

helpline 0845 456 0678

New Patron for Prostate Cancer Support

Although we are a patient led organisation, which gives us a unique understanding of how patients feel, we are proud that many members of the medical profession support our association – indeed many of our local support groups have medical staff (nurses in particular) as regular attendees at the meetings.

Mr Patrick O'Reilly, MD, FRCS, known to so many of our members and patients at Stepping Hill Hospital as Paddy O'Reilly has been a supporter of PCS (Prostate Cancer Support) since its early beginnings as PSA, when Roy Nixon and others first established the Cheadle group.

We are delighted that Paddy has accepted our invitation to become a Patron of PCS. Paddy has presented at our Regional Meeting at Christie and supported our only national conference held in Manchester Town Hall in 1999.

In Paddy we have an eminent professional who will be a tremendous asset to our organisation. His activities have not only been limited to Stockport. He has worked and gained experience in America and Australia and is a member of the European Association of Urology. His list of qualifications is extensive, including a

recent honorary award as a Fellow of the Royal College of Surgeons, Edinburgh, presented to him in 2004. He is the immediate past President of BAUS (The British Association of Urological Surgeons).



Mr O'Reilly founded the Department of Urology at Stepping Hill Hospital in 1981. It has since developed from a one man unit to an internationally renowned major Department. It has 5 consultant staff who work out of a dedicated free standing Department providing urological care to Stockport, Tameside and Macclesfield. It is a urology training centre for young surgeons, and has 7 Urology Specialist Nurses. It is a major cancer centre with particular emphasis on the management of

prostate and bladder cancer. It is now a major laparoscopic (key-hole) minimally invasive centre, performing operations such as kidney removal, kidney reconstruction, stone surgery and recently radical prostatectomy for cancer through telescopes instead of classical incisions. This produces a marked reduction in pain and length of stay for these patients. The Department has won Awards for Hospital Doctor of the Year (Mr O'Reilly), Urology Unit of the Year (3 times) and the coveted Charter Mark.

Paddy has published 6 medical textbooks, 12 chapters in scientific textbooks, 74 papers in peer reviewed scientific journals and has made in the region of 60 national and international presentations. He has also published five novels – yes, novels! Writing under the pseudonym Patrick Riley, they are medical thrillers - the latest entitled Serious Deceit. He is working on the 6th which he hopes to complete by Spring 2007.

Paddy once told me that writing is his way of relaxing, although he also lists Music, Manchester United Football Club, Sale Sharks Rugby Club and Merlot among his hobbies. Hmm - "red wine" - good for the prostate!

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News of groups, people and a list of donations also appear throughout this issue.

Over 30,000 men are diagnosed with prostate cancer every year in the UK

Symptoms to look out for:

- Frequent need to pass urine
- Delay or hesitancy before urinating
- Pain in passing urine
- Dribbling
- Blood in urine
- Inability to get or maintain erection
- Back pain

BUT many men show no symptoms in the early stages so discuss this issue with your GP especially if there is a family history.

Welcome back to *Prostate Matters*!

When we first introduced our newsletter back in September 2004 it was our intention to produce a minimum of three and hopefully four issues per year.

We chose not to produce a simple news sheet. Instead our aim was to produce a high quality document which would not only be interesting to our members, but also to other readers who were likely to support the aims of *Prostate Cancer Support*, such as members of the medical profession. We know that we have achieved the first (our members' survey showed that 95% of respondents looked forward to and rated *Prostate Matters* very highly) and we have also received some compliments from both doctors and nurses.

While this is very pleasing, it adds to our disappointment at failing to produce a copy since 2006. We are an organisation which (with the exception of one part time office administrator) is run totally by volunteers. Therefore, there are only a limited number of activities on which we can focus, unless we can recruit more volunteers from our membership. This last year has seen us put more effort into the support of our newer local groups; the development of the Prostate Cancer Support Federation and, in the case of the chairman, Europa Uomo (European Prostate Cancer Coalition). As a result, this is the first newsletter of 2007—rather late in the year—but we will attempt to have another with you by the end of the year.

