

prostate matters

the voice of prostate cancer patients and their families

Newsletter of the Prostate Cancer Support Federation  Issue 19 Winter 2013

Contents

Page 1 - 3

Making Support Groups More Effective By Terrey Garrigan

Page 3

The Federation welcomes Frank Chinegwundoh

It's a Man Thing - The App

Reviewed by David Smith

Page 4

Men, Women & Food after Prostate Cancer

Research by Larry Mróz PhD

Page 5

Boxing Day Tractor Run

Paul Markal

Page 6

Report from Droylston

By John Coleman

Santa-Cruz Rally by David Casley

Page 7

Avalanche hits Reading!!

By Steven Allen

Page 8

Macmillan Cancer Support

By Kara McDonnell

Worried or concerned about prostate cancer?

National Help Line

0845 601 0766

Prostate Matters Editor: Hugh Gunn
email: editor@prostatematters-uk.org

You can download this newsletter direct from our website. Go to:

www.prostatecancerfederation.org.uk/ProstateMatters_latest.pdf

The Federation email address is:
info@prostatecancerfederation.org.uk

This newsletter is published 4 times per year

If you would like to comment on an article, or publish a report of your event in Prostate Matters, please contact The Editing Team

Prostate  Cancer Support Federation

the voice of prostate cancer patients and their families
Reg. Charity No. 1123373

Prostate Cancer Support Federation 2013 Annual Conference & AGM

The theme for the Prostate Cancer Support Federation's 2013 Annual Conference is Clinical Trials – what they are, why participation might be good for you, what is being trialled, and how to get on them. We have some of the top names in the field to speak to us. This year we meet in London, at the Friends House, in London, on Tuesday 14th May, commencing at 11:00 a.m.

As usual, at our Annual Conference, we will also be holding the Federation's Annual General Meeting. There are some important issues to discuss, and we will be presenting, for approval, some significant changes to the Constitution that are designed to make the Federation more effective as the only patient-led, independent, UK-wide prostate cancer charity.

Thanks to the continuing generosity of Prostate Cancer UK, attendance, including lunch, will be free. To book a place, please send an email to bookings@prostatecancerfederation.org.uk, or phone 01420 22560 (yes, that's right, only 5 digits).

Making Support Groups More Effective; Patients Working Together

Prostate Cancer Support Federation Workshop

Thursday 22 November 2012, University of Warwick

At the Federation's Autumn 2012 Workshop speakers were invited to share the benefit of their experience with Support Group Leaders in order to help them run their Groups more effectively.

Sandy Tyndale-Biscoe, Chairman of the Federation, opened the meeting, welcoming delegates and observing that with the merging of The Prostate Cancer Charity and Prostate Action these were interesting times. He asked the question: Is there a need for an independent patient-led, UK wide organisation? And, if so, what should it accomplish on its own, what should it do in collaboration and what should it leave completely to others?

John Anderson, former Chief Executive of Prostate UK, spoke on "Leadership for Support Group Organisers"

John's talk focused on the idea that leadership is about listening to people, that it is important to develop individuals into a team and as a leader

to get to know them, to serve them and to support and mentor them. Empathy is important and above all a passion about what you are doing.

The three main leadership skills are:



John Anderson

Knowledge, Belief and Communication: Knowledge is power; know what you are offering, Believe in what you are doing; do not be afraid to put your emotions on show, Communicate with

Continued on page 2



Janssen sponsored the print production of this newsletter. Control of editorial content was retained by the Prostate Cancer Support Federation.

Continued from page 1

your members; learn about them and get to understand them. John told us that a good leader uses “We” never “I” and inspires people to have confidence in themselves.

Ann MacEwan, Support Group Development Manager for Prostate Cancer UK, gave a talk entitled “Two Ears, One Mouth – Consultation with Support Groups”. Ann told us that Prostate Cancer UK supports men by offering a Helpline staffed by specialist nurses, by providing Fact sheets, Booklets and Toilet cards (to enable men to have priority use of a loo when out). PC-UK also offer Peer support; linking people together who may have a similar problem. Their website has information on publications, news items, campaigns, details of support groups and various on-line forum to supplement support groups and to share ideas. They also fund research into causes and treatments.



