

prostate matters

the voice of prostate cancer patients and their families

Newsletter of the Prostate Cancer Support Federation  Issue 17 Summer 2012

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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](http://www.prostatecancerfederation.org.uk/ProstateMatters_latest.pdf)

The Federation email address is:

info@prostatecancerfederation.org.uk

This newsletter is published 4 times per year

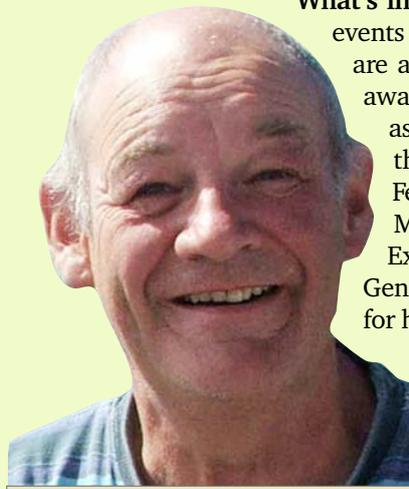
If you would like to comment on an
article, or publish a report of your event
in Prostate Matters, please
contact The Editing Team

Prostate  Cancer
Support Federation

the voice of prostate cancer patients and their families

Reg. Charity No. 1123373

Prostate Cancer UK – working with the Federation



Sandy Tyndale-Biscoe

What's in a name? Well, quite a lot, if the recent events at The Prostate Cancer Charity (TPCC) are anything to go by. Many readers will be aware that TPCC has recently rebranded itself as Prostate Cancer UK. Last April, at the time this re-branding was being planned, the Federation welcomed TPCC back as Partner Members, and Owen Sharp, the Chief Executive came to the Federation's Annual General Meeting. He spoke about his vision for how his charity, by an order of magnitude bigger than any other working in the prostate cancer field, would look forward to time of greater collaboration with patient support groups, working particularly with the Federation.

We can now begin to see signs of deeds to support those fine words. The re-branding has many threads to it, and if you want to take a closer look you can do so at their website (<http://tinyurl.com/brtkw46>), but underlying them all would appear to be a strong focus on men, and representing them in the battle against prostate cancer. For example, the new logo (the 'man of men') is designed to be more noticeable to men; in their words: "This strong figure built from familiar symbols communicates our aim to reach and represent all men."

This is territory that is pretty close to home for the Federation. Should it be a cause for concern? It would be pointless to claim that the relationships between TPCC and the Federation in particular, and many support groups in general, has always been a comfortable one. The discomfort was epitomised by the decision by TPCC three years ago to resign as Partner Members of the Federation because they felt that, with publication of the Real PCRMP, we were pushing to strong a pro-PSA testing stance.

But the unease went further than that. It is, at first sight, quite remarkable how patient support groups often have a very strong streak of independence: a desire to do their own thing, and to do it their own way. Even the vanishingly small element of outside control that some think comes with



Continued on page 2

Janssen 

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

membership of the Federation is too much for some groups. On reflection, this is actually not surprising. Patient support groups are mostly set up by, and led by, highly motivated individuals reacting to their own experience of prostate cancer. Each such individual sees things differently and therefore has different priorities. It was the view of many in the support groups that their independence was threatened by too close a relationship with the PCC.

So, Owen's talk was listened to with care, and in the end, some relief. He showed an understanding of what support groups can do and how they are motivated, and a desire to work with them. Above all, there was no indication of any desire on the part of the big charity to exercise control over the army of patients represented by the Federation and its member organisations.

Warm words do not, of course, always reflect what's happening, but we're happy to report that a good dialogue with Prostate Cancer UK has started. In particular, we wanted to be sure that our strategic objective, represented by the appointment of Rowena Bartlett as Development Director, of being the primary voice of prostate cancer patients and their partners throughout the UK, and within 5 years, developing the Federation to the point at which it is self-sustaining, is not a problem to them. In short, we wanted to be sure that neither charity would view the other as competition. I am happy to say that Owen Sharp has given us assurance that he is entirely happy with our aspirations, and intends to support the Federation in achieving those aims.

He has also indicated continuing support for a project very close to our members' hearts, Riskman, by funding the outstanding shortfall for the current phase of the project, to the tune of £9,000 – a very welcome signal of commitment to patient power.

Having established that we are not in competition we now need to work out in detail what we can do together. But first we have a clearer consensus amongst ourselves of what the Federation should be doing. It's all very well to "act and speak for prostate cancer patients and their families" (as we say on our web site), but what does that actually mean? In particular, what is it that members expect the Federation to do for them? And in our relationship with Prostate Cancer UK, what it is that, (a) only the Federation can do, (b) is best done in collaboration with PC-UK, and (c) should be left to PC-UK to lead?

In the next few weeks, Rowena will be working up a dialogue with members to find answers to the first question (there may be many). At some time in the Autumn we expect to hold a small workshop involving leaders of our most active support groups to refine these answers into what might (in management speak) be called a 'mission statement' for ratification at the next Annual General Meeting. Once we have a solid view of this, (and we won't wait until the next AGM) we intend to sit down with staff from Prostate Cancer UK and set about answering the second question above.

One last thing. We are, as everyone knows, enormously indebted to Prostate Action, and its predecessor, Prostate UK, for the support they have given from the creation of the Federation onwards. It is absolutely true to say that without that support, the Federation would not exist, and prostate cancer patients would not have a voice. I am happy to say that everything I have described above has been discussed with Emma Malcolm, CEO of Prostate Action, and is going ahead with her full approval. The relationship may change in some ways, but in essence will remain the same.

So, it may not be too early to say "the future's bright; the future's man shaped".

Autumn Workshop - Clinical Trials

We haven't fixed a date yet but just letting you know that we are holding another workshop around late October/early November. This time we plan to focus on Clinical Trials, with various speakers bringing us up-to-date on clinical developments in the field of prostate cancer.

As usual, attendance will be free to members. Group leaders will be informed of details in the next few weeks.



Channel 4 is looking for people who would be interested in participating in The Food Hospital series.

The ground-breaking Channel 4 programme returns for a new series, exploring the potential health benefits of food in treating a wide range of illnesses and ailments – everything from insomnia to heart disease.

Do you have an illness or condition that significantly affects your life?

Are you under active surveillance for your prostate?

Do you have raised PSA levels but are not on hormone treatment?

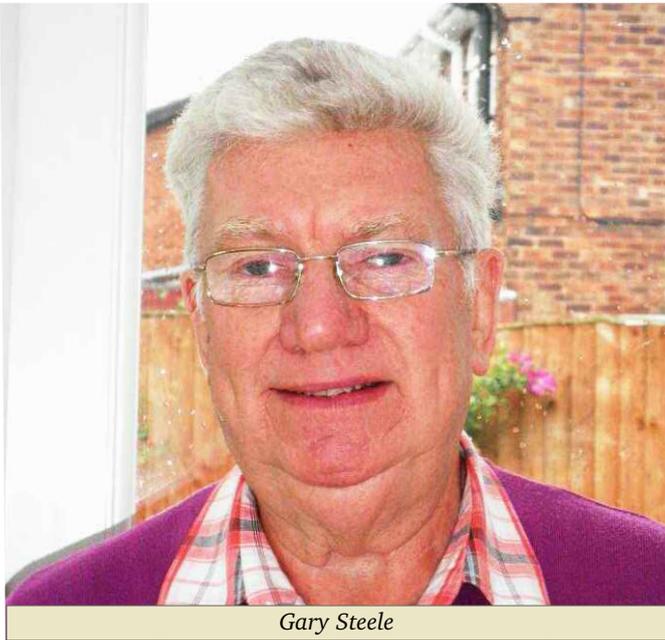
Are you willing to follow a scientifically devised diet which might help to improve your condition /health, and / or symptoms?

Our team of medical experts, including a GP, a specialist medical Consultant and a leading Dietitian will work closely with the patients to devise individual diets targeted at their particular condition and will monitor their progress.

Please get in touch for more information.
Call Bethan on 020 7907 0867 or email foodhospital@betty.co.uk

Gary Steele Receives the MBE

Leighton Hospital Group



Gary Steele

We are delighted to inform you that Gary Steele has been awarded the MBE in the 2012 Queens Birthday Honours List.

