle

So it was that on July 29th over two hundred people found themselves in the garden of his house in Claverdon, Warwickshire, listening to music of all genres from 2pm until Midnight. Incredibly it poured with rain on the Friday before and the Sunday after, but on the day its self, the sun shone. We turned up with our folding chairs and some even pitched tents and stayed over night. We had the most delicious bbq with jerk chicken, followed by

gorgeous puddings and water melon, whilst feasting on the seamless stream of music, from SKA to Barry White and modern jazz to big ballads. Something for everyone.

Prof. James himself, changed from his normal sharp suit, to very fetching green shorts, floral shirt complete with a straw hat and danced enthusiastically until late.

Among the bands taking part, was Stuart Battle, who organises PROSTaid's own Jazz Day at the Musician Public House in Clyde Street, Leicester. He played a rousing rendition of 'Peter Gunn' and his own hilarious composition 'It's A Man Thing'.

This can be viewed on You Tube at <http://tinyurl.com/pmm3eud>



Stuart Battle performing It's A Man Thing

A brilliant day enjoyed by patients and non patients alike and he has expressed a wish to hold another one next year. If he does and you can, please give him your support.

Reading Prostate Awareness Day and Feather Flags

Derek Jackson Reading PCSG

Reading Prostate Awareness Support Group are shown here proudly showing off their new Feather Flags at a recent awareness event.

Unfortunately, it poured with rain all day, so the foot fall and enquiries were few, but the flags stood up to the battering well and will be a welcome addition to their awareness armoury..