Ann MacEwan

We heard about some of the new services that PC-UK are offering such as their Get Back on Track scheme which is about fatigue management. Another is Get Informed, a study being piloted in Scotland on informed decision making; asking the right questions and getting the correct information back. PC-UK are working towards having a more regional presence, including appointing Community Nurses. You can find out more about how they can help at www.prostatecanceruk.org

Ann told us about research being done by Aberdeen University about supporting the needs of men with prostate cancer. Their aims include identifying good practice, looking at what makes a group appealing or unappealing and how leaders can improve their group.

The survey initiated by PC UK earlier in the year suggested that they need to improve their communication so that groups understand better what PC-UK do and how groups can benefit. Better routes should be developed for seeking and

gathering the views of groups. Training advice on running groups and courses for patients and carers are needed and help given to groups on how to raise awareness of prostate cancer.

Kara McDonnell from Macmillan Cancer Support is a Macmillan Co-ordinator in the West Midlands, one of 13 co-ordinators in the UK. Kara explained that a Macmillan Co-ordinator will visit a support group as long as 15 people will be present. She talked about “How Macmillan can help you with your support group”, explaining that their services include provision of a telephone support line, learning and development courses, befriending opportunities, help with bereavement, £500 grants for support groups, on-line training for carers and Information, available both in leaflet form and on-line at www.macmillan.org.uk

Kara told us that people attending groups value the opportunity to share their experiences and she asked delegates to make suggestions as to “How can we develop our support group to make this experience wider to help more people?”. Ideas included raising awareness via men’s groups such as Rotary or the workplace, attending courses run by Macmillan and other organisations, “being better at what we do”, talking to medical professionals and making GP’s aware of local support groups, linking a newly diagnosed man to talk to another who has been in the same position.



Kara McDonnell

Delegates were then asked to consider “Aside from support groups, how can the needs be met by an increasing number of people affected by prostate cancer?” Delegates thought it important to make sure that women know about groups and make their men aware of symptoms. Also raising awareness via radio, TV, newspapers etc. Other comments were that men need to be given follow-up information either at diagnosis or at their follow-up appointment and that there is a need for good urology nurses.

After a break for lunch, we heard from four speakers who told us about various aspects of leading a support group.

Mike Harrison, Chairman of Prostate Cancer North West spoke about “Starting a new support group”.



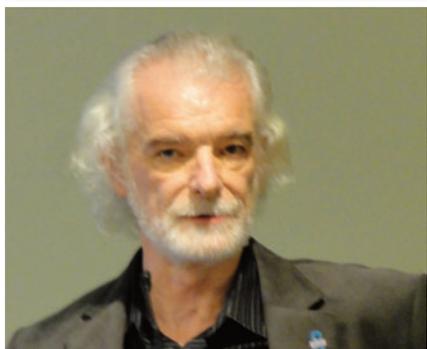
Mike Harrison

After being diagnosed in Feb 2007 Mike was in shock, scared and felt very alone. Following a radical prostatectomy he made a rapid recovery with no side effects but, left with a desire to help others, he decided he would like to start a support group. He contacted Mike Lockett, now sadly deceased, who ran a group in the North West and was so impressed with the group that he joined their executive committee.

Mike told his story about how he started a group. He met with PALS at his local hospital and Macmillan staff from a local hospice. He drafted a constitution and in Sept 2010 the first meeting was held with some twenty attendees. Mike did a radio interview and he designed and produced a leaflet about the fact that groups help people to cope and learn to live with the disease.

Mike’s meetings take the format of a round robin discussion for an hour, then a tea break followed by a speaker. Approx 30 members attend each meeting. He started the group with a £500 grant and has managed to raise £6,000 since. They have a committee of seven who meet outside the group time to discuss various ideas for raising awareness and fundraising.

Roger Bacon from PCaSO told us about “Running a large devolved group”. He explained that PCaSO has over 1,000 members across the three counties of Dorset, Sussex and Hampshire. The group started as PSA in 1999 and two years’ later broke away from PSA to become PCaSO. In 2008 another PSA group in Dorset joined and extended into Sussex and a year later PSA disbanded and all existing groups joined PCaSO with West/East/Central branches. PCaSO hold regular meetings, produce a quarterly newsletter and charge a £12 one-off fee for membership. They



Roger Bacon

have had success applying for funding from Astra Zeneca and other pharmaceutical companies.

