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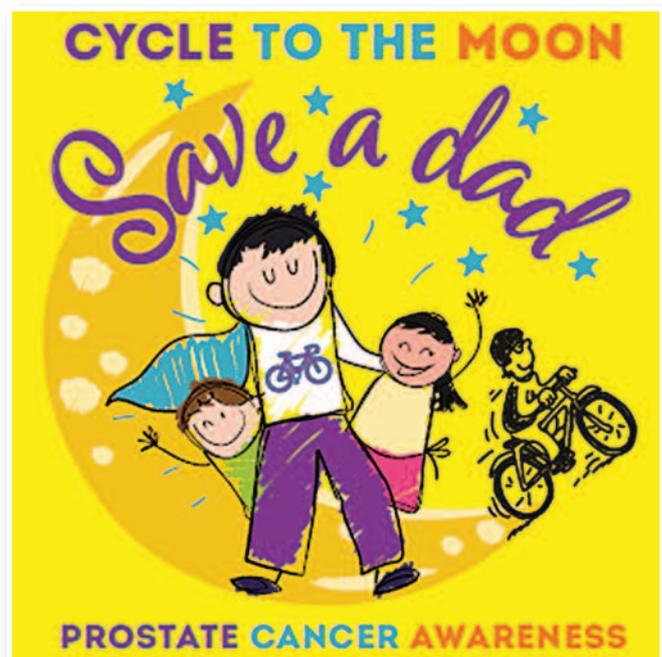
Tatton Park, Manchester

Cycle to the Moon, Save a Dad

Many readers will be familiar with this initiative, first mentioned at our AGM.

We are pleased to announce the appointment of Dave Fergus as our fund raising manager, who will plan and organise this event, which we hope to run in May/June 2018. Dave comes to us with 20 years of successful fundraising and event management. The plan is to work with our support groups, friends, relations, sports and cycling clubs to raise £250,000, roughly the distance from here to the moon. We would then use this money over the next three years to secure the future of the Federation and put in place our "Save a Dad" campaign by working with secondary schools across the country.

We will be writing to all support groups to seek their help in making this exciting initiative a success. If any of our groups have a connection with sporting celebrities or influential individuals who would be interested in lending their support please send an email to: roger.wotton@tackleprostate.org



tackle Has now produced a Lapel Pin Badge. Each group has been sent a complimentary ten. If you need more, we would suggest a donation of 50p each plus P.P. Please contact rob.banner@tackleprostate.org.

Lady's Talk

Kate Gunn



Five years ago I wrote from a wife's perspective about my husband Hugh's diagnosis of advanced prostate cancer (PSA 760) and treatment, which was Zoladex followed by chemotherapy five years later. This was followed by Abiraterone and then Enzalutamide which all kept him going for another six years.

Then we faced the huge psychological step of more chemo. It's hard to accept it once, but twice is really, really hard. Ten sessions treated a soft tissue mass, but failed to tackle the bone metastases. This was starting to get really scary. We were told of a trial at the Royal Marsden in Sutton which requires the patient to have the BRCA 2 gene. For months we travelled from Leicestershire to Surrey, a car journey, two trains and a bus journey and the same in reverse (six hours in all) plus clinic time. A twelve hour day. It was exhausting, but we hoped it would provide a good treatment. Unfortunately, five years of Zoladronic Acid had made his bone's so hard that a bone biopsy failed to provide a tumour sample. That was hard to take. Back to square one!

So, Radium 223 was suggested as the most suitable treatment in this long trail. A radioisotope injection every month for six months. The first was quite stressful, as even the name is frightening, but all went well and other than the usual side effect of tiredness, Hugh felt fine. However, number five produced nausea and bone pain and necessitated a blood transfusion. He had number six and

again nausea and bone pain, but Oramorph and Cocodamol have been his helpmates. So, what next? A PET scan to see what is happening with the bone mets...

