

prostate matters

The Newsletter of The National Federation of Prostate Cancer Support Groups

Free Help Line - 0800 035 5302

prostate cancer

Action for patients

Registered Charity No. 1163152

November 2019 issue 46



Roger Wotton, retiring Chairman

Roger retires...

Roger Wotton, Chairman of Tackle since January 2015, has stepped down as a Trustee due to ill health. He said:

"It is with deep regret that I announced my resignation as a trustee of Tackle. This is entirely due to the progressive nature of my advanced prostate cancer. At the moment I have reached the end of the road for any further therapy and it is unfortunate that this has developed over a relatively short period of time. The last five years with Tackle have been some of my most enjoyable and I will really miss the challenges, the camaraderie and the work in helping men and their families suffering from this terrible disease."

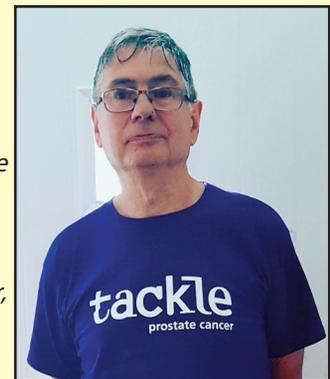
...and Ken is the new Chairman

Ken Mastris has been elected the new Chairman and commented on behalf of the Board:

"Roger has worked tirelessly to raise awareness of prostate cancer and to put forward the prostate

cancer patients' views. He has always made himself available to help member groups, be it advising them about how to set up a group or coming along to speak at their meetings. During his tenure, he visited over 50 groups across the country. He has also been passionate about working with other prostate cancer charities so that we can be more effective together, and has been very successful in putting us in a sound financial position. We are extremely grateful for the enormous contribution he has made to Tackle."

Ken has been a Trustee of Tackle since 2010 and Vice Chairman since 2015 and, until recently, was chairman of Europa Uomo which acts as the voice of men with prostate cancer in Europe.



Ken Mastris, new Chairman of Tackle Prostate Cancer

Tackle scores with Wiltshire Walking Football team

Tackle has teamed up with Wiltshire Walking Football Club to help raise awareness of prostate cancer. And the team manager is... Tackle's new trustee, Alphonso Archer!

Walking football is springing up all over the country. It's a game for the over-50s with rules that outlaw running and allow no contact between players. Over-head height restrictions and indirect free kicks mean it's safe and enjoyable. So anyone who has always loved the game can get back into it for their health and wellbeing.

Tackle have offered to supply all the Wiltshire recreational sessions with new bibs and are also providing the Over-50 and Over-60 teams with a new set of shirts each.

"We are looking forward to the collaboration ... to raise awareness and funds. This (is a) useful way of encouraging men with prostate cancer to get regular exercise, stay healthy and have a better quality of life."

Roger Wotton

"... Tackle is not only an appropriate name to be associated with walking football but a very appropriate cause for the age group ... and, currently, mainly male players."

Tony Norton, Lead Volunteer/Organiser, Wilts Walking Football (recreational) & Chairman/Club Secretary, Wilts Walking FC

"This is the perfect partnership for us as we aim to get prostate cancer high on the agenda until it becomes a disease of less significance."

Alphonso Archer, Trustee Tackle Prostate Cancer

Alphonso's football story

Alphonso played football until he was 47, then gave up. During his treatment for prostate cancer, Alphonso heard about walking football, took up the game and found it helped him get through that very challenging time, both mentally and physically. And he's never looked back!

"Scoring a goal feels no different from when I was five years old. Now I'm 55, it still feels the same," says Alphonso.



The over 50s with Alphonso (front row, centre) wearing their new shirts

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My experience with PROTON BEAM THERAPY by Timon Colegrove, Secretary Oxford PCSG



Timon Colegrove underwent proton beam therapy after being diagnosed with prostate cancer aged 56. Here, he shares his personal journey.

A little over two years ago, I was in the process of selling my company and I decided to have a thorough health check-up. I was tired from the strain of building and sustaining my business over 35 years but otherwise fit and healthy so I wasn't expecting anything to be amiss.

My blood test results revealed a slightly raised PSA level. I was told it was 5.2 – for a man of my age (56 at the time) it shouldn't really be more than 4. I began to really worry when an MRI scan revealed some 'shadows' in my prostate, and I was booked in for a Trans Perineal Biopsy to find out what was going on in there.