Gary is Chairman of our Leighton group and an active member of the PCS North of England Executive Committee. He is a one-man crusade in promoting awareness to Prostate Cancer and has actively raised men's awareness throughout Staffordshire, Cheshire, the North West and the whole of the UK with his campaigning.

He has devoted a great deal of time and energy in travelling around the country, setting up temporary "Drop-in" information centres at Supermarkets, Shopping precincts etc., along with talks at various Working Men's Clubs, Probus & Rotary Clubs. In addition to this he goes to Companies and Businesses and anywhere he is invited to promote awareness to Prostate Cancer, he also provides medical advice on the National Help-Line when required.

He initiated setting up the Support Group at Leighton Hospital, Crewe and helped to compile a register of men willing to talk to newly diagnosed patients and their families regarding the treatment, care and living with cancer.

The group relies on him for information, transport arrangements for treatment and funding, funding being his speciality as he has, almost single handed, raised over £600,000 to date, which has been used for vital equipment, research, staff specialist cancer training and promoting awareness.

He arranges functions, special nights, concerts, including Big Band concerts, 60's Nights and Fashion Shows.

He and Mr. Pradip Javle, the specialist and surgeon who diagnosed and operated on him, took part in The BUPA Great North Run and raised over £8,000. This sponsorship was used for research and providing equipment for the care

and comfort of patients admitted to Leighton Hospital when diagnosed with Prostate Cancer.

Gary is also a member of the Manchester and Cheshire Cancer Network Steering Group and The Cancer Collaborative Council as the patient representative for Prostate Cancer.

He has appeared on national and local TV programmes as well as local radio "phone-in" programmes. He will do whatever he can to promote awareness to this most common cause of cancer in men.

Gary arranges PSA blood testing days for men 45 & over with our acquired Bioscans which provide an accurate result in just 10 minutes.

The group have initiated and sponsored several unusual & challenging events on an annual basis, such as Half-Marathon events & climbing Mount Snowdon and an annual fishing match & B.B.Q, on the Cheshire Broads on the second Saturday in August. Also they sponsor an under 7's football team, Woodford F.C. & junior cricket team, also an MG class F racing car, entered at all the major meetings in the country, in the name of **Prostate Cancer Awareness**.

The group is now in its 12th year of existence and was primarily set up by Gary Steele. Gary has been responsible for raising funding and providing a local Help Line, books and leaflets of information and promoting a very vigorous campaign of awareness. The group has during the past 12 years provided necessary equipment for both Leighton Hospital and Northwich Infirmary. Provided funds to train the Surgeon & Theatre Staff in Laparoscopy Radical Prostatectomy operations sending them to France as no such facility is available.

The Prostate Cancer Support Federation is also very grateful to Gary for his unstinting support on many occasions. Not least, Leighton Hospital PCSCG's recent £3000.00 donation to Riskman.

'MY MAN' Ladies Educational Seminar

'MY MAN' LADIES EDUCATIONAL SEMINAR



Friday 16th March 2012 at 11am

Join us for lectures and Q&A discussion on the management of prostate cancer

There will be buffet lunch served with soft drinks

Venue The UCH Education Centre
1st Floor West
250 Euston Road
London NW1 2PG
Ticket £25.00

To express an interest in attending this event please inform a member of the prostate clinic or contact:

Georgina Wilson at the
Prostate Cancer Research Centre on
0207 679 9595 or email
gwilson@prostate-cancer-research.org.uk

The lecture will be hosted by Dr Heather Payne and there will be guest speakers. Its aimed at women, so they have a chance to ask questions that perhaps they may not feel comfortable asking in front of their partners with their consultants. Saying that everyone is welcome should partners / husbands want to attend.

What does the Federation mean to you?

- tell us what you want

Rowena Bartlett, Development Director

In **Sandy Tyndale-Biscoe's** article in this edition about the Federation and Prostate Cancer UK working together, he asks the question "What is it that members expect the Federation to do for them?" Since being appointed in February as Development Director for the Federation, I have been looking at exactly this point.

We need to establish just exactly what it is that the Federation is for. One of the important questions is, is our primary purpose support or advocacy? Or is it, in fact, both? This is especially relevant now that we are working more closely with Prostate Cancer UK (formerly The Prostate Cancer Charity). It's important to ensure that we avoid duplication and the resultant wastage of hard-won funds. We also need to make sure that the role of each charity is clearly defined in order to reduce confusion; thus allowing people to access help more easily. Most of all, we need to make sure that we are providing you with the help that you need and in the best way.

To do this we need to go through a consultation exercise; finding out from the Trustees, the Group Leaders and as many members as possible how you all see the Federation's role as we move forward.

We cannot support you properly unless you tell us what you want so, please, take the time to fill in the form on the following page Please return this form to me by email to: rowena@prostatecancerfederation.org.uk, or by post to:

Rowena Bartlett, Coldrey Farm Cottages, Lower Froyle, Alton, Hampshire, GU34 4ND.
The form, with comments can also be filled in on line.

Thank you.

Rowena Bartlett,
Development Director, PCSF



Rowena Bartlett

What would you like the Federation to do for you?

What do we do well?

What do we less well?

What more could we be doing?

Some ideas for change ...

What was the greatest challenge in setting-up your group? How helpful would it be to provide a start-up pack for new groups? What about if we could arrange an area representative to advise on how to set-up a group?

Are you struggling with your fundraising? What about a fundraising pack with ideas and suggestions?

We think the website could do with a bit of a freshen-up. What would you like to see changed or added? Would you like forms that can be filled in on line?

The Prostate Cancer Federation is a very long name. Should we change it?

And anything else you would like to say.....

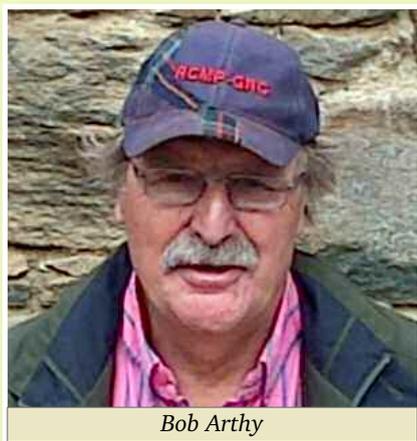
Name: Support Group:

Address:

Post Code:..... Email:

Please put your comments on a separate sheet of paper

Testosterone Kids Bob Arthy - F.O.P.S



Bob Arthy

Having prostate cancer can give a new impetus to life which might well have perished with boredom had the Tiger not struck. The Friends of Prostate Sufferers was set up in '09 to make mid-aged men aware of possible

prostate problems and to help sufferers like Denis, who was distraught till he talked to members of our group with a higher PSA than his 90 odd....He then kicked depression in the head, went back to work, and on the last New Years day...which originally he thought he'd never see.... he came out with the phrase 'A wasted day is one without laughter' which is now our new Motto.....

I would like to see more cross fertilisation of ideas and am very happy to give our FOPS presentation of chat and song to any local group as it went down well at a recent Aberfeldy Rotary meeting. I was delighted to receive a letter from our MSP John Swinney offering his help to raise awareness especially in Highland Perthshire, for

we sufferers are impatient testosterone kids. Testosterone kids are those who succeed at whatever metier or level in life they have chosen. They stand out from the crowd. They are driven. Problem is when mid-age approaches and the apparatus tends to lie moribund too often for too long....Tis then the fluids, like milk, 'curdle' and prostate cells can become ugly distorted and cancerfied.....But like the train that comes into the station if you're early you'll catch it in time...But if you leave it too late it ain't gonna wait then you're at the End of the Line..... So hit www.thefops.org.uk and get a PSA TodayYou know it makes sense....

South West Public Health Observatory

Urological Cancer Hub

The Urological Cancer Hub has moved. It is now part of the National Cancer Intelligence Network website at www.ncin.org.uk/urologicalcancer and includes:

- Urological Cancer Profiles – statistics for every Local Authority, Primary Care Trust and Cancer Network in England
- Reports – a growing series of reports on urological cancer in England
- Factsheets – highlighting key data on incidence and mortality for each urological cancer type
- Advice – signposting to information for professionals and the public

www.ncin.org.uk/urologicalcancer

The Urological Cancer Hub has moved

The Urological Cancer Hub has moved to the National Cancer Intelligence Network website:
<http://www.ncin.org.uk/home.aspx>

The Hub provides information for health professionals and the public on urological cancers in England. Its focus is on presenting key statistics in a clear and usable way.