Gary Steele from PCSG Leighton Hospital had the audience in fits of laughter, in a presentation in which he spoke about “Fundraising for support groups” telling us of the success his group has had, including being able to fund a voice-activated endoscopy unit for his local hospital. He talked about organising runs, fashion shows, a Jazz event, sponsoring a racing car an MG Class F, and even a wing walk on a light aircraft!



Gary Steele

Rob Banner from PROSTaid gave good advice on “Marketing a support group”. He observed that no two groups are the same; some fundraise, others just want information and support. Some want a quiet meeting while others prefer something a bit more upbeat and lively but they all have a common goal which is to achieve the very best for each and every one of their members. All groups need



Rob Banner

money and marketing is very easy, it’s just asking people. His advice was : Get to know people and ask for their help; you would be surprised how often they say yes. Another tip was to work with your local hospice; ride on their brand name.

As the event drew to its close, **Sandy Tyndale-Biscoe** reminded delegates that he had started the day by asking about the role of the Federation. He explained that the Federation had spent a great deal of time considering this question and had identified three priorities:

- 1) Support for support groups,
- 2) Education of clinicians

3) Early Detection

He then asked for delegates to say which they considered most important.

The vote was informal but the results were: of equal importance, both at about 40%, Early Detection and Education, with Support for Groups considered less important at approximately 20%. This provided a good indication of what members see as priorities and will be enormously helpful in shaping the Federation’s future direction.

With thanks to Terry Garrigan, SECHC for taking all of the notes

The Federation welcomes a new Trustee: Frank Chinegwundoh, Consultant Urological Surgeon at Barts

The Federation welcomes a new Trustee: Frank Chinegwundoh, Consultant Urological Surgeon at Barts.

We are delighted that Frank has joined our Board of Trustees, adding to the considerable expertise already provided by David Baxter-Smith, consultant urologist, who has long advised the Federation on things clinical.

Frank trained in urology in London and the West Midlands and spent two years in full-time research in London, which culminated in a Master of Surgery degree by thesis.

As a consultant Frank is the urology lead at Newham and introduced one-stop clinics for haematuria and prostate biopsy. At Barts and The London, he introduced specialised services for prostate cancer and andrology. He pioneered the one-stop general urology clinic at Barts in 2009, provides the prostate brachytherapy service and prostate cryotherapy service and leads the andrology service.

In 2011 he completed one year pilot project for the Department of Health, running a men’s community prostate



Frank Chinegwundoh

clinic in Newham with the evaluation published October 2012. This project won a national award in 2012 – QiC excellence in oncology awards –saving lives category.

Frank is well-published and is the reviewer for several learned journals. He has been the Chairman of charity Cancer Black Care since 1998 and was a Trustee of Prostate Action from 2003-2012.

Although only just appointed, Frank has already started making a contribution; working with David Baxter-Smith to establish a Clinical Advisory Committee for the Federation.

It’s a Man Thing - The App

This is a wonderful application both for those who are concerned about their prostate and those of us who have it in all its stages. "Its a Man Thing" has an easy to use to interface and takes the user through the A to Z of the prostate and its cancer. It is well worth the £1.99 plus a voluntary donation.

I have an Android 7" tablet with Jelly Bean 4.2 which does not permit me to expand the text to fill the screen but I have been told that this will be fixed. It still worth buying even with this fault.

David Smith 'A prostate cancer sufferer', operating system - Jelly Bean 4.2.

“It’s a Man Thing” has been produce by PROSTaid and is available from the Apple App Store or Google Play.

Men, Women & Food after Prostate Cancer

Larry Mróz PhD Centre for Men's Health, Institute for Health & Wellbeing Leeds Metropolitan University

Would you like to help develop nutrition education and counselling as part of a survivorship program for men who have been diagnosed with prostate cancer and their partners and families?

I am Larry Mróz at the Centre for Men's Health, Institute for Health & Wellbeing, Leeds Metropolitan University.

What is the purpose of this study?

Diet and lifestyle improvements can help some men after a prostate cancer diagnosis, yet many men have a hard time changing what they eat. I'm Larry Mróz - a researcher from Canada who studies ways to help men improve their diets as they deal with prostate cancer. If you have been diagnosed with prostate cancer in the past 5 years and are interested in talking about food and eating, I would be grateful for your help.