Unwelcome results

After the operation, I received a phone call from my consultant asking me to come in to discuss my results. Immediately I feared the worst. My girlfriend (now my wife) came with me and was holding my hand as we heard the words, "I'm very sorry to tell you Mr Colegrove you have cancer." It was an unnerving and surreal moment. I was still in some discomfort from the biopsy but otherwise I felt healthy and well.

How could I have cancer?

Moving swiftly on to a treatment plan, my consultant (a surgical oncologist) outlined a 'nerve-sparing prostatectomy'. He drew a sketch to illustrate how they would cut around my prostate while hopefully preserving some nerves allowing me to 'feel some sensation'. The operation comes with a 40% chance of impotence and a 40% risk of incontinence, he added – as if these were just widely accepted side effects.

Looking for other options

I went on holiday and tried to put my diagnosis to the back of my mind. When I returned, I started my own research. I spoke to people who had undergone a radical prostatectomy; all of them had encountered problems. Two men had become impotent after surgery; another required permanent hormone therapy. A further man had to have surgery again because of bleeding. The brutality of the operation and its accepted risks alarmed me.

Here we are in the 21st century and this bygone-era butchery is all you can offer me...?

I decided to attend an Oxfordshire Prostate Cancer Support Group meeting. The guest speaker that evening was Professor Karol Sikora, from the Rutherford Cancer Centres, who spoke about proton beam therapy. A solution with close to no side effects? It immediately piqued my interest. Wanting to know more, I found an

article about some British men who had undergone proton beam treatment in Prague and reported no side effects.

Fantastic!

Who will help?

At the next meeting with my consultant, we discussed my reservations about surgery, and briefly touched on brachytherapy (where radioactive seeds would be implanted in my prostate). When I raised the topic of proton therapy, it was instantly dismissed: "There's no data to support it," was the brusque response.

I then made an appointment with an oncologist, primarily to discuss the brachytherapy option (which carries the same side-effect risks as surgery), and discovered he was aware of proton therapy and was thinking about studying it.

"Aha! An endorsement from an oncologist," I thought.

I engaged with the Rutherford Cancer Centre, who requested my scans, and Dr Jason Lester called me, saying they may be able to help. By now I had read the articles about Simon Hardacre, the first patient to be treated with proton therapy in the UK at the Rutherford Centre in Wales. I found Dr Lester's explanation of proton beam treatment very reassuring, and my girlfriend and I were given a tour of the newly-opened facility's premises and equipment.

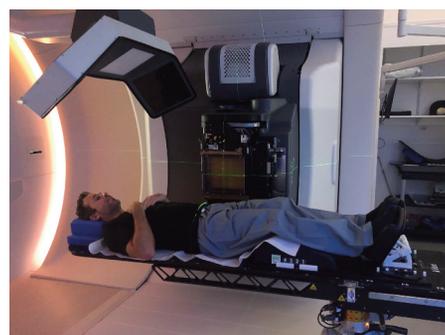
After the meeting I weighed up my options and decided that proton beam treatment gave me the best chance of beating prostate cancer and resuming a normal life afterwards.

The process begins

The first point of call at the Rutherford was to start hormone therapy – two injections, a month apart. This was the worst part of my entire treatment. It gave me an insight into impotence as my libido diminished. My girlfriend was very supportive but I felt as though I was losing my vitality and attractiveness; I felt inadequate. It went on for six months and it was utterly distressing – I very much feel for those left permanently impotent by their cancer treatment.

I also elected to have an operation to put in a spacer (a biodegradable balloon), which the Rutherford recommend to protect the bowel from the effects of the radiation. The spacer would stay in place over the course of my treatment, and dissolve naturally afterwards.

I was scheduled for 20 fractions of proton beam treatment, which would be administered on working days over a month-long period. I had got engaged (no feeling sorry for myself now!) so my fiancée and I booked an AirBnB in Wales and began our new routine.



How was it for me?

Each morning I had to self-administer a mini enema and drink a prescribed amount of water; I would go in to the Rutherford Centre in Newport at 10am and, after my

treatment, my fiancée and I would spend the rest of the day exploring Wales. The proton beam therapy was painless and the whole procedure was very well monitored and efficient. I was usually in and out in under an hour.