The Urological Cancer Profiles:
<http://tinyurl.com/cvsenm>
 present data on incidence, mortality and survival for each urological cancer type by local authority, primary care trust and cancer network, so you can see how one area compares with another. They also give you a snapshot view of urological cancers in your local area.

The Urological Cancer Factsheets:
<http://tinyurl.com/c64ouuk>
 summarise the key data in downloadable pdf format. Both the profiles and the factsheets have recently been updated with the latest available data.

Other resources on the Hub include reports and useful links to other sources of information.

For more information about the Hub, please visit
www.ncin.org.uk/urologicalcancer

WHILST WE AWAIT THE OUTCOME OF THE RISKMAN TRIAL – WOULD YOU LIKE TO HELP SAVE A FEW LIVES?

By Graham Fulford



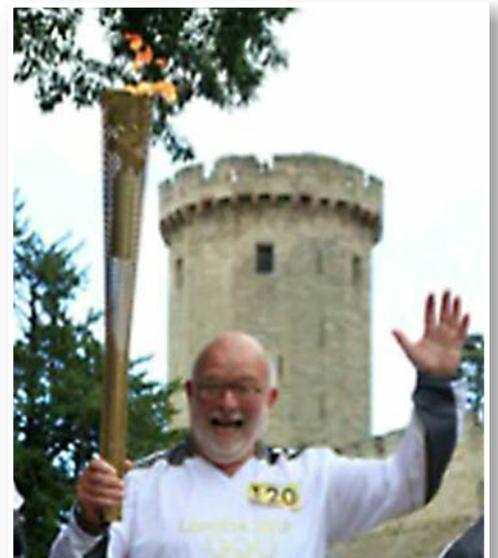
The Bioscanner in Operation

Doesn't time fly in the world of prostate cancer? It's now nearly a year since we launched our first ever "Bioscan only" PSA testing session in Warwick on 18th August 2011 quickly followed by a second session in Rugby on the 1st September at which a man with a high reading had the sense to see his GP quickly, was then 'fast tracked' to the local hospital and was being treated with radiotherapy by the middle of October! Six weeks from the original indicative test to treatment! It doesn't get better than that!

Since that time we have helped 8 individual groups to start up offering a 'point of care' 'indicative' PSA testing system using Mediwatch Bioscans whereby the results are given on the night. We have been working with Mediwatch for the past 4 years or so and between us have developed a complete package whereby men attending a session are counselled, given a PCRMP about the pro's and con's of testing and if they want a test leave with an appropriate green, amber or red letter. In the case of the amber and red letters they are given David Baxter-Smith's telephone number should they have any concerns they would like to discuss and in the case of red letters a letter to take to their GP pointing out the importance of the need for a full follow up of our indicative result including if possible a 'free to total' Psa test as well as a standard full lab Psa test. In over 95% of our 534 cancer finds to date where a 'free to total' facility was available the men had an abnormal 'free to total' score as well as a high basic Psa reading. A very interesting statistic I'm sure you'll agree. Because of our long standing link with Mediwatch we can help you secure £7,000 of equipment (four Bio scanners, 1 network printer for results and 200 strips for testing) for just £3,200. Moreover, full training and ongoing support is available from Mediwatch, David Baxter Smith and ourselves. If this is something you are interested in we can arrange a talk and demonstration and even help put on a training session and trial event for say 40/50 men at a relatively modest cost before you commit to the 'bigger picture'.

Since launching the Bioscan programme we've helped to carry out approaching 2000 tests using this system. We would love to see this figure double or even treble in 2013. Strength in numbers and all that ! If you would like more information contact Graham Fulford on 07831 156071 or at: gfulcharitabletrust@tiscali.co.uk In the meantime why not visit us at:

www.grahamfulford.org.uk and see Graham and see Graham carrying the Olympic Torch!



Well Done Graham!!

Don't Ignore Prostate Cancer Signs!



Calvin Wood

A RETIRED granddad-of-four Calvin Wood said he only found out he had prostate cancer through a routine visit to the GP.

Since then Calvin has worked tirelessly to raise awareness of the disease and tell people "the first symptom of prostate cancer may be no symptoms" at all.

The 69-year-old, from Irby, was diagnosed in 2001 and treated with 32 bouts of radiotherapy in 2002 before he was given the all-clear three months' later.

Today he added his voice to NHS Merseyside's **Year Of Action On Cancer campaign**, which is encouraging Merseyside men to be cancer aware.

For **Everyman We Cancer Awareness Month**, NHS Merseyside is raising awareness of prostate and testicular cancers, with the support of Mr Wood, who now devotes his spare time to supporting Merseyside men with the same condition.

According to figures from the NHS, prostate cancer is the second most common cancer diagnosed in Liverpool men, with around 225 cases every year. Prostate cancer cases in Liverpool men represent 18% of all male cancers in the region.

Mr Wood, who has had regular check-Ups for the past 10 years, has been chairman of the Wirral and North Cheshire Prostate Cancer Support Group for nearly eight years. He

said: "When was diagnosed as having prostate cancer it was a real shock.. *"I had not experienced any symptoms at all and it was only thanks to a routine visit to my GP for something else that the cancer was spotted. Ever since my diagnosis I have been keen to raise awareness of the condition. "It is vitally important that gents are aware of it and ask their GP about a Prostate-specific antigen blood test if they have any concerns. I helped set up the support group in 2005 because I wanted to be able to help others in the same boat as me."* The group has about 200 members from Wirral and beyond. "Normally we have around 30 ladies attending too, who come along to the, meetings with their partners to get information about, services and treatment. It is also an opportunity to share any concerns family members may have about prostate cancer too. A lot of the time you would not even know that the people in our meetings are ill and the important thing about our group is a positive atmosphere and a chance to share experiences and information!"

Prostate cancer is the most common cancer in men. Each year in the UK about 36,000 are diagnosed with prostate cancer. It accounts for 25% of all newly diagnosed cases of cancer in men. NHS Merseyside launched its **Year Of Action On Cancer** earlier this year with NHS Cheshire Warrington and Wirral at the Liverpool Cancer' Research UK Centre.

It aims to educate residents on all aspects of cancer from prevention, early detection, research and innovation and treatment available.

NHS Merseyside chairman Gideon Ben-Tovin said: "There are lots of innovative services and treatment options available in the region and the positive news is in many cases a man can live for decades following treatment for prostate Cancer."

Prostate cancer normally causes no symptoms until the cancer has grown large enough to put pressure on the urethra, resulting in problems associated with urination. Symptoms can include needing to urinate more frequently and feeling that your bladder has not emptied fully:

- Visit www.wirralprostate.org

Or email wirralpcs@gmail.com

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

Prostate Cancer Support Federation

the voice of prostate cancer patients and their families

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Charity No. 1123373

www.prostatecancerfederation.org.uk

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Gloria Hunniford

Development Director

Rowena Bartlett

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Emma Malcolm,
David Baxter-Smith,
Rob Banner,
Bob Arthy

Medical Advisor:

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

The Torbay Prostate Cancer Support Association Receives The Queen's Award



Peter Hosking & David Wakefield pictured The Lord Lieutenant of Devon

final selection and recommendation to The Queen.

Details of winners are announced annually on 2 June (the anniversary of The Queen's Coronation).

Winning groups receive a certificate signed

by The Queen and a commemorative piece of crystal for display at the group's main place of operation. The Awards are presented on behalf of The Queen by the local Lord-Lieutenant or Lieutenant-Governor.

Many different types of organisations have won the award since it was launched, including groups working to improve the local environment, running community centres, managing play schemes and supporting families.

The Chairman and Trustees are delighted to report that we were nominated by a variety of people.

Nominations were made by TPSA members, medical staff of local hospitals, members of the public and prostate cancer patients and their carers.

Thank you all!

The Queen's Award for Voluntary Service is an annual award made to recognise and reward excellence in voluntary activities carried out by groups in the community.

The award was announced in 2002 as part of celebrations for The Queen's Golden Jubilee, and was first known as The Queen's Golden Jubilee Award.

It is given for outstanding achievement by groups of volunteers who regularly devote their time to helping others in the community, improving the quality of life and opportunity for others and providing an outstanding service.

Groups must be nominated: for example, by beneficiaries of their work, members of the public, representatives of public bodies, or other voluntary groups.

Nominations are assessed by a regional committee before being passed to a national committee for

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	