The main purpose of this study is to better understand how we can help men improve their diets after a prostate cancer diagnosis, and how a man's relationship – especially with his wife or partner - influences what he eats. Men often rely on the women in their lives to take care of their diets and couples develop ways of dealing with food within their relationships. I would like to ask men and their wives or partners (or other important people in their lives) about what and how they eat.

Several men who have been diagnosed with prostate cancer and their wives or partners are being asked to help with this research. If you decide to help you will be asked to fill-out a brief food journal for one week and then participate in a face-to-face interview. You can choose a suitable time and location either at the Institute for Health & Wellbeing in Leeds, or your home. You also have the choice of either being interviewed separately and privately, or together with your wife or partner in a joint interview.

We hope that those who help out in this project find it an interesting and enjoyable experience. For many people, taking part in research is a way of getting their voices heard and to have a say about topics that are important to them. This study will help us to better understand how you think your diet has been influenced by your wife or partner and relationship. The findings will therefore provide a better understanding of the nutrition education or counselling needs of men who have been diagnosed with prostate cancer.

Who should get involved?

I would like to interview men who have been diagnosed with prostate cancer in the past 5 years and who are interested in talking about food and eating. I would also like to interview their wives or partners. You have the choice of either being interviewed separately and privately, or together with your partner in a joint interview.



Larry Mróz PhD

Closing date for application. None

When will this activity take place? The programme started in October 2012 and will run until 2013

Where will this activity take place? This activity will be casual, one-time, recorded, face-to-face interview with you and your wife or partner. You can choose a suitable time and location either at the Institute for Health & Wellbeing in Leeds, or your home.

How to get involved:

Please contact:

Larry Mróz
Centre for Men's Health, Institute for Health & Wellbeing
Leeds Metropolitan University
Queen Square House
80 Woodhouse Lane, Leeds:
Email: L.Mroz@Leedsmet.ac.uk
Telephone: 0113 812 3612

For further details go to
www.prostatecancerfederation.org.uk/mroz.pdf.

Boxing Day Tractor Run 2012

Paul Markal, Prostate Cancer Support Group, Kidderminster

This was the second consecutive year that a tractor run had been organised on behalf of the Group to raise funds. The tractors met at Keenes Farm opposite the Wyre Forest Visitor Centre, Callow Hill. The planned route was to enter Bewdley via the bypass and gather in Dog Lane Car Park before visiting Little Lakes Leisure Park then returning to the farm. Like most organised events it didn't go to plan. The flooding in Bewdley prevented the tractors from entering Bewdley via the Bridge, and as there was no alternative (if Bewdley was to remain on the planned route) but to negotiate the narrow roads passing the Hop Pole Inn and down the hill into Bewdley.

This year I managed to talk one of our members, Mike Carr, into joining me (dressed as pirates) to do a little tin rattling and pillaging. We thought the pirate theme might add some additional colour and flair to the overall event. Now for those of you who don't know me, I don't do things in half measures. If we were to go dressed as pirates then we had to look the part which included all the accessories that pirates carry, eg. Muskets – and in this case muskets which fire party poppers with some alarming effects, daggers and a 2ft cutlass!!

Prior to the event, I was at home putting the finishing touches to my outfit and weapons when my daughter arrived and as she is a little more street wise than I give her credit for, she took one look at me and said "Dad, you know you could be arrested for carrying fire arms and offensive weapons"! On reflection, I thought it may be prudent to seek advice from the local constabulary . The last thing that I



would want on the day would be to be confronted by an armed police response unit. Details of the event were logged on an incident report at Kidderminster Police station. They also wanted to know how many tractors would be involved in the Run. I said that I was not sure but we had up to 25 last year.

On the morning of the event, the weather cleared and at

about 9.30am the tractors started to arrive at the farm. We didn't have 25 – in total there were 53 plus 4 Landrovers, and at 10.00am they formed a convoy and headed for Bewdley. I had a flash back of my conversation with the police officer when I said that I thought there would be about 25 tractors on the day. Fortunately we, as a group, were not responsible for the tractor element of the event. The tractors did cause some delays en route but the majority of motorists took it all in good spirit.