This has been a twelve year journey and we have always tried to lead a normal life as much as possible. Talking to other wives, there seems to be a common experience. Some husbands keep it all to themselves, whilst others throw themselves into endless activity so that they don't have time to think. Some wives feel shut out whilst others can feel left behind. I have been to every appointment with Hugh, blood tests, scans (CAT, MRIs, PET) chemo sessions and a transfusion and it can not only take over your life but become your life. Because of side effects, you sometimes have to give up what you used to love, whether it is walking, dancing, sport and even holidays. Travelling is tiring. Getting up in the mornings is a slow business or a sleep in the afternoon is needed or he may need to go to bed early. You can't go out for a meal because he has lost his appetite or you can't go the theatre, cinema or concerts because he may fall asleep or the seats are too uncomfortable. This is hard on the partner too as their lives can be put on hold as well, but it is important to try to keep doing what you enjoy to protect your own mental well being.

Family life goes on with all its ups and downs and there may be elderly parents who are being looked after too. Wives may also have their own issues, including cancer treatment and some wives feel that if they have curative treatment, that they can't speak about their own anxieties, when their husbands remain unresolved. Moods sometimes don't match and this can all lead to tension. When you have no control over your life, your health or your future, it is a very frightening and frustrating situation and it is very easy for both parties to get depressed. Not only are a lot of patients on anti depressants, but their wives are too. At the same time a lot of wives feel inadequate if they are struggling to cope whilst other people seem to manage, but how do they know when a lot of wives are ashamed to admit it. This is where a support group can help. If you can meet others in the same boat and are encouraged to speak openly, it can really make a difference. All of this is made harder if you have no family near or no family at all.

However, this generation of men have more treatment options available than ever before and for many this will give a good quality of life for a long time. If you feel alright, make sure you make the most of it, because there may be days when you don't. Every day is a bonus and don't wait for better ones to come along.

New Support Group Established In Daventry!



Following a successful PSA Test day organised by Steve Jacobs (right) and Rick Hill (left) at Daventry Rugby Club in September, Rick and Steve teamed up with Caroline Langlands (centre) to establish a support group in Daventry with the aim of providing a platform for men and their partners to talk through the diagnosis, treatment, effects and issues surrounding Prostate Cancer.

They were particularly keen to involve partners in these discussions understanding that it is more than a man thing.

The response to the PSA Test Day, in conjunction with the Graham Fulford Trust was overwhelming. More than 220

tests were carried out and through donations and sponsorship, over £4,500 raised. Rick and Steve also thanked Northampton Saints, England and British Lions star Courtney Lawes for contributing signed rugby balls as part of a draw to raise funds.

There then followed a Radio interview with Rick, Caroline and BBC Radio Northampton backed up with social media and web presence to market the group.

And... On the 18th October the Daventry Prostate Cancer Support Group (DPCSG) held its first meeting at the Early Doors Ale House (owned by Caroline) in Daventry.

The evening was a resounding success with men and their partners all involved in a lively, engaging forum. There is always uncertainty when setting up a group like this but we were overwhelmed by the response and deeply moved by some of the stories.

The material provided by Tackle Prostate was greatly received and helped provide background and insight to the groups discussions.

This is just the start for us and we are already planning our next meeting in November.

If anyone is in the area and wants to get in touch or attend the meeting, Rick has set up a website DPCSG.co.uk and can also be contacted at Support@DPCSG.co.uk

Everyone, including partners would be most welcome.



Held its second PSA blood test event. Maria Buckley Secretary MK Prostate Cancer Support



MK Prostate Cancer Support held its second PSA blood test event on 7 October 2017. It was very successful but we were slightly disappointed at the end of the event as we initially thought that only ninety-nine people turned up for the test - a bit below our expectation. However, when the final count arrived a few days later, we had indeed had 100 men come for the test. This was great news! The jump from two to three digits made us feel we had passed a big milestone. Onwards and upwards!

The venue for the PSA event was ideal - a community hall with café facilities and a meeting room for the blood test. Our volunteers who helped greet and register the attendees and those who served refreshments were very enthusiastic and friendly. We were also lucky to have many organisations who helped to spread the word of the event. We attracted people from as far away as Bedford. Many others responded to our

press release in the MK Citizen and from different Facebook pages and websites. Our flyers in local supermarkets notice boards, shops, etc. attracted many from the neighbourhood. A few people brought their friends and families along too. We were especially pleased that several black people turned up as their ethnicity puts them at higher risks of having prostate cancer.

Our PSA test results showed 90 greens, 3 ambers and 7 reds. This 10% rate is at the higher end of a typical PSA test which normally lies in the range of 6.5%-10%. This implies that there are still many men in our area who are at risk.

The PSA blood test event is an invaluable service to promoting awareness of prostate cancer. We were appalled by reports from some attendees that there are still GPs in Milton Keynes who refuse to provide the test. MKPCS plans to conduct the service each year as long as it is needed. We hope that Tackle will support us in our endeavour. We didn't receive enough donations on the day to fully meet the costs of setting up and conducting the event. A basic PSA test costs between £15 and £20 per person. MKPCS is a small support group, relying solely on public donations to help to achieve its objectives. Please contact us if you would like to donate towards our next event.

On another matter, in accordance with the Data Protection Act, MKPCS has just finished an exercise requesting people in our mailing list to opt-in to stay in touch. The large number of contact details left for our mailing list from this PSA event is very long, but it is encouraging to see so many people interested in our group.

READING LIONS ROAR EVEN LOUDER FOR PROSTATE CANCER...

Stephen Allen. Chair Reading PCSG



In 2013 the Reading Lions Club organised the first ever PSA screening evening in Reading. The overwhelming response far exceeded even the most optimistic of the of predictions with 489 men having blood taken in 4½ hours. An article in Prostate Matters ('Avalanche hits Reading', Issue 19 Winter 2013) recorded the detail of this.

Rather than rest on their laurels, Reading Lions went on to make this an annual event with ever increasing numbers of men attending each year. This not only required a move to a larger venue but created many other organisational issues from not only arranging the swift processing of huge numbers of blood samples but also the more mundane but equally important matters such as accurately recording data, arranging adequate car parking etc.



Originally hosted by the local NHS hospital for the first event, the challenge to provide sufficient space for subsequent events was taken up by one of the private hospitals in Reading, the Circle Hospital. They have been pivotal in supporting the event even when expected numbers were increasing year on year. Luckily they are situated adjacent to the Madejski Stadium who offered use of car parking facilities for all who came.

Over 5 years 4372 tests have been performed with a staggering 1501 men attending at the last session in 2017. What started as an evening event has now had to become an all day one.

The aim of PSA testing events must obviously that a different set of men should attend each year. Reassuringly, in Reading 75% - 80% of tests done have been with new attenders.

The original project was overseen by John Mack – a seasoned Lions Club member. That every year each event has run smoothly despite increasing numbers is undoubtedly due to his never-failing

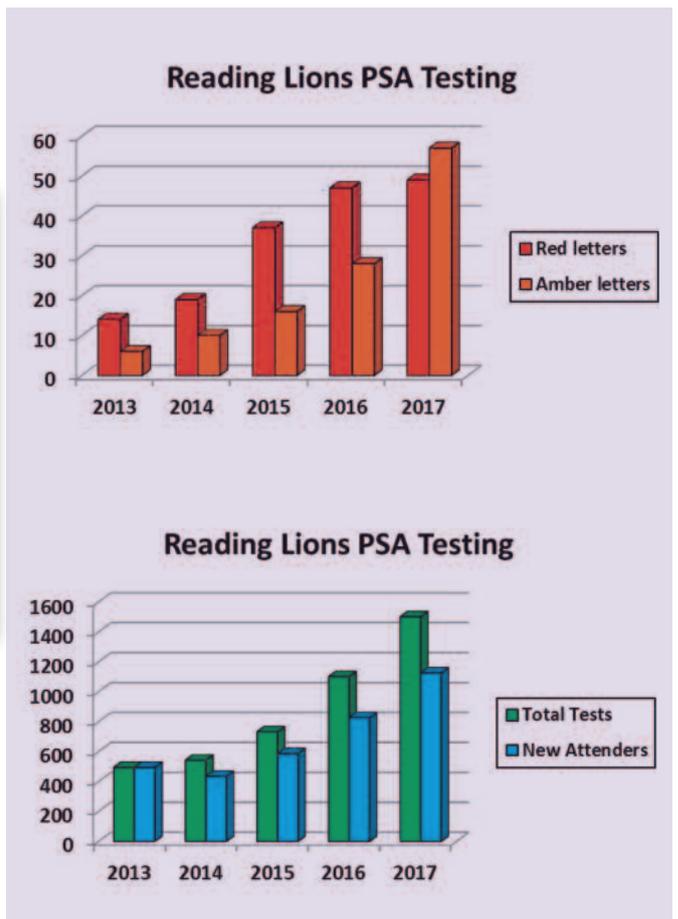
enthusiasm, his refusal to accept 'NO' for an answer and his amazing ability to engender a massive team spirit in those who work alongside him.

Has it all been worth it????.....Undoubtedly YES!!

PSA testing in Reading has identified a significant number of asymptomatic men who were totally unaware they had prostate cancer. Overall, 4% of attenders had Red letters. Many needed urgent medical assessment. Many went on to have aggressive treatment. Also of interest is the ever increasing number of amber letters being sent year on year. This may well in part be due to the upgraded scrutiny of results which now assesses the rate of change of PSA levels in recurrent attenders.

Newer treatments for PCa can potentially produce fewer side effects – but are generally only appropriate if the tumour is still localised within the prostate capsule. Early diagnosis is an essential part of the process. Raising Awareness of PCa and promoting the use of PSA testing is a critical to this process. PSA screening is still a contentious issue but opinions are slowly beginning to change. Events like this are integral to the continued raising of awareness and treatment of prostate cancer.

The Reading Lions are to be congratulated on their incredible achievements.



*** John Mack's achievements have been recognised by the Lions Club International Foundation in awarding him the Melvin Jones Fellowship – their highest honour – given in acknowledgement of his dedication to humanitarian service in his community.

He has also written a 'bible' containing information for Lions Clubs about how these events were organised. Anyone wishing to access this can do so by contacting him: johnmackcfl@gmail.com

Riding the Rollercoaster. Roger Wotton

I finished Chapter 1 of my story at the end of 2016 on a high note (see Prostate Matters Issue 35), with my PSA reducing after being prescribed Bicalutamide tablets as a hormone therapy following the failure of Cyberknife radiotherapy.

Since then, for several reasons, I feel as if I have been riding an emotional rollercoaster. I'm sure readers will recognise some of the issues I have encountered, even if they haven't readily talked about them. This can be a problem with prostate cancer, which in my view is the poor relation. I know many men don't want to talk about it and others do but maybe don't have the opportunity or a ready listening ear to do so. Added to this, I believe prostate cancer is a very individual issue and why someone like me (some would say reasonably intelligent and grounded) still struggles with the psychological aspects of living with this disease.

I was reminded recently of one aspect of living with prostate cancer while listening to a CD of Churchill's speeches. In one of his early speeches in 1938 he talked of despots and tyrants in the world saying "A little mouse, a tiny little mouse of thought appears in the room, and the mightiest potentate is thrown into panic". I think this is a good analogy for our PSA test. "A single number, a small change to the only indicator we have and even the hardiest soul starts to wonder what is going on". This is one aspect of the rollercoaster we all travel on, looking over our shoulders at times and wondering what the next reading will be. How many of us I wonder are like bears with sore heads in that twilight period of uncertainty between having the test and getting the results?

Don't get me wrong – my glass isn't half empty most of the time but it might be helpful to share with you how the story has developed.

The PSA reading of 0.12 in February didn't last long – three months later it was 0.36 and the clinical advice was "there can be a variation with Bicalutamide – have another test in 4 weeks". So my wife brought the dreaded envelope home from the surgery with the next test result in early July. It was 1.36. I was not a happy bunny. Fourfold increase in four weeks!

That weekend coincided with a visit of my 90 year old mother, with us to celebrate my grand-daughters second birthday. I popped out to pick up some groceries and on my return found my mother in tears and my wife very angry. I discovered my wife had told my mother everything that had happened to me over the past year. I have to tell you my mother had not been aware the prostate cancer had returned and I had planned to tell her in my own time and in my own way, believing she did not need to know ALL the finer details. Suffice to say my mother, in her lovely supportive way, thought I had been "cured" (her word). So, I was then angry and it ended up being a weekend I would not wish on anyone.

In the conversations that followed my wife asked some startling questions such as "How do you know your oncologist is giving you the best advice"? "What treatment options might be available if you looked at travelling to the USA?". Why don't we spend some of our savings and go private?"

I'm not blaming anyone as my whole family is very supportive but it does indicate the strength of feeling and build up of emotion that can occur. It probably had to happen and I realise some of the discussion and questions



were a bit off the wall but that's how individuals and particularly loved ones can react.

So, it was clear Bicalutamide was not working on its own and I then started on hormone therapy proper, with my first LHRH Analogue injection (Decapeptyl) in early July. I know many of my friends and colleagues are on hormone therapy and have been for years so this was no more than bowing to the inevitable. I was then due to see my oncologist just four weeks after having the injection so another PSA test ensued and this came back at 2.6! Here we go again, I thought – does this mean after Cyberknife failure and Bicalutamide failure I'm now looking at Decapeptyl failure? Could it get any worse? Well, my oncologist suggested a further PSA test six weeks on as five weeks is too soon to see results. Fair enough I thought. Then the real hammer blow came in September, almost three months after the injection, when the PSA test came in at 6.8, two and a half times increase over July!

"This result is not what we want" was my oncologist's response and a further Choline PET scan showed progressive lymphatic disease but my bones were clear. That was about the only piece of good news. Apparently I'm in the small and exclusive group of men for whom first line hormone therapy (Zoladex, Decapeptyl, etc) does not work! Many others of course enjoy several years with this treatment.

So I have now started on Enzalutamide. I had always thought of this drug as being for patients much further along the journey than I am. I need to change my mental model to one where this second line hormone therapy is now being used earlier in a patient's treatment plan. As a result of campaigning by Tackle and others it is now available before chemotherapy.

The other thing I need to say is I recognise many patients out there will be saying – "I'd give my right arm to have a PSA as low as 6.8" but in my case it was virtually zero with no intervention for nearly five years. It's all relative and we are all different.

So, let's see what happens in a month's time when I'll find out if this fourth treatment option works! Thank goodness we have several therapies available these days. Oh to get off the roller coaster!

The East Lancashire support group stand with two members at the early morning send off on Monday 12th June for Jeff Stelling. He was setting off from Burnley FC on his 25 mile, 12th leg (15 marathon walks in 15days) to Huddersfield FC.



The GP's Role In Diagnosing Prostate Cancer

by Dr Sam Merriel NIHR Academic Clinical Fellow Centre for Academic Primary Care



Dr Sam Merriel

In the room were men with a mix of cancer stories. Some had just received their diagnosis and wanted to hear from peers about what happens next. Some had undergone surgery or radiotherapy and were in a post-treatment monitoring phase. Others were receiving systemic therapy for more widespread disease. An ex-member's partner filled the role of secretary of the patient group, carrying on her late loved one's legacy to support men like him. I know all of this because these men (and women) were so willing to be open with me and each other about their experience of prostate cancer. "My PSA's on the rise. Going back to chat to the specialist next week" said one of the older members of the group. "I've just started hormone therapy. Never knew how tired it would make me feel" shared a thin gentleman with a warm smile.

Then came the questions for the invited speaker. "I had to wait two years before my GP agreed to order a PSA, and it was 335! Why don't GPs want to do the test?" came a challenge from the back of the room. "If I'm feeling poorly during my treatment, is it worth seeing my GP or should I just go back to the specialist?" asked one of the younger men. "I was on the group that wrote the latest local guidelines. Do GPs get taught about things like that these days?" enquired another, sitting in the front row.

As GPs, we go along for the ride on our patient's journeys through illness every day. For many men with prostate cancer, it is something they will live with for months or years, and some will become experts in their condition. In these intensely pressured times for general practice, engaging with patient groups is a wonderful way to gain insights we might miss in day-to-day consultations. Primary care researchers can gain from patient engagement and involvement too; from suggesting new avenues for research through to helping develop ideas and proposals. "Send them to us", suggested a sage-looking man, spectacles in hand "and we'll teach them a thing or two".

*My sincerest thanks to PROSPECT, a prostate cancer support group in Bristol and South-West England, for sharing their stories and their thoughts on our research

Dr Sam Merriel is an NIHR academic clinical fellow in general practice researching cancer prevention and early diagnosis in primary care.

I was recently invited to address the annual general meeting of PROSPECT, a local prostate cancer support group. The brief I was given was to discuss the GP's role in diagnosing prostate cancer and the latest research in this area; a daunting task to tackle in a room full of men with prostate cancer at various stages on their cancer journey.

I spoke of the GP's role across the continuum of cancer, from prevention and early diagnosis through to survivorship support and palliative care. I tried to discuss some of the latest studies in the field, such as the PROMIS study and the CAP trial, in a digestible form for these men. I also mused with them about the potential role new genetic technologies will have in the future in guiding GPs in determining cancer risk prediction and making diagnoses earlier. However, it was the general discussion that followed that was most enlightening for us all.

Prostate Cancer Cardiff Support Group. Tony Barwell

Visit of our President on Monday 4th September 2017 followed by AGM

Our Chairman for the evening, Keith Cass welcomed all members and friends to hear a talk by Professor Kynaston of University Hospital Cardiff, on a review being undertaken in England and Wales on the quality of Prostate Cancer care. The National Prostate Cancer Audit was being undertaken by the Clinical Effectiveness Unit (CEU)

The audit started in England in 2013 and Wales from 2014. He explained that the collection and submission of high quality data by individual hospitals underpins the ability of the CEU to determine whether the care that men get is in accordance with recommended practise and to identify where improvement was needed.

The Audit was on a very specific basis, hospital by hospital. Findings for England disclosed that less men with small cancers were being treated radically and that some men with high risk cancer were not getting adequate treatment.

Thus the delivery of care was important and an assessment of the process of detection was under review. What were the best ways of detection, eg. MRI scans to ensure the best treatment?

The Audit included an examination of the experience of Patients 18 months after diagnosis and in England it was demonstrated that most men were happy with their treatment.



Data collection in Wales started a year later than England and its input aimed to ensure accurate and complete data with each record being signed off by a Clinician. All six Health Boards provided data to a high standard.

In Wales the period April-Oct 2015 showed that three quarters of men diagnosed responded and their experience of care received was very positive. Where treatment was either radical surgery or radiotherapy there were, from time to time, side effects. Men are encouraged to see clinical nurses or other healthcare professionals who can then provide support for their condition.

In the period April-Oct 2015 12% of patients received radical prostatectomy, robotic assistance was given in 60% of cases. 33% received radiotherapy, almost all with radical intent.

Professor Kynaston reminded the meeting that detailed finding of the Audit could be found under the heading NPCA. Both Clinical and Patient findings are recorded in detail.

Replying to questions he assured the meeting that these audits provided valuable feedback to ensure that all Healthcare professionals dealing with Prostate Cancer identified and utilised best practise.

Professor Kynaston's talk was followed by The AGM where the Committee of five members were re-elected and the Annual Accounts approved.

Cotswolds Prostate Cancer Support Group (Gloucestershire group news). Roger Powell

The Cotswolds Prostate Cancer Support Group continues to have a busy time, providing support, and raising awareness of prostate cancer, in the Gloucestershire area.