In this issue there are a number of articles which will appeal to those of you who like to know some of the technical detail behind prostate cancer including articles on PSA kinetics from John Dwyer and an article relating to biopsy discomfort provided by Drs Nigel Parr and Joe Philip (Wirral Trust Hospitals), which they originally submitted as a letter to the *British Journal of Urology*. To balance these, there are also articles on incontinence, clinical trials and a copy of an article by Liz Lynne MEP and co-founder of MEPs against cancer.

For the first time, we have included the names of some of the members of PCS who sadly have died since our last publi-

cation. We have not done this previously, but have changed our policy at the request of our readers.

In the past, we have included articles on diet, nutrition and cancer prevention. Lack of space has prevented us from doing so in this issue, but our next issue will focus on this and will have a report from the WCRF (World Cancer Research Fund) that will be publishing, in November, the most comprehensive report on this subject for the past ten years. For those of you who can-

not wait, you can register to receive this on their website at <http://www.wcrf.org>.

We hope you enjoy this latest issue of *Prostate Matters*.

Next Prostate Matters: Report on WCRF expert report; news of the Federation and Europa Uomo; news from the groups; we also hope to bring you the latest information on the progress of Abiraterone Acetate trials being carried out on difficult to treat cancers.

PSA Kinetics

John Dwyer (April 2007)

Summary

It is difficult to specify particular levels of serum PSA for referral to biopsy. In some patients PSA level is raised but remains steady and is not changing with time, whereas in other patients PSA may not be raised (according to a defined 'normal PSA') but may be increasing rapidly as time passes. Similarly, it is not straightforward to use a single PSA level to specify 'treatment failure' (e.g. following Hormone manipulation, radiotherapy, brachytherapy, HIFU etc.).

Consequently, there is increasing interest in considering the **rate** at which PSA level increases as time progresses: which gives rise to the term "**PSA Kinetics**". Two measures are in current use **PSA Velocity (PSAV)** and **PSA doubling time (PSADT)**. The first of these is defined as the increase in PSA level divided by the corresponding increase in time. This is straightforward, as discussed below.

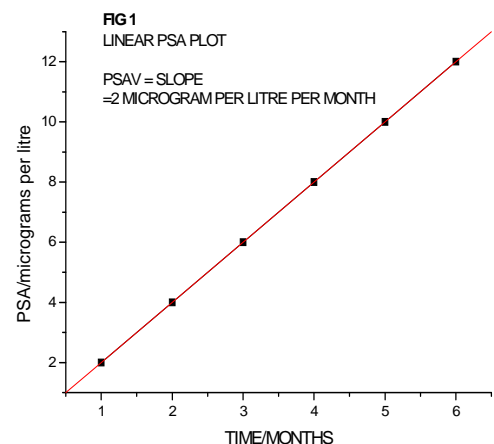
The second measure PSADT has been defined as the time for PSA level to double. However, this is not an adequate measure, since it depends upon which PSA value the patient chooses to start the count from. Consequently, PSADT is estimated by assuming that the pattern of increase in PSA level, with corresponding increase in time, follows a growth pattern typically found in many biological processes, known as "exponential

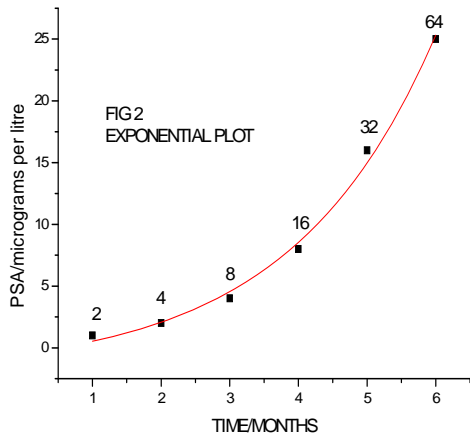
growth".