During our fundraising in Bewdley, I approached a gentleman and his wife and asked if they would like to make a donation. The lady pointed my musket at the gent's head and he yielded by placing £2 into the bucket. The gent then asked where all the tractors came from and what were we up to. I explained that we were pillaging in Bewdley to raise funds for PCSG. The gent then said he thought pirates like Vikings raped and pillaged. I said that we do do the former but it was only by appointment!!

We moved on from Bewdley to Little Lakes Leisure Park where we continued our bucket collections with the help of the Wardens and we were also

presented with a cheque for £50 from the management. In total £716.53 was raised for the Group's funds.

I hope this activity will now become an annual event and if so, I could do with some more help on the bucket collecting front.....Please!!

Gift Aid

Did you know, if your group is a registered charity, you can claim GiftAid from HMRC on personal donations given to the charity. This will increase their value by 20% at no cost to the charity or the donor. To register or to find out more, go to:

www.hmrc.gov.uk/charities/gift-aid-toolkit.htm

Please Check Your Details

Please would all affiliated members check on the PCSF website, that their details are correct on both the map:

<http://tinyurl.com/429ee7f>

and the contact web page:

www.prostatecancerfederation.org.uk/membershipList.htm

If there are any alterations, please contact:

Sandy Tyndale-Biscoe

Email webmaster@prostatecancerfederation.org.uk

Droylsden Support Group.

By John Coleman

The Droylsden Support Group has been revitalised over the past year by the Urology Specialist Nurses from our local hospital (Tameside). The nurses attend every meeting and encourage their patients to attend as they feel that meeting other patients helps them to decide upon the type of treatment to have and to deal with the effects of any treatment.



Urology Nurses Shirley and Kerry

On Thursday 11th October 2012 a fundraising concert was held by the group, the nurses did most of the organising of the event and sold most of the tickets, which was a sell-out. We were very fortunate to have Jackie Dijon and Dom Collins to perform for us, Jackie used to be the warm up act at comedian Bernard Manning's club and Dom was a comedian appearing on some of his shows.

The concert was a great success with top class performances by Jackie and Dom and including a duet sung by Jackie and one of the Consultant Urologists Mr. Richard Brough. His performance was so good we are thinking of booking him for our next concert.

The aim of the concert was to raise funds towards the purchase of a Robotic Arm to be used in prostate operations at another of our local hospitals – Stepping Hill.



Consultant Urologists

During the concert a raffle was held for the many prizes donated by local businesses and football clubs. Among the prizes were a signed Manchester City shirt, a signed photograph of Manchester United's Wayne Rooney when he was team captain, a signed photo showing Mike Summerbee and other Manchester City players holding the Premier League Trophy, a free car service and MOT, a selection of jewellery and many other items as can be seen

Santa-Cruz Rally

By David Casely, Prospect, Bristol

Back in November our prostate cancer support group Prospect was approached by the Santa-Cruz rally organisers to see if we would like to take part in their December event. They had seen our web site and decided that our group would be a suitable "good cause" for which they could raise money. Each year they choose two good causes to help.

Santa Cruz has been raising money for local good causes for several years through their rally events (you can check out the web site on www.santa-cruz.co.uk). We were of course delighted to take part by having a prostate cancer awareness stand at the rally's final destination point - the Fry's Club in Keynsham Bristol.

Scores of VW owners took part in the Santa Cruz rally in decorated (Christmas theme) vehicles from Easter Compton to the Fry's Club. It is amazing how many varied Father Christmas models one can get on top of a VW Camper Van. Apparently the furthest travelled van for the rally was from Hull - such is the growing appeal of the event.



Mike Broxton, Richard Ormerod, Bernard Smyth and Malcolm Gamlin

Prospect members Mike Broxton, Richard Ormerod, Bernard Smyth and Malcolm Gamlin did their bit by running an information stand, distributing leaflets and talking to men and their partners about prostate cancer. It was a great afternoon; a lovely family atmosphere with children's entertainment provided and a very special raffle with quality donated prizes - the first prize being a pair of Eurostar tickets. The food and drink were good too!

The event organiser, Richard Dagger, with his wife Michelle and some of his event team came to our January Members' Meeting at Bristol Aerospace Welfare Association (BAWA) and presented the Group with a cheque for £1,250 which represented half of the money raised from the December rally. This is a big boost for our funds and we are very grateful to Richard and the Santa Cruz team for their donation.

from the photograph.