The brilliant and dedicated team of radiographers ensured that I was well looked after and that I understood every aspect of the treatment. The culture and the warmth at the Rutherford Centre is exactly what one would wish for if facing cancer.

My only side effects during the month-long period of treatment were an increased need to pass water, which quickly returned to normal afterwards. My hormone levels – which had been suppressed to the equivalent of castration – took longer to recover, but I am now feeling as vigorous as ever (my wife agrees!). My post-treatment PSA level is negligible – and has remained so. All in all, I feel just fine – cured of a disease I never knew I had. I was very fortunate to be able to pay for my treatment. However, I would have done whatever it took to afford proton beam therapy – even sell my house – because our health is the most important thing in life.

Clarion call

People are suffering dreadfully because of prostate cancer and it can be avoided for many, which is why I feel obliged to share my journey. Prostate cancer kills more men than breast cancer kills women! Men need to know that there may be an alternative to surgery and conventional radiotherapy.

This is a clarion call; I truly believe clinicians have a moral duty to share awareness of this alternative treatment with few, if any, side effects.

Timon is available to speak at groups about his experiences with proton beam therapy. Please email him at: timoncolegrove@gmail.com

Editor's note

Prostate Matters thanks Timon for this personal and impassioned account of his experience with Proton Beam Therapy. The debate about PBT continues to be active and Tackle supports the treatment being available on the NHS.

We would like to point out that we also receive many stories of positive experiences and successful outcomes following surgery and other treatment options that are currently available on the NHS.

Body image survey by Caterina Gentili

Caterina Gentili is a PhD student from the Centre for Appearance Research at the University of the West of England, Bristol.

Her work focuses on the psychological challenges that prostate cancer patients on ADT have to face daily. In particular, her research aims to shed more light on whether ADT side effects (such as breast enlargement) might negatively affect patients' relationship with their bodies, and their self-confidence.

Caterina is also interested in whether exercise helps patients to feel better about themselves, improving their psychological and physical health.

The study

With the help of Tackle Prostate Cancer, Caterina recently conducted a survey on ADT, exercise and body image. Body image is the subjective evaluation that people make of their bodily appearance and functioning.

The survey was filled out by 60 PCa patients on ADT, 60 PCa patients who never had ADT, and by 60 cancer-free men of the same age.

The survey included several questionnaires, measuring body

image, masculinity issues, exercise habits, and fear of being negatively judged for one's appearance and physical performance.

Caterina's predictions

Comparing the group of men on ADT with the other groups:

Caterina expected that patients on ADT would suffer from more body image concerns and would show greater fear of negative appearance and physical performance evaluation; and that these concerns would cause them to face more masculinity issues when compared to patients who never had ADT and the cancer-free men.

Looking at the group of men on ADT separately:

Caterina expected that men in this group who had a greater fear of negative evaluation for appearance and physical performance would have stronger masculinity issues and body image problems. She also predicted that lack of exercise would reinforce this negative circle.

Results and further research

Comparing the groups:

What Caterina actually found was that patients on ADT did not suffer from more body image concerns and fear of

negative appearance and physical performance evaluation compared to the other groups. So it seems that ADT is not directly linked to negative body image and that PCa patients tend to be resilient against these problems. Caterina feels that future research should investigate the coping strategies that PCa patients naturally put in place to deal with these issues.

The ADT group separately:

But when Caterina looked at this group separately, she found that IF they had high fear of negative appearance and physical performance evaluation, then they were more likely to suffer from masculinity issues and body image concerns. She therefore thinks that future research should explore strategies to help PCa patients avoid comparing themselves to others, as this could lead to poorer mental health outcomes.

However, she found that lack of exercise did not contribute to maintaining this negative circle.

Many thanks to everyone who contributed to this survey.

A warm welcome to our first female Tackle trustee



After attending the 2019 Tackle AGM with her husband, and hearing of the appeal for a new trustee – particularly a female one – Jacqueline Manthorpe applied for the job and Tackle is very pleased to welcome her onto the Board.

Jacqueline's experience includes 18 years in commercial insurance, 20 years as a registered nurse, and four years of continuing counselling study and practice.

Jackie says:

"I have first-hand experience of being both a cancer carer and relative of someone with cancer. I actively engage with a local PCSG and work pro bono for two charities as a counsellor. I look forward to engaging with the other trustees and working towards making Tackle more successful and sustainable for the future."

What does your Patient Representative do?

A report by Steve Allen, patient representative, Tackle Prostate Cancer

Since I took over this role from Hugh Gunn there has been considerable activity in many areas. I had thought it would merely be an involvement with NICE but far from it! I discovered that Hugh had been involved with so many other organisations/bodies. Such a role might not be interesting to many members but, perhaps because of my medical background, it provides me with an insight into developments in diagnosis and treatment and is both fascinating and quite hard work!

What qualifies me for this job?

A good question. My diagnosis and treatment days are now over 11 years ago, and I've been lucky not to need treatment for a recurrence of my cancer. However, I have experienced considerable problems with incontinence and sexual dysfunction. I also talk to a large number of men with PCa and hear their views and opinions. Tackle also have a Clinical Advisory Board from who I can take advice.

Three major areas of my current activities

Involvement with regulatory bodies

Offer opinions

I provide patient opinion on the appraisal of drugs and treatments that are totally new or are older drugs that could be used in new clinical scenarios to bodies such as NICE and the Scottish Medicines Commission. Two areas under current review are:

1. The use of drugs in patients who have already had initial therapy with surgery or radiotherapy, then had a recurrence treated with hormone therapy but now find their PSA rising – but where no spread can currently be detected. Some drugs, such as abiraterone and enzalutamide can only be used currently when secondary spread has been identified. Chemotherapy (docetaxel) is already used in this context and there are other drugs which could be used in a similar way.

2. The assessment of potential drugs for use in combination therapy to treat men who at initial diagnosis already have very advanced and aggressive disease.

There are also some newer drugs and treatments undergoing assessment by NICE/SMC. One important one is the injectable gel SpaceOAR® (which already has approval for limited trial use in the NHS). This aims to decrease radiation damage to the rectum by physically increasing the space between rectum and prostate. Many other ongoing appraisals are still confidential.

My role in such bodies does not involve discussion of relative costs of treatments. I feel my job is to ensure all appropriate treatments can be made available to those whose lives are affected by prostate cancer irrespective of costs and the numbers of patients involved.

NICE Guidelines

Tackle is a stakeholder in giving patient opinion on changes to guidelines published by NICE. The guidelines are extremely influential in determining how patients are treated in the 'real world'. Tackle gave considerable feedback when the latest guidelines were being drafted, not only through me, but other members of the Clinical Advisory Board – Frank Chingwundoh and Chris Booth.

Give feedback

National Prostate Cancer Audit

I sit as one of the patient representatives on the committee that oversees this activity. The Audit provides a source of considerable information each year on the incidence and management of prostate cancer.

Represent patients

Increased patient involvement

There is a general consensus from most regulatory bodies (and the pharma industry) that they should be as transparent as possible to both patients and public. They wish not only to have opinion on how to change current processes, but also to understand what patients want from them — information, support etc.

They are looking for a wide diversity of opinion and input. This is something with which I need considerable help – my opinion alone is not enough. When appropriate, we will contact support-group leaders and ask them to canvass their members for people willing to help – both patients and their partners. Meanwhile, if you would like to know more about participating, please contact me by email: drstephenallen@btinternet.com

Can you help?

Meetings are often London, but travel expenses should be paid by organisations concerned.

Equally, if there is something that you feel should be addressed by any of the bodies with whom Tackle works, then do not hesitate to contact me.

I believe it is vital that we patients have a say in decisions that affect our future. What I aim to do is just one small part of that process.

Lions team up to help fund PSA test!



When Peter Constable (left, with his wife Sharon), had a check at Spire Parkway

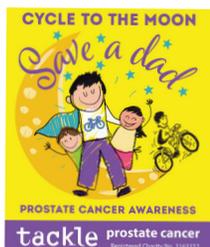
Hospital in the spring, his world was turned upside down when tests revealed he had early-stage prostate cancer.

After an operation and recovery, Peter decided to host a charity ball to fund a PSA test session like the one he'd attended. He and Sharon teamed up with Shirley Lions, who have hosted several PSA events, and were keen to raise funds to host another.

More than £7,000 was raised in Peter's honour through ticket sales, competitions, raffles and tombolas. Finding out they'd raised enough to hold a PSA test event was the best moment of all for Peter. Martin Conlon, Shirley Lions President, announced the test for April 18 at Shirley Methodist Church.

Sharon said: "When he spoke at the ball (it) made me weep with relief that his cancer was discovered so early and removed."

Cycle/Bike to the Moon latest news



Another successful year, with our fundraising campaign raising superb sums to help Save a Dad.

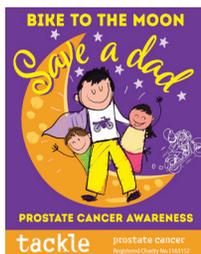
We have now collected just under £20,000 – a great result!

Many thanks to all the:

member groups
cycling clubs
motorcycling clubs
and gyms

that took part.

We really appreciate your support!



Tackle ManVan update



Those who attended this year's AGM will remember seeing the Tackle ManVan.

We have been working with Professor Nick James of Queen Elizabeth Hospital, Birmingham, and the Unite Union to get it up and running and we are very pleased to report that, as of October, the project has received official confirmation for use in a pilot study as a Well-Man Clinic including PSA testing.

Final details

However, before Tackle members can start hiring it, we need to finalise arrangements as to precise costs, distance it can travel, length of hire and insurance.

We will keep you posted.

Alphonso: action man!

Alphonso Archer, intrepid walking footballer and Tackle trustee, has always had a fear of heights but still decided to face a paragliding jump, which he did on 24 August 2019 on Babadag mountain, Turkey – wearing his Tackle bib (see front page story).

Alphonso said: "The whole experience was extremely scary but with the Gravity paragliding team you immediately felt that you were in the hands of professionals."

The journey up to the mountain was frightening and everyone started talking about their experiences which helped those doing it for the first time.

"I see this jump as a metaphor for people with prostate cancer to tackle their fear head on. It's only when you open up and talk to family, friends and professionals that these fears start to subside."

Alphonso, below left, prepares for his skydive



Shepway Veterans on top of the world with over £6,000 fundraising climb



L-R: Martin Flood, Kayrul Meah, Simon Holder, Mark Buck, Adrian Morris, Alistair Hammond, Brian Begley

Shepway Veterans, a group of men over 45, from Shepway in Kent, was founded by Alistair Hammond after losing his father-in-law to prostate cancer. All the other members have been affected by cancers in some way, too.

They have just completed the challenge of a lifetime: climbing the three highest peaks in the UK: Ben Nevis in Scotland, Scafell Pike in England and Snowdon in North Wales, while raising awareness and funds (they raised £6,445) for Tackle Prostate Cancer.

After a year of meticulous planning, from training schedules to kit, accommodation and transport, it all came together seamlessly.

Alistair reflects on the challenges they faced

After a sleepless night, they undertook their first climb.

"Ben Nevis was first and, although steep and never-ending... it (was) the most straightforward."

Next, Scafell Pike – the shortest climb of the three, but by no means the easiest.

"... we (finally) made it up and onto the plateau where the climb to the summit faced us. The weather was closing in... so no pit stops at the top..."

Exhausted and with tired legs, the group drove the four and a half hours to Llanberis, Wales, to meet Snowdon.

"Snowdon was going to be tough... We chose the Miners route... which proved tricky as the route wasn't clear and... the wind was gusting at 60 mph."

Digital donations

The group has received fantastic support from local company LIFElabs.io (LIFElabs) a Fintech blockchain company who will provide a facility for donations to be accepted in digital currencies, such as Bitcoin, Ethereum and LIFEToken. LIFElabs have agreed to help sponsor aspects of the challenge and will match fund donations received – up to £5,000. The LIFEToken community have donated 13 million LIFEToken.



The Shepway Vets team at the summit of Ben Nevis

Very well done and thank you to all the Shepway Veterans for their valiant climbs and great fundraising!

Phil Collins (tribute artist) gigs for Tackle

Chris Perry, a fantastic Phil Collins tribute artist and Tackle supporter, has been holding a series of concerts to raise awareness and funds for prostate cancer and Tackle.

During the break between his two sets, Chris talks about prostate cancer and likes to mention the time he and his crew took a PSA test so that they knew what they were talking about when raising awareness. Chris didn't know what the PSA test was and his crew told him it was a DRE. They made sure Chris was at the front of the queue, and once the phlebotomist had taken the blood sample he asked, "Is that it?" (clearly very relieved!). She said it was, and he turned to find everyone roaring with laughter.



A splendid prize table!

The management and volunteers at the venues collected prizes, and held raffles and other events. He has raised over £3,000 for Tackle so far.

Men have told Chris that, after his speech, they've been tested and prostate cancer has been picked up early, potentially saving their lives.

Report by John Coleman, Trustee, Tackle Prostate Cancer

Thanks for spreading the word, Chris, and to you and everyone else who helped to raise much-needed funds.

Inspiring talks in Cardiff



Professor Howard Kynaston (right), Head of the Urology Department, University Hospital of Wales, Cardiff, with Cardiff Group Co-Chairman Tony Barnwell

Cardiff PCSG runs an active programme of talks relevant to prostate cancer. Recently, experts have spoken on:

- The treatment of advanced disease
- Spying on cancer
- Can immunology cure cancer?
- The development of novel anti-cancer drugs with help from computers

Members often say how reassured and optimistic they feel after hearing about research and advances in diagnostic techniques and therapeutic regimes for prostate cancer patients.

In September, Group President, Professor Kynaston, gave a positive talk clarifying the findings of the NICE Guidelines (2019), and answered members' questions.

The November talk is on Diet and Cancer.



East Lancs PCSG on a mission!

Gordon Haycock of the Burnley Pendleside Rotary Club presenting a cheque to Stuart Marshall

Dave Riley (Chairman) and Stuart Marshall (Sec.) of the East Lancashire PCSG have embarked on a 'mission' to create awareness of prostate cancer within local organisations and industry. Recently they spoke at two Rotary Clubs – the Burnley and Burnley Pendleside Clubs.

They talked about the work they do as a Support Group offering help and advice to men diagnosed with prostate cancer and their partners. They moved on to the importance of PSA testing, the lack of a national screening programme, and the many blood-testing events that East Lancs Group have organised since January 2015 – including the costs.

There was much interest and support – and delight, when both Rotary Clubs gave a donation.

Beds PCSG have been busy!

The Beds PCSG have been very active during 2019. So far, three awareness events have taken place with another four lined up. The group have had T-shirts printed with the logo 'A PSA test could save your life' on the back, and also have pens with their web address on.

Fundraising for PSA testing has come from several successful grant applications, donations, a walking football tournament and from collection tins in pubs in the area. The generosity of the pubs' clientele is quite impressive!



A PSA testing event was held in Luton in July, with 83 men attending, and Graham Fulford Charity Trust phlebotomists helping. Seven red letters were sent out from this event. A second testing event is planned for Luton before the end of 2019.

Two other PSA events are being arranged in Bedford, one specifically for BME men. It has proved hard to get BME men to attend, so this one-off event targets them.

Report: Brian C. Webb (Chairman), Beds PCSG

East Suffolk PCSG raise money for scanner

The East Suffolk PCSG have recently helped to purchase a bladder scanner for the radiotherapy department of Ipswich Hospital.

The group raised £4,700, including a donation of £550 from Suffolk Ballroom Dancing Club, towards the much-needed piece of equipment, which will speed up diagnosis and treatment of prostate cancer patients.



Handing the scanner to the Radiotherapy Dept.

Starting a new PCSG – the TAPS story

Tamar Valley Health (TVH) Practice has 16,000 patients of whom, statistically, 250 might be expected to have prostate cancer. I am one of those. As a member of the TVH Patient Participation Group (PPG) I felt we could support local PC patients by starting our own Support Group, which has the strong support of both TVH and PPG.

The first meeting in October 2018, attracted about 20 people. It was hosted by TVH in Callington Health Centre. TVH publicised it with posters in its two surgeries and an email shot to PCa patients. We now hold monthly meetings and have about 40 people who have attended at least once and about 15 who have been at most of them.



Chris Greensted (second from L) and members of TAPS

We formed a five-person Steering Group and agreed a name (TAPS) and a Constitution so we could open a bank account and begin to raise funds. We have agreed that our purpose is to grow TAPS as a support group and raise awareness of PCa in our area. We have spread the word by flyers to parish newsletters, posters in surgeries and email shots.

The first fundraising event was a tea party by St Anns Chapel Committee. One of our Steering Group made a presentation and, subsequently, our local Councillor gave us a grant from the Councillors Fund, and Tackle provided a start-up grant.

Since then we have had talks by a TVH GP; by a Consultant Urologist at Truro Hospital; and by a skin-care specialist. Prior to the first AGM in September, we carried out a satisfaction survey. Broadly, members were content, although it is clear that the real draw is medical speakers.

Issues still to resolve

1. Difficulty attracting medical speakers to a rural location.
2. What activities would work for non-speaker meetings?
3. How do we get members to participate more and how can we best support them?
4. How useful could social events such as walks, fishing trips, pub/café socials etc. be? What else could we run?

TAPS would welcome advice and ideas from other groups. Please feel free to contact Chris Greensted, Chair TAPS at: tapsinfo555@gmail.com

tackle

prostate cancer

www.tackleprostate.org

The National Federation of Prostate Cancer
Support Groups

Tackle Prostate Cancer is the campaign name of
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Ambassadors

David Gower OBE

Damian Hopley

Lord Rose

Captain Julian Burgess

Supporter

Jason Leonard OBE

Honorary President

Sandy Tyndale-Biscoe

Our volunteers

Trustees:

Ken Mastris, Chairman

Alphonso Archer

Rob Banner

Professor Frank Chinegwundoh MBE,
Clinical Advisor

John Coleman, Secretary

Erik Friis-Scheel, Finance

Jackie Manthorpe

Helpline coordinator: John Coleman

Information officer: Alan Ashmole

NICE coordinator: Steve Allen

Regional coordinators:

John Coleman North West

John Burton London

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

Editor's note

Many of our articles contain links to
information on the internet.

The best way to access these is to go to
our website: www.tackleprostate.org
where you will find the web edition of
this and past issues of Prostate Matters
with live links.

The Tackle Helpline

0800 035 5302

- is open every day including all Bank Holidays
- is always manned by a prostate cancer patient
- has 12 Helpliners, who can refer you to a patient who has had a particular treatment
- is coordinated by Tackle trustee John Coleman

Tackle is very grateful to Droylsden PCSG, Greater Manchester, for funding the Helpline for the last three years.



CHAPS, the men's health charity, campaigns for awareness of and access to PSA screening for prostate cancer. It flags up advances and tracks reports from scientific journals and conferences. Some recent messages are:

- There are NO new markers to replace PSA as the initial screening tool for PCa.
- DO NOT stop screening at age 70.
- Men in PSA screening programmes run for up to 20 years now consistently benefit from 50% reductions in the PCa death rate compared with men not screened. The European Urological Association recommended national PSA screening programmes to the European Parliament.
- A raised PSA must be followed by second-line tests BEFORE a prostate biopsy.
- Active Surveillance is a safe option for apparent non-aggressive PCa.
- Minimally invasive treatments for early, localised PCa continue to show reduced side effects and good cancer control/cure.

The evidence clearly shows that, to reduce his chance of dying from PCa, a man should start PSA screening at no later than 50. All men over 50 in the UK are entitled to a PSA test in current NHS regulations.

PSA testing events

If your group is holding a PSA testing event, we'll add it to the list on the Tackle website. Email info@tackleprostate.org with the date, time, town, postcode, contact name and phone number.

Contribute to Prostate Matters

Without you, we would not exist!
Please keep contributions coming to:
editor@tackleprostate.org (send photos separately at high resolution).

Edited by Cheryl Lanyon; Printed by Automedia Limited, Loughborough.

Thank you to everyone who contributed to this edition.

Check your details

Unless otherwise requested, your details will appear on the list of groups on our website.

We ask 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 you require any corrections, contact Simon Lanyon: simon.lanyon@tackleprostate.org.

Fundraising tips



Here's another brilliant way to raise funds for Tackle at no cost to yourself.

easyfundraising turns your everyday online shopping into free donations.

How? Just go to their website, type Tackle Prostate Cancer in the 'Search for a cause' dropdown box and click on it to choose it. You'll be taken to the Tackle fundraising screen. Click on 'Support us for free' and you'll get to a page where you set up your account.

Then, when you start online shopping, go to the easyfundraising website or app first, choose your retailer and start shopping as usual.

There are 3,783 retailers to choose from and when you buy, the retailer makes a small donation to say thank you and easyfundraising sends those free funds to your cause.

Don't forget to sign up all your family, and tell your friends, too!

If you have any fundraising tips, let us know and we'll publicise them in future issues.



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