In what follows PSAV and PSADT are further explained and exemplified. The advantages and limitations associated with the use of PSA Kinetics will be outlined in a subsequent newsletter

PSA VELOCITY

PSAV is more appropriate where increase in PSA with time is approximately linear, as in Fig 1, for which the values of PSA ($\mu\text{g per litre}$): are 2, 4, 6, 8, 10) and the corresponding times (Months): are 1, 2, 3, 4, 5, 6. The straight line (linearity) in Fig 1 implies a constant increase of PSA with time i.e. a constant velocity (speed) [for comparison consider a car in motion such that it covers a fixed mileage each hour i.e. has a constant speed (velocity)]. Usually, PSAV is estimated using all the ex-

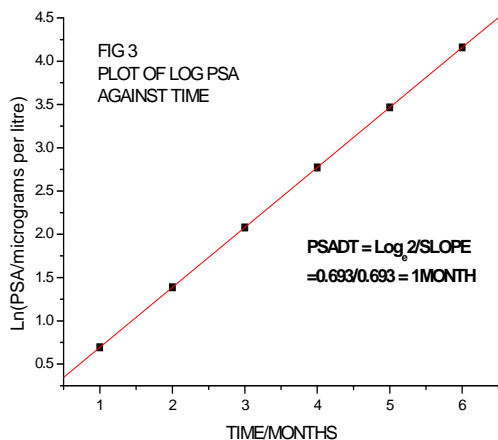




perimental measurements of PSA, by calculating the slope of the line fitted to the data (Fig 1). However, for the data in Fig 1, all the points are on the same line so that the (constant) slope can be estimated using any two values of PSA and their corresponding times. For example, if we use the second and fourth points representing an increase in PSA from 4 to 8 (i.e. 4 PSA units) and divide by the corresponding increase in time, from two to four months (i.e. 2 months) we get a PSAV of (4 PSA units)/2 months = 2 µg per litre per month. Using any other pair of data points will give the same answer, for linear plots as in Fig 1.

PSA DOUBLING TIME

This is frequently expressed as the time for the PSA level to increase by a factor of two. However, this measure is not well-defined for a linear increase as in Fig 1. For example, if we calculate the



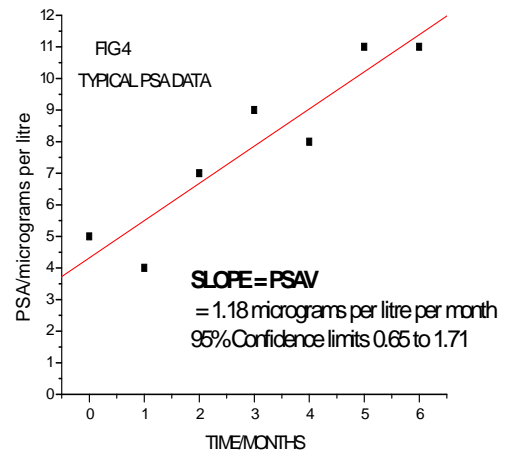
time to double from PSA = 2 to PSA = 4, we see (Fig 1) that this takes place in one month, so we estimate the doubling time to be one month; whereas if we consider the time to double PSA from 4 to 8, we find that this requires two months. For these linear plots we see that doubling time depends upon where we select the first PSA point. This is clearly unsatisfactory, although it is sometimes still used (and not only by patients).

PSADT is particularly relevant where PSA is increasing in a non-linear pattern. For example it is often considered that cancer cells increase by a ‘doubling process’ such that one cell divides to make two cells. Then two cells become four and four become eight etc, so that the cells follow a growth pattern 2→4→8→16→32→64, which represents *exponential* growth as shown in Fig 2. In Fig 2 the PSA values are included on the graph to emphasise that the PSA doubles in a fixed time; in the example PSA doubles every month. Note that, for exponential growth, PSA velocity (PSAV) is not constant.

Typically, PSADT is calculated by plotting the logarithm of PSA against time which produces a linear graph (Fig 3) and facilitates the use of all the data points to estimate the slope. Logarithms of numbers are available on most calculators and computers and some of you may still have the old log tables. Although log to base 10, as used at school, is adequate most seem to use log to base ‘e’ (ln), in which case the doubling time is obtained by dividing log to base ‘e’ of 2 (written ln2) by the slope of the line. Since ln2 = 0.693, and the slope of the line is, in this case, also 0.693 (Fig 3) we obtain a doubling time of one month, as above (Fig 2). Above we see that by taking logarithms we can, for ease of calculation, transform a nonlinear (curved) plot into a linear plot. It happens to be the case that a *linear* plot of PSA versus time will remain linear when plotted as Log PSA

versus time, and this is frequently used to calculate a doubling time. This can be justified if we accept that small sections of an exponential growth curve such as that in Fig 2 can be approximated by a straight line. That is, we assume that our limited data represent a selection from a larger exponential growth curve. [Note: PSADT is most useful when initial PSA is small, (e.g. after treatment) or when a ‘baseline’ value can be accounted for.]