The total raised from the concert was over £1,250 and the group decided to increase it to £1,500 which was presented to the Consultant Urologists from our local hospital who attended our Christmas Party. This concert was the first we have ever done and it was such a success we plan to do more in the future.

Avalanche hits Reading!!

By Steven Allen, Reading Prostate Cancer Support Group

On 24th January 2013 an avalanche hit Reading's Royal Berkshire Hospital. No, not more of the snow from the previous week, but an avalanche of men attending the first ever PSA screening session in Reading. In just 4½ hours 489 men attended to have their blood taken for PSA analysis.

The evening was organised by the Central Reading Lions Club. The first such screening event to be arranged by a Lions Club was at Bridgnorth in Shropshire. The great success of their first event then not only spawned what is now a yearly occurrence but similar events organised by other Lions Clubs around the country.

Central Reading Lions Club had picked up on this and decided to do something similar. Arguably more used to being involved with fundraising BBQs, firework evenings and the like, this was a very new venture for them.

The project was managed by one of their more prominent members, John Mack – a powerhouse of enthusiasm and vitality, and someone in whose vocabulary the words 'no', 'impossible' or 'unlikely' simply do not exist.

Good organisation is essential

The venue for the evening was the Royal Berkshire Hospital – home of a Urology Unit with a national reputation for the excellent management of prostate cancer and where all of the blood samples would be processed.

The hospital layout fortunately allowed for the use of a large waiting area for the initial reception, completion of forms etc and there was additionally a League of Friends tea bar which did a brisk trade for the whole evening. The pathology dept was only 30 metres away, complete with a secondary waiting area and 4 purpose designed phlebotomy areas. John Mack (a hardened business man) had negotiated a financial contract with the hospital and pathology management to cover all costs of taking and processing the blood samples.

The event was timed from 5.30pm to 9.30pm. Using this time-scale allowed the free use of the large nearby staff car park – how often can you now park at a hospital for free!

On the evening, the Lions had a machine that worked with military precision – car park attendants, reception staff, patient data forms and even an ample supply of pens with which to fill in the forms. You name it, they had thought of it.

Steve Allen, Chairman of the Reading Prostate Cancer Support Group, said: *"I was staggered by the organisation and the number of volunteers involved. If we, as a small support group, had tried to take on such a project, we would have been overwhelmed by the public response."*

Publicity is the key



Nearly 500 men came for testing that evening

How on earth do you get 500 men to come? As one of the Lions said: *"Publicity is the key – if the public do not know about it, then they don't come."*

5,000 flyers had been printed and distributed – many by the Lions Club Santa Claus as he visited the Reading area as part of the Lions pre-Christmas fund raising. Posters and flyers were sent to Golf Clubs, other Lions Clubs, local companies and displayed on community notice boards. 2 local radio stations and the local press gave good coverage.

John Mack said: *"We hadn't a clue whether 20 or 200 would turn up. We never dreamed that so many would come."*

However, the whole team rose to the challenge, particularly the phlebotomy team. Even Steve Allen was drafted in to help take bloods in the latter half of the evening (as well as being Chairman of the local prostate cancer support group, he is also a recently retired Consultant Anaesthetist at the Royal Berks Hospital.) Rarely did anyone wait longer than 30 minutes for their test.

What about the cost?

The Lions had underwritten all costs, but had sensibly obtained some financial

funding from local companies. A robust financial contract had been agreed with the hospital. Apart from the strategic placement of collecting buckets for those who wished to make a donation, the tests were free.

Keeping things medically supervised

As with previous similar events, David Baxter-Smith was involved and agreed to over-see the reporting of results to patients with the standard red /orange / green letter system that has been used in the past. Also he will follow up all patients with abnormal test results to ensure they seek appropriate treatment locally. David came on the night and every 30 minutes gave a brief talk about PCa to the waiting throng. How he retains his constant drive and enthusiasm is quite amazing.

To be honest, the local urology unit had shown support – but from a distance. They were not actively involved at any stage but, equally, were not hostile to the project – as has been the case in other parts of

the country. One of the local Consultant Urologists dropped in to see how things were going on the evening. It was staggering to find later from David Baxter-Smith that, despite having done 300 or so such events, this was the very first time he had been able to meet with a urologist local to the area concerned.