They've had regular talks and presentations at the group's main monthly meetings, held on a Monday evening at the excellent Maggie's Cancer Centre in Cheltenham, with a usual attendance of around 30 to 40. (See picture). In recent months these have included excellent presentations from two members of 'Tackle's Clinical Advisory Board, Professor Nick James and Dr Jon Rees, (whose talks are available on the CPCSG group's website), as well as a consultant surgeon, an oncologist, a continence nurse, an ED expert, medical detection dogs, a solicitor and others. The group also has a separate informal evening pub get-together for its 'Prostate Cancer Partners' every month, which continues to be well-supported.

The group's volunteers have manned their information tent at major classic car events, village fairs and agricultural shows, talking to many hundreds of people to spread the word on prostate cancer awareness. Awareness presentations have also been given to Rotary clubs, Probus clubs, sports clubs and others, and also to church groups with predominantly African/Caribbean congregations.



group around Gloucestershire, and plans are in hand to have another in the spring of next year, (funds permitting!).

At their last free public PSA test, held in Stroud in May, over 430 men were blood tested in three hours, and 42 were found to have significantly raised PSA levels, needing follow up. This was the fifth test held by the

The Cotswolds Prostate Cancer Supporter Group is pleased to be using the Tackle Designed Website Template

<http://www.cotswoldsprostatecancer.org/>

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The National Federation Of Prostate Cancer
Support Groups

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Rob Banner

John Coleman Help Line Co-ordinator

Keith Cass MBE

Helpline Co-ordinator: John Coleman

Helpline No. 0800 035 5302

Information Officer: Alan Ashmole

Regional Co-ordinators:

Chris Burrows	Midshires
John Coleman	North West
John Burton	London
Hugh Gunn	Heart of England
Brian Jones -	Wales
Robin Millman -	North East
Sandy Tyndale-Biscoe	Western Counties
Allan Higgin	South East

Our support:

Group Liaison	Simon Lanyon
PR & Marketing	Siobhan Connor
Fundraising	Dave Fergus

The Editor would like to thank
everybody who has contributed to
Prostate Matters.

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

Prostate Matters Delivery IMPORTANT

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

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

A Letter From Graham Fulford



Dear All

Hot on the heels of our 1200th cancer
find....ours and all the groups that
is.....is the achievement of my
sponsored "double challenge"....hit
79.6 kilo's a day early and the Welsh
wind Gods briefly relented earlier
today to enable me to complete the
zipwire challenge. A huge adrenalin
rush I can highly recommend!! So if
you've sponsored me....thanks very
much! If you haven't there's still time!!

All this on top of many of you voting
for us in the Masonic 300th Centenary
Charity Grant awards enabling us to
obtain a fantastic £4,000!! Thank you
all!!

As if that's not enough I can now
announce we've been voted by
Coventry FC Supporters to be one of

the six nominated local charities the Club will work with in the 2017/18
Season....and that was out of 700 Nominated local Charities! A big public thank
you to Andy Woodfield who I believe was instrumental in our name being put
forward and for no doubt mustering votes. More than anything it's a huge
compliment to all the "team" who help to spread the word about what we're
trying to achieve...so a heartfelt big thank you and hug to you all. As it happens
working with the Coventry and North Warwickshire PCSG we'd already set up
a programme of testing sessions starting at St Finbarrs Sports and Social Club
on 14th October....so imagine my delight when the people in the Community
Department at Coventry told me they sponsor "walking football" for the over
50's at St Finbarrs every Friday morning! A perfect target group for testing and
real evidence for those supporters who voted for us that we aim to help their
community. Whilst on the football theme we're testing at Burnley FC on 30th
September and Blackburn FC on 28th October...and hopefully the Rugby boys
are getting the message....having been to The Stoop twice we tested over 220
men at Daventry RFC last Saturday and Northampton Saints have offered the
organiser of that event a match day bucket collection....so who knows it may
be testing next!!

Watch this space!! Regards Graham