Fig. 4 shows typical experimental data which are scattered about a straight line. We can calculate the PSAV directly from the slope of this line, as above. An estimate of the ‘best fitting’ line could be made ‘by eye’, but where possible this is calculated using appropriate computation. This allows us to estimate the



{approximate} errors associated with computed PSAV, and these are shown as 95% confidence limits which allow us to say, with probability 0.95 [or 19 to 1 on] that the value of PSAV is within the range 1.79 to 0.68. By taking logarithms of the PSA values in Fig 4 we can estimate a PSADT, as in Fig 3, on the assumption that our data are a selection, approximately linear, from an exponential growth curve (Ans. PSADT = 4.3 months).

This note is intended to provide some background to the definition and measurement of PSA kinetic parameters. In a later issue of Prostate Matters we will review recent literature, and update the position presented in the Dec. 04 issue.

At many of our Christie talks, the subject of Clinical Trials is mentioned by the speakers. Also patients frequently ask how they can be involved in trials or can get an update of how trials are progressing. As a result, we contacted the Medical Research Council to ask if they would provide information on this subject. They kindly provided us with the following article.

MRC Clinical Trials Unit

The Medical Research Council (MRC) is a public body that encourages and supports high quality research. It aims to improve and maintain public health and to contribute to national health and quality of life.

The MRC Clinical Trials Unit (CTU) in London is the MRC's centre of excellence for running clinical trials. It was formed in 1998 by bringing together two long-standing research offices: the MRC Cancer Trials Office (Cambridge) and the HIV Clinical Trials Centre (London). The MRC CTU provides evidence through the design and conduct of large, prospective, high quality, randomised controlled trials (RCTs, also known as "clinical trials") that compare two or more treatments, as well as other studies such as systematic reviews, meta-analyses and related epidemiological studies. The research is conducted to strengthen and expand the evidence-base for health care nationally and internationally.

There are three main scientific groups at MRC CTU: Cancer Group, HIV Group and Other Diseases Group. The HIV Group focuses on RCTs in UK and Africa and works closely with researchers across Europe and North America. The Other Diseases Group was formed with the Unit as an opportunity to run trials in disease areas where little research had been undertaken previously. This Group is collaborating with many organisations including the Arthritis Research Campaign, National Blood Service and British Thoracic Society and is conducting trials in medical fields such as diabetes, multiple sclerosis and tuberculosis.

MRC CTU Cancer Group

The Cancer Group conducts RCTs for patients with cancer that compare treatments with respect to important outcomes such as survival, recurrence, toxicity/unwanted-effects and quality of life. These are trials are run in many different tumour sites. The types of approaches being compared depend on the standard

care for that tumour type and site but the Cancer Group has run trials that have included comparisons of chemotherapy, other new drug agents, radiotherapy and surgery or combinations of these. Additionally, comparisons have been run of the best methods of following people after their treatment, such as how often CT scans should be performed.

Randomised controlled trials

RCTs are the "gold standard" method for assessing new approaches to prevention, management and treatment of diseases which is why they form the backbone of the MRC CTU's research portfolio. They are fundamental to evidence-based health-care and have been used for 50 years. RCTs are particularly important because they provide a systematic and rigorous method for assessing new approaches.

The MRC CTU vision is that all treatment decisions should be based on robust evidence and that if such evidence is lacking, there should be an appropriate trial for patients to join, if they wish.

In RCTs, people who choose to join the trial are allocated at random to the control group or to (one of) the research group(s). Usually, this is done by using a computer-based method. It means that neither the person joining the trial nor their doctor chooses the treatment they will receive. Random assignment is very important because it means that the overall groups of people receiving each treatment should be similar. Therefore, if there is any difference in the outcomes of the people in these groups, we can presume this was likely due to the treatment that was allocated. The number of patients required to join current MRC CTU trials can range from less than one hundred up to several thousands of patients.