But why are such evenings needed?

Many would say that it is little short of a scandal that there is no national PSA screening programme. Even worse, patients are still being advised against testing by ill-informed GPs – often in younger patients in their 50s. When will people realise that the earlier an aggressive PCa is found then the better it can be treated. As Steve Allen said: *"PSA screening done in an appropriate way is not scare-mongering. It is just plain common sense"*

There is little doubt that the evening in Reading will pick up some patients with PCa that can then get earlier treatment. Equally, it will also reassure the majority of men that they have nothing to worry about.

Prostate Cancer Support Federation

the voice of prostate cancer patients and their families

22 High Street, Stockport
Cheshire SK1 1EG
Tel: 0161 474 8222
Charity No. 1123373

www.prostatecancerfederation.org.uk

Patrons:

Dr. Thomas Stuttford OBE
Gloria Hunniford

Chief Executive

Rowena Bartlett

Federation Trustees

Chairman:

Sandy Tyndale-Biscoe

Vice Chairman:

Ken Mastris

Secretary:

David Smith

Treasurer:

Hugh Gunn

Mike Harrison

Mr. David Baxter-Smith

Rob Banner,

Bob Arthy

Dr. Frank Chinegwundoh

Medical Adviser:

Mr. David Baxter-Smith

To View other roles carried out by volunteers, please visit:

<http://tinyurl.com/3psctpv>

Prostate Matters is published four times a year, providing news, information, personal memoir and opinion about prostate cancer. It also reports, quotes and cites published medical views and research findings about prostate problems.

The Federation does not promote any treatments or dietary, drug, exercise or lifestyle change intended to prevent or treat a specific disease or condition. Anyone who wishes to embark on any such treatments should first consult with and seek clearance from a qualified health care professional on any treatment or lifestyle changes

Macmillan Cancer Support

By Kara McDonnell

From its early beginnings, founded in 1911 by Douglas Macmillan, Macmillan Cancer Support has grown to become the largest cancer care and support charity in the UK. We can help support groups through:

1. Our website: www.macmillan.org.uk. The website has a wealth of information and also online forums and communities you can join.
2. Through the website you can also order free leaflets and guides around specific cancers and also information such as tips when setting up a support group.
3. Our support line on 0808 808 0000 Monday to Friday 9am-8pm. The support line speaks 120 languages and can give information about cancer and also benefits advice.
4. Attending or organising Learning and development opportunities with our team. Macmillan offers a range of free courses, workshops and e-learning for people affected by cancer including carers, family members, volunteers and community members. Topics available include loss and bereavement, listening and responding and buddying and befriending. Our online training

resource is called LearnZone and is also free. If you are you living with and or beyond cancer? Would you like to join other cancer survivors and take part in an online self help course designed to help you make the most of your health and well being? Please go to <http://tinyurl.com/c9uvphf> to find out more. We will be sharing a number of top tips and strategies to help you move forward. You can also "meet" other people living with cancer through the discussion forum, moderated by an online facilitator, to share ideas and offer support to each other.

5. We also have regional training events as well including the Helping Overcome Problems Effectively course.
6. Our grants programme. We offer grants to support groups. You can apply for a grant to cover start up costs or for groups to expand and extend their reach. This could be useful if you are thinking about adapting your group to include an activity element or to feed your views into the Health services.

For more information please look online or alternatively contact you local Macmillan Involvement Coordinator. We are spread all over the country so there will be one allocated to your area. Our contact details can be found through the support line, <http://tinyurl.com/ahwvxsl>

or:

<http://tinyurl.com/ahwvxsl>



Kara McDonnell

Resources available from the PCSF,

please fill in the number required in the boxes, cut out the form and send to:

Prostate Support Federation, Mansion House Chambers, 22 High Street, Stockport, SK1 1EG

Postage and Packaging will be charged

Setting up a support group	Name:
Role of a Clinical Nurse Specialist	Group:
Clinical Trials	Address:
The Real Prostate Cancer Risk Management Programme
Understanding Cancer Waiting Times Post Code:
Knowledge Empowers, Treatment Information Booklet	phone:
It's A Man Thing, Awareness Card	Email: