For the past few years we have been generously helped with our finances by Prostate Cancer UK, which has provided up to 50% of our core funding with the aim of helping the Federation find its feet, get established and secure its future. 2016 is the last year of this transitional funding so we have to find alternative sources of funds to enable us to continue the work we are doing. Although we have not been as successful as we might have hoped to raise additional funds during this period we are now putting in place a number of fund-raising initiatives to sustain the Federation going forward. This request for funds from groups is one such measure. I made it clear in my emails to groups that local needs come first and we would not wish any spare monies to be donated to the Federation unless local needs were being met.

Some groups have already responded with donations ranging from a few hundred to a few thousand pounds, and I am aware other groups are still considering this request. If any member wishes to know more about the details of our finances, where our money comes from and how it is spent, your local support group has been provided with details. However, I think it is worthwhile answering one question here that is often asked:

What value does the Federation provide to local support groups and their members?

We are acutely aware that the Federation has to demonstrate value to its members and others if it wants to continue to be known as the national voice of prostate cancer patients. It is worth pointing out that, unlike many charities, we do not have an office, we currently have no employees and very much rely on voluntary help and support from Trustees and others.
The Federation has an excellent Clinical Advisory Board, something that is often understated. Amongst the seven clinicians on the Board there are three professors and all the members are leading clinicians in their own field, be it Urology, Oncology or Primary Care. All give their time voluntarily. Having this resource is invaluable to the Federation, whether for understanding the impact of the latest drug or treatment developments, supporting our public relations activities, or helping our campaigning efforts. It also provides a patient’s voice direct to senior clinicians, which they in turn value.

We know that support groups find our conferences and workshops extremely useful, and we are always listening to valuable feedback from members in order to table topics that interest them. We endeavour to put together conference and workshop programmes that help groups stay in touch, network with each other and pick up tips and information on latest developments. The consensus from groups is that they would like to see these continue.

Many of our support groups are well established. Completely well established, completely self-sufficient in terms of money, resources and materials and they enjoy good local contacts. Others are not so fortunate or have just started. There are still vast areas of the country where there are no support groups. One of the things Tackle does is to help new groups get established. Since my involvement with Tackle we have seen the number of groups go from 65 to 86. Whether it is with publicity material, practical advice, a visit, a website template, the sharing of best practices or a small grant, we do what we can to develop new groups and extend our national reach.

Tackle undertakes significant lobbying and campaigning activities on behalf of groups. It sits on several NICE committees and presses the case for more equitable availability of drugs or improvements to the treatment pathway for the benefit of prostate cancer patients. In this edition of Prostate Matters you can see a summary of the real progress that has been made on several fronts. This leverage is something we will continue to exercise on your behalf.

Finally, at the National level, the Federation is able to liaise and stay in touch with many other charitable agencies on your behalf. As well as working with Prostate Cancer UK we also participate in a cancer charity coalition to make sure we play our part in making government agencies aware of prostate cancer issues and with developments such as the Cancer Drugs Fund. We also work where we can with charities such as CHAPS (Men’s Health) and Orchid (Male Cancers). In fact you can read elsewhere in this edition of Prostate Matters about my interview on London Live Breakfast TV with Orchid’s CEO talking about the importance of early diagnosis of prostate issues.

I do hope the answer to this question helpful. If you have other questions, please get in touch with your local support group or feel free to email me at roger.wotton@tackleprostate.org

It’s NICE Working with Tackle!  
Hugh Gunn

Let me take a moment to share with you the importance of recent work Tackle has undertaken with the National Institute for Health and Care Excellence (NICE). Many readers will not be aware of how we work behind the scenes on behalf of members. Perhaps the best way of describing this is to describe my involvement as Tackle’s main representative.

We regularly represent Tackle on NICE sub-committees looking at new prostate cancer drugs and treatments. I have served as a “voice of the patient” representative on the committees for the following drugs:

- **Abiraterone**, for use both after chemotherapy and before considering chemotherapy
- **Enzalutamide**, again for use both after and before considering chemotherapy
- **Degarelix**, specifically appealing the Final Assessment Document (FAD) and attending a hearing at the Department of Health to act as an appellant against the NICE decision. We successfully appealed for Degarelix to be available for patients with spinal metastases
- **Cabazitaxel**, successfully reversing the decision to withdraw the drug from the Cancer Drugs Fund. In this, Tackle was joined by Professor Nick James, Dr Alison Birtle, Professor Heather Payne and Dr Amit Bahl - all very senior consultant oncologists. The outcome of many letters and meetings in London was that Cabazitaxel was reinstated, reappraised by NICE and passed for mainstream NHS use.

This is the treatment I am now receiving, and without it I fear I would be very near the end.

- **Radium 223**, which was originally passed for use in men who had ben given Docitaxel, this left a significant group of patients with few treatment options available. NICE looked at this again and have now passed it for use for all patients who need it.

Over the last five years Tackle has worked hard on behalf of patients and we have together played an active part in all of the submissions and appraisal committees for the above treatments, which have all now been passed.

This success represents a massive change in the treatment for those men suffering from advanced prostate cancer and can significantly lengthen their survival time. We will continue to represent the voice of prostate cancer patients in this way and our achievements to date is something all of Tackle can be proud of. I am proud to have been personally involved with many of these decisions.
It is well known that Prostate Cancer is more of a risk to West Indian males than it is to European males. The Walnut Group does have a regular attendee from the Preston Caribbean community, who has been affected by PC for many years, but thankfully lives a stable life today.

It was felt that West Indian males were as reluctant as anyone else to seek medical help when ‘downstairs’ matters weren’t as they should be. A discussion took place at one of our support meetings on what action could be taken to increase awareness and encourage participation in a PSA blood test, among the African-Caribbean community.

An approach was made to the leaders of the African-Caribbean community to discuss the idea of a joint social evening, taking the form of a gentle ‘get to know each other’ evening with some Caribbean music, and food. Invitations would also extend to wives. Representatives of the Walnut Group PCS and the Montserrat and Friends Association attended the meeting.

The event was to cost maximum £650 including room hire, food and music. The evening was to be billed as a social event with the aim of an informal approach on the subject of Prostate Cancer awareness and to demonstrate the experiences of the Walnut Group PCS across a wide spectrum of cancer journeys.

Overall, the event started at 7pm finishing at 11pm – proving very worthwhile with some 41 people present from the African-Caribbean community and 14 members from the Walnut Group. The format of the evening was considered to be a reasonable model to follow in future and the feedback from our hosts was that they were a little disappointed that there were not more attendees from their side.

Financials
The ‘Care and Share Evening’ cost a total of £605 to put on but a grant of £500 was provided by the Trustees of Tackle Prostate Cancer to help fund the event, for which the Walnut Group is most grateful.

Conclusion
Such an event is a good way of breaking the ice with other ethnic groups that have their own communities. Cultural differences need to be considered. The Walnut Group has opened up communication with the African-Caribbean community in Preston in an effective way, and we feel sure they will benefit from this in the future.

<table>
<thead>
<tr>
<th>Drug</th>
<th>Tackle Involvement</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enzalutamide Chemo (Pre) Naive</td>
<td>Patient Rep. on NICE Appraisal Committee (STA). Patient Rep. on CDF rapid reconsideration of Radium-223 dichloride for treating metastatic hormone relapsed prostate cancer with bone metastases</td>
<td>From September 2016, passed for use for all patients, providing there is no known visceral metastases (soft tissue)</td>
</tr>
<tr>
<td>Radium 223 dichloride</td>
<td>Patient Rep. on NICE Appraisal Committee (STA)</td>
<td>Passed for use in patients presenting with spinal mets.</td>
</tr>
<tr>
<td>Firmagon (Degarelix)</td>
<td>Patient Rep. on NICE Appraisal Committee (STA) and on appealing the FAD. Tackle became an appellant and had to give evidence twice at appeal hearings</td>
<td>Passed for use in patients presenting with spinal mets.</td>
</tr>
<tr>
<td>Abiraterone</td>
<td>Patient Rep. on NICE Appraisal Committee (STA) and on appealing the Appraisal Consultation Document (ACD)</td>
<td>Passed for use after Docetaxel</td>
</tr>
<tr>
<td>Abiraterone Chemo (Pre) Naive</td>
<td>Patient Rep. on NICE Appraisal Committee (STA) and on appealing the Appraisal Consultation Document (ACD). Made the front page of the Times.</td>
<td>Passed for use before Docetaxel</td>
</tr>
<tr>
<td>Cabazitaxel</td>
<td>Appealed against removal from CDF and attended the new Appraisal Committee (STA) as a Patient Rep.</td>
<td>Put back on CDF and then passed by NICE for NHS use</td>
</tr>
</tbody>
</table>

The Walnut Group PCS, Preston African Caribbean Community Event Friday 2nd September 2016

Colin Piddington - (Chairman – Walnut Group PCS)

Results
The welcoming talk on behalf of the Walnut Group was given by Brian Lilly who quickly established a rapport with the audience, and thereby starting the event off in good style.

The Walnut Group engaged well with the Caribbean club members and many issues were raised and addressed in small informal groups.

Overall, the event started at 7pm finishing at 11pm – proving very worthwhile with some 41 people present from the African-Caribbean community and 14 members from the Walnut Group. The format of the evening was considered to be a reasonable model to follow in future and the feedback from our hosts was that they were a little disappointed that there were not more attendees from their side.

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The East Lancashire Prostate Cancer Support Group in conjunction with Gary Steele MBE and his team of qualified Phlebotomists have held their 3rd PSA blood testing event.

In February 2015, some 273 men were tested, in February this year 465 men were tested with an estimated 150 to 200 men having to be turned away due to shortage of time and the possibility of materials running out. The majority of these men had been queuing for over an hour which left us with the dilemma as to whether we should hold another event fairly quickly to appease all those who had been disappointed.

We therefore decided that we would hold another event and called it “Extra Time” Blood Testing Event, in line with the football theme. This event was held on Saturday 2nd April and again the event was a massive success as another 382 men came to have the test (1,120 total). Just under 10% of those tested have been advised to visit their GP’s for further consultation.

Stuart Marshall, Secretary of the East Lancashire Group says that the overwhelming turnout and success at these events proves that men are concerned about Prostate Cancer and are prepared to be tested - particularly in a social environment and at a time convenient to them! - National Screening???

We offer our thanks to all the people who volunteered in helping make these events such a great success, - not to mention the potential for saving men's lives.

Barry Kilby’s Prostate Cancer Charity for subsidising two of the events.

Burnley FC for providing their facilities free of charge, publicity in the matchday programme and notifying the media etc.

Gary Steele & his team of Phlebotomists

Radio Lancashire for airing their Saturday morning programme live from Turf Moor & the interviews and bulletins during the week leading up to the event.

Farmhouse Biscuits, Nelson for donating their famous biscuits.

All the people and organisations who helped by displaying posters & leaflets.

Not least our very own members and friends for their support and volunteering on the event days.
Dear Sir

I thought it timely to thank your organisation for the tremendous effort to secure many drugs for the benefit of prostate cancer patients. Your work clearly involves a group of people with the knowledge and enthusiasm coupled with hard work to achieve the desired result.

It is comforting to know that should I ever be in the position of needing further help there is a group doing its best on behalf of patients.

Neil is a member of the support group, PCS Central England and his letter is very heartening and much appreciated. Thank you!

A warm thank you
Neil Rathbone

The following letter has been received from Neil Rathbone.

Neil is a member of the support group, PCS Central England and his letter is very heartening and much appreciated. Thank you!

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A warm thank you
Neil Rathbone

Useful Tips For Coping With Advanced Prostate Cancer Treatments

When you go onto hormone treatment, you may find your skin becomes more sensitive and even itchy. Lots of people have found this is greatly relieved and even alleviated by using Aveeno shower gel and body lotion. It is available from any good chemist.

You may also experience hot flushes. A small hand held, battery operated fan can be useful. Also if you find you get very hot at night in bed, then a hot water bottle filled with very cold water placed under your feet, is a great help.

Don’t wear too many layers of clothing. With your own internal heating you will not need to wear thick or heavy jumpers. Some people find it better to wear cotton rather than wool.

If being on hormones makes your mouth dry at night, it is worth asking your dentist to prescribe a toothpaste called Duraphat 5000, which helps to protect your teeth.

If you are having chemotherapy, be prepared for a lot of hanging around. Take things to occupy you and be aware that if you lose your hair you will feel the cold, so get a hat.

As an advanced patient, it is very important to keep your mind and body active. Take up a new interest, hobby or challenge or join a group such as U3A or see if you have any skills which might be of use to your local support group. Maybe even start a group if there is not one in your area. Don’t let cancer define you, especially if you have to retire.

If you have any useful hints, please let us have them.
"Do this every week", "Didn’t know ukuleles could sound like that", "Best night out this year".

Those are just some of the remarks of supporters who attended a ukulele based fun night in the Swan Inn, Dobcross, Saddleworth. The Swan has just been awarded the best venue in the Manchester Fringe Festival.

Danielle “Nancy” Perkins of the Mersey Belles and ukulele songwriter, instrumentalist Liam Capper-Starr, together with the Stockport Ukulele Players, (SUP), provided the music and the fun. Liam, (from Norwich), and Danielle, (from the Wirral) were fresh from the Isle of White Ukulele Festival. All ably supported on bass by Big Jim, (the best window-cleaner/ bass player in Dobcross), who also set up the sound system.

Much of the night was about audience participation. Forsyth’s, (proving they are the friendliest music store in Manchester), kindly donated two drums of kazoo’s which were a big hit, all adding to the zany atmosphere

It was all in aid of a good cause too. Steve Sankey, (who together with his wife Penny organised the event), explained:-

“Last year I was diagnosed with prostate cancer. Obviously the NHS, Christie’s Oldham and the big national charities all did their bit, but there was always that feeling of being processed through a system and at times feeling a bit lost. The best help for me came from the Oldham branch of the Prostate Cancer Support Group. They are members of the only nationally patients led charity, Tackle Prostate Cancer. The Oldham group was set up by a small group of prostate cancer patients in 1995. Since then, they have joined Tackle and become part of the organisation providing self-help and support. In a typical monthly meeting, people affected by prostate cancer get together in very informal setting and discuss any problems or developments they may have. Between the members there’s a wealth of practical experience and it’s especially valuable to the newly diagnosed and their families. All are assured of a warm welcome”.

Besides the usual raffle at these types of events, a really sweet sounding Mainland tenor ukulele was up for auction. This was kindly donated by Mary Agnes Krell of the Great Northern Ukulele Festival.

Prostate cancer awareness was emphasised at the start and also in a light-hearted quiz. The big message was to all men over 45 years old – Get a Prostate Specific Antigen (PSA) test NOW! If you are in a higher risk group with a brother, father or uncle having prostate cancer, or if you are of black ethnicity the recommended age for testing comes down to 40. It is just a simple blood test. One in eight men will be diagnosed with prostate cancer in their lifetime.

The total proceeds which will be used to promote the Oldham group now stand at £1200 with further donations still arriving. Not bad for a one night event. Penny and Steve would like to say a massive thank you to all involved. Especially gratifying was the fantastic response of the ukulele community.

It wasn’t all plain sailing when MK Prostate Cancer Support set out to raise awareness of prostate cancer with a more proactive approach. The group has been actively and successfully giving awareness talks to different groups and attending health events to achieve its objectives since starting up in late 2014. However, we learned that obtaining a PSA blood test from a GP’s surgery was somewhat of a postcode lottery. Then, in 2015, we gained experience in helping with a PSA testing event organised by the Freemasons. This prompted us to investigate the challenge of organising our own PSA blood testing event open to all men in the Milton Keynes area.

Each blood test costs over £16 per person, and the group has limited resources. We have only a very small number of active volunteers. Attempts to organise a joint event with another group failed and we had insufficient financial support from members, so the idea went dormant for a while.

However, Aylesbury Vale Prostate Cancer Support Group initiated a financial backup after one of their members raised concerns about our difficulties. As a result of this, and with the encouragement from the Graham Fulford Charitable Trust, Tackle and others, MKPCS explored further funding resources and successfully applied for grants from Tackle and the Milton Keynes Community Foundation. We were further boosted by the publicity when a picture taken with the Mayor at one of our events was published in the local paper.

The MKPCS PSA blood test event took place on Sunday 23 October in the Masonic Hall Bletchley, Milton Keynes. The article was written well before the event for this issue of Tackle Matters. MKPCS hopes that our experience will be of interest and encouragement to other groups who may wish to organise PSA blood tests in their own areas.
On Monday 8 August a meeting took place in Hyde, Cheshire at a local hotel to allow the current Tackle Helpliner Team to meet and discuss a range of issues to help to streamline and improve their input whilst on telephone duty.

The meeting was also designed to provide an opportunity for many of the team to meet each other for the first time. It was organised by John Coleman and facilitated by myself.

The discussion centred around typical scenarios that a Helpliner will face whilst on their weekly duty e.g. the type of calls that are generally received, how to handle them and how to share best practice across the whole team.

We also discussed ideas of how we can influence an increase in the weekly numbers which have dwindled drastically over the last 5 years or so because of all the many alternatives now on offer on the internet and elsewhere.

Feedback from all who attended suggests that the meeting was most useful and gave everyone the chance to link up with the rest of the team. Ideas were shared, which we hope will take our purpose further and make us a stronger, cohesive support network.

Arrangements were made for the people travelling to Hyde to meet the previous evening, stay overnight after dinner together, and to bring their wives along who then met up the next day whilst us chaps were talking!

Those present were: John Coleman, David Collacott, Keith Hobby, Phil Ormersher, Terry Fowler, Don Gibbs, Stephen Lipman, Neil Ashton, John Lovatt, John Goodridge, Dorothy Sugden (Macmillan Nurse), Simon Lanyon (from Tackle), Darrell Baguley (North West England Co-ordinator), Colin Hubball and Roy Sowersby. Gary Steele MBE was invited as a guest.

There were also video-conferencing inputs from Roger Wotton and Hugh Gunn, who were both unable to attend the meeting personally.

VOLUNTEER REQUEST

The meeting highlighted a number of important changes and improvements that we could make as Helpliners. One of these was to update the list of people who are willing to volunteer to speak to callers who ask about specific treatments. The referee list we currently use has not been updated for a number of years and really needs input from those of you who have had the more recent treatments e.g. robotics, HIFU, latest radiotherapy methods, hormones and cyberknife procedures to name but a few.

Most of the current volunteers have had earlier-style treatments so we can’t always provide an appropriate referee for these newer processes.

May I therefore issue a plea to you to offer your services as a volunteer? This involves giving us your name and contact details and printing them in our Handbook so that, when we get someone who wants to talk to a man who has had the relevant treatment, we can refer them on to you for your experience and help. A simple telephone discussion is all that is required. The referee list would also benefit greatly from women volunteers. Many calls we get are from women who want to talk (often more seriously than their men!) about a host of issues. It would be terrific if we could also build up a list of women volunteers to discuss issues in the same way as the men. The women volunteers add value because they can talk about the effects on them and the wider family that have occurred since ‘their man’ has been diagnosed.

Please do give this careful consideration and if you are interested please contact either myself on 07973 667770 or one of the ‘Tackle’ team on the numbers contained in this issue.

Peter Young, a member of Mount Vernon Cancer Care Support Group, writes poems about his condition to help others. Here is one of his poems. Another will be published in the February Edition. If anybody else has any contributions, please would you send them to:

hugh.gunn@tackleprostate.org

Cancer sounds just like a crab:
Painful if it takes a grab!
But cancer illness is not like that
It comes as silent as a cat
It will hide inside there to grow,
No warning given so you won’t know
And then when it knows its time is ripe
It attacks before treatment it could wipe.

Check what symptoms you could find,
Keeping cancer in your mind.
If there is aught go to your quack

Cancer Checking
Check for cancer - you attack!
The hospital a diagnosis make,
If it’s there treatment take.
It may be good and go away
But some fight back and could outweigh.
Some cancers very slowly grow
There are others who are not slow
Some can be extremely quick
They very soon would make you sick.
Prostate cancer is one that’s slow -
Check your blood if you don’t know.

Four in five are pussy cats
A tiger, one in five are brats.
Metastases? That means its spread;
This does not mean you will be dead!
Mine had spread when it we found
In 1996 I’ll be bound,
But here today I’m still alive
Having fun, I still survive.
Mine must be that pussycat
Curl up warm on comfy mat!
Welcome New Members

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

Mount Vernon
Prostate Cancer Support Group
Catchment Area:
Herts. Beds. and Middlesex
Contact: Susan Hordyj
Email: sue.hordyj@nhs.net
Tel: 0203 8626 2555

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 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

Tackle @TackleProstate
Text Giving - Text: TACK13 £

Follow us on Social Media
http://tinyurl.com/o2blofo

MEDICAL DETECTION DOGS CHARITY
Stuart Marshall  Sec. The East Lancs Group

The East Lancashire Prostate Cancer Support Group recently organised a trip to see the Medical Detection (sniffer) Dogs and Medical Alert Assistance Dogs in action. 16 people including 4 from the Walnut PC. Support Group (Preston) travelled to the laboratory at Milton Keynes on a mini bus provided by Mario Coaches of Burnley.

The dogs are highly trained to detect medical conditions such as Diabetes, difficult to detect Cancers and Nut Allergies to name a few. More recent success has been the ability of the dogs to detect Prostate Cancer by ‘sniffing’ vials of Urine samples with an amazing 95% accuracy! Medical Detection Dogs also train the dogs for Medical Alert Assistance work to assist people with long term life threatening conditions. The majority of them are already paired with individuals with brittle type 1 diabetes and they are trained to alert their partners when their blood sugar levels are becoming dangerously low hence preventing hypos. There have also been successful trials to detect Malaria in children. It was a fascinating experience being able to see ‘first hand’ what these amazing dogs are capable of and how they are helping people and saving lives. The whole trip was enjoyable, fascinating and enlightening.

The visit was of particular interest to members and officials of the Prostate Cancer Support Groups. All the men who attend group meetings have had some experience of Prostate Cancer and would all have had a normal blood test, usually taken from an arm.

Stuart Marshall Sec. of The East Lancs Group said that the Detection dogs attended one of their group’s three Blood Testing events at Turf Moor where 75 of the 400 men who attended to have their PSA blood test also provided a Urine sample for research at the Medical Detection Dogs Charity. The charity trains dogs to detect the odour of cancer volatiles in samples from patients, currently urine and breath samples. We were then invited to an actual demonstration where 5 dogs all individually detected Prostate Cancer in 1 sample out of 8 urine samples with 100% accuracy!

Free Help Line - 0800 035 5302