Designing and Conducting Trials

Designing and conducting RCTs is not a simple process. First, there are discussions to choose which treatment approaches are should be assessed. An RCT should always compare the standard treatment (ie the treatment that would be given if there was no trial) with one or more research treatments (ie potential new approaches). Before the new approaches become widely used, it is important to assess whether they are safe and effective and that the balance of their positive effects and negative effects is appropriate and acceptable.

When designing and conducting a trial, the clinical community must be in a state

of equipoise; this means that there is no good evidence already that either of the trial approaches is better than another. If there were not a state of equipoise, it would not be ethical to run a trial. Before the study, some doctors may feel more positive about a research treatment, others may be more cautious; but it is important that, together, good evidence is collected so that the clinical community overall can draw strong conclusions.

There is often a perception (particularly reflected in some media) that "new is better", but this is perception is often not true. According to a recent report from the US Food and Drug Administration, the majority of new drugs that are tested never make it to market. This is because they are shown not to be more effective than standard drugs or because they have worse side-effects than the standard treatment. We cannot know in advance which drugs (or which approaches) will be the ones to advance treatment and help more patients.

RCTs are not lightly undertaken. Each RCT run by MRC CTU will undergo a series of peer reviews before any patient is approached for the trial. There will be rigorous scientific and statistical review (peer review) by the funding body as well as review by expert committees (such as the National Cancer Research Institute) and in-house review; the study will also be reviewed by a Research Ethics Committee (REC). The REC will pay particular attention to whether a study is fair on the patients and whether the Patient Information Sheet (the written information given before signing up to a study) is appropriate.

Designing and developing a trial is a collaborative process. Staff at MRC CTU work closely with staff from hospitals to ensure that there is a broad range of expert input into all aspects of managing and assessing the disease area and in clinical trial practicalities and appropriate statistical methods. Collaboration with other trial organisations is often essential for large studies to succeed, and the MRC CTU conducts several studies jointly, or in parallel, with other large trial organisations both within and outside the UK. In addition, many MRC CTU trials are open to participation from doctors worldwide. Results from all MRC CTU studies are published so that the information is available to health professionals, researchers and patients alike. The data from the trials are also used for further trial-associated research and meta-analyses. Meta-

analysis involves bringing together the results of a number of trials that have looked at similar treatments for the same illness or condition.

Many trials also collect health economic data because new treatments need to be assessed for cost-effectiveness by the NICE (National Institute for Health and Clinical Excellence) before becoming widely used.

Joining trials

Clinical trials cannot be performed without people kindly volunteering to join them. Joining a trial may not necessarily benefit the patient who joins but the knowledge gained by the doctors will help improve treatment for patients in the future; in the same way, the treatment choices we make now are based on data provided by clinical trial volunteers in the past.

For trials assessing treatments in cancer, the patient is usually approached by a hospital doctor or nurse involved with a study; MRC CTU does not have direct contact with patients at any time. Before joining the trial, the patient would have the trial explained to them in full and the hospital team would make sure that the trial is right for the patient and vice versa. The patient should be told what would happen if they join the trial and also what would be standard care if they didn't join the trial. Only if the patient agrees to join the trial would they be entered. And, of course, even after joining the trial the patient can stop trial treatment at any time; stopping trial treatment would not affect their standard of care and they should be asked to continue with study follow-up visits to check for any lasting effects.

Patients are always monitored carefully whilst on a trial. New information can become available during a trial. Most MRC CTU trials are reviewed by an Independent Data Monitoring Committee (IDMC). This committee looks at the incoming data during the trial and advises whether data from the trial are convincing earlier than planned. Usually, no-one other than the IDMC and the trial statistician see the data while the trial is running so that overall equipoise is maintained.

Prostate cancer trials

The MRC CTU has an active portfolio of trials for patients with prostate cancer. Recently we have demonstrated, in

MRC PR04, that a first generation bisphosphonate drug (clodronate) does not improve cancer outcomes for men with disease that has not spread. We have also shown, in MRC RT01, that escalated doses of radiotherapy given using newer radiotherapy methods, lead to some improved cancer outcomes for men with early stages of prostate cancer, albeit with some increase in radiation side-effects.

Two trials are currently open to recruitment. The first, STAMPEDE: MRC PR08, is recruiting men who are being given hormone therapy for prostate cancer. The RCT is assessing the additional use of three drugs or their combinations. The drugs in question are a chemotherapy drug, docetaxel (Taxotere), which has recently been approved by NICE for men with more advanced prostate cancer; a third generation bisphosphonate, zoledronic acid (Zometa), which may protect bones; and a simple, oral Cox-2 inhibitor, celecoxib (Celebrex, Onsenal) which may also help outcomes. STAMPEDE will recruit 3000 men in the UK and Europe over the next 5 years and we hope that at least one of these novel approaches will show good evidence of benefit compared to standard hormone therapy. The second trial, PATCH: MRC PR09, is a feasibility study for the same patient group. It is investigating whether long-term hormone therapy may be given using skin patches instead of monthly injections. There is some data to suggest that the patches may be a more effective way to deliver hormone therapy but this needs to be researched. PATCH will recruit around 200 men in the UK over the next 2 years. If treatment with patches is safe and acceptable in PATCH, a large scale randomised controlled trial will be undertaken. A new trial will start to recruit 4000 men from UK and Canada this summer - RADICALS: MRC PR10. RADICALS is an RCT for men who have already previously chosen to have surgery to remove their tumour and is making two comparisons. First, for some men, doctors know whether to give radiotherapy soon after the operation or to wait until the PSA (prostate-specific antigen) level starts to creep up; but, for some men, the best time to use radiotherapy it is not certain and *these* men can join the Radiotherapy Timing Comparison of RADICALS. Radiotherapy may help in terms of prostate cancer outcomes but is associated with side-effects; for many men PSA levels will not rise and radiotherapy would not have been needed. RADICALS will allow us to better describe the balance of risks and benefits. Second, the trial is also for men starting

radiotherapy at any time after their prostate operation: some doctors do not give hormone therapy with radiotherapy, some give it for a short time and some for a longer time (about 2 years), but the optimum duration of hormone therapy (or whether it needs to be given at all) is not known. Therefore, the Hormone Duration Comparison will address this question. This trial will be open widely across the UK. Therefore, men who are due to have surgery soon may expect to discuss this trial with the doctor. Similarly, men who have had surgery but have not yet had radiotherapy may expect to discuss this trial with their doctor if their PSA levels rise.

In summary, MRC CTU is a centre of excellence for running good quality clinical trials to help improve health outcomes in the UK and internationally. This research cannot be undertaken without the willing support of thousands of patients each year. Their time and effort is much appreciated. Additional information on MRC CTU and on information specific trials on the MRC CTU website.

Matthew Sydes
Senior Medical Statistician
Cancer Group
MRC Clinical Trials Unit

Links

About MRC CTU --

www.ctu.mrc.ac.uk/

About clinical trials --

www.ctu.mrc.ac.uk/TrialInfo.asp

About patients and trials -- [http://](http://www.ncri.org.uk/default.asp?sectionID=What_We_Do&pageID=Patients)

www.ncri.org.uk/default.asp?sectionID=What_We_Do&pageID=Patients

About trials in prostate cancer -- [http://](http://www.ncrn.org.uk/csg/downloads/Prostate%20CSG%202005-6%20annual%20report.pdf)

www.ncrn.org.uk/csg/downloads/Prostate%20CSG%202005-6%20annual%20report.pdf

Editors note. After completion of *Prostate Matters* we received an article written by Jim Stansfield (a patient and member of PCaSO) who has taken part in a number of trials and is also a patient representative on the NCRI Prostate Clinical Studies Group. Jim's article includes specific reference to the STAMPEDE and RADICALS trials and will appear in our next issue. If you would like to receive an early copy please contact the office (0161 474 8222).

Leading by example

Marshalling political support for the fight against cancer is a key part of tackling the disease – which is why Liz Lynne helped set up MEPs against cancer

The following article appeared in the European Parliament Magazine in February for World Cancer Day. The Magazine is distributed to all MEPs, Commission officials, Permanent Representations and other Brussels stakeholders. The article has been reproduced in Prostate Matters with the kind approval of Mrs Liz Lynne who is the Liberal Democrat MEP for the West Midlands Region.

Being diagnosed with cancer can feel like receiving a death sentence. This happens to 5500 people in Europe every day and has a profound impact on their lives and the lives of their loved ones. One in three Europeans is diagnosed with cancer and the disease kills one in four people. Every family in Europe is touched in some way by this devastating disease. I worked hard to form the group MEPs against cancer (MAC) in 2006, with two other MEPs Alojz Peterle and Adamos Adamou, and with considerable help from the European cancer patients coalition. Since then, the group has grown in size to over 44 members, who have joined forces across political groups and member states to support EU citizens and patients in particular in their fight against cancer. Europe has the knowledge to provide timely and effective cancer prevention, screening, treatment and

care for all EU citizens. But it needs political will. MEPs against cancer can help build that political will.

Screening programmes can help reduce deaths from certain cancers, yet in some member states they are poorly implemented or non-existent, despite the recommendation from member states on screening for colon, cervical and breast cancer. Every year thousands of people die unnecessarily from cancer because their treatment is below standard or is given too late. The chance of surviving cancer is largely dependent on where one lives and is treated, and this is one area where I believe that pressure from MEPs against cancer can make a real difference. Last year I put my signature to a MAC statement calling on all European health ministers to take steps to combat the considerable inequalities in health and cancer survival rates within member states and across the EU. We hold regular meetings and conferences, such as last October, when the members held a meeting on the issue of national cancer plans and what can they do to help raise awareness and increase treatment. Since its formation, MEPs against cancer has continued to call on health commissioner Markos Kyprianou to develop a cancer task force for the EU, which is vital if we are to achieve our goals.

Cancer affects both women and men



Liz Lynne MEP is the co-founder of MEPs against cancer

alike, and one of my priorities for 2007 will be to raise the issue of prostate cancer. Men can learn from the way women now view breast cancer and must start talking and thinking about the dangers of prostate cancer.

There is a great deal of research going into prostate cancer and, if detected early,

“MEP’s Against Cancer is sending a strong political signal that immediate and concerted action is needed to reduce cancer rates and improve cancer outcomes.

One of the ways we try to achieve this is by ensuring that best practice is shared across the EU and that the gaps that exist in cancer prevention, diagnosis, treatment and care between and within member states are eradicated”

the chances of survival are good. But if we in Europe are going to really tackle the problem, men must not be afraid to find out the facts and be prepared to talk about it and visit a medical professional. Over 202,100 men were diagnosed with prostate cancer in the EU in 2004. And yet Luxembourg remains the only EU member state to have an active national screening programme.

MEPs against cancer is sending a strong political signal that immediate and concerted action is needed to reduce cancer rates and improve cancer outcomes. One of the ways we try to achieve this is by ensuring that best practice is shared across the EU and that the gaps that exist in cancer prevention, diagnosis, treatment and care between and within member states are eradicated. I am delighted with the work that MEPs against cancer has achieved so far, but we face a huge challenge if are to make a real difference and tackle the cancer epidemic that Europe’s ageing population faces.



Liz Lynne signs the declaration creating MEPs against cancer, with Alojz Peterle, Adamos Adamou and Markos Kyprianou

Survey of Members Views

Along with our last Newsletter, we sent out a survey asking members or just readers of *Prostate Matters* for their views on the activities and effectiveness of PCS (PSA NoE as it was at the time) and their level of satisfaction as members.

In fact all replies received came from members of PCS, although a small number were also members of the nursing profession, i.e. they were not patients. We were a little disappointed with the number of responses as only 22% of the membership replied. This is a significant drop against the number replying to our previous survey conducted almost three years ago.

On the plus side, the responses were very positive showing significant support for our activities and approach. People were asked to rate a statement (or respond to a question) as “being in agreement with the statement”; or “disagreeing” or “neither agreeing nor disagreeing”. There were many comments made by members showing that the response was not just a “tick in the box” exercise.

A common question in each section was asking members if they would be prepared to assist or to become volunteers. This met with a varied response depending on the area being covered.

A summary of the key points is covered below, but a detailed analysis of the survey can be provided by contacting the PCS office on 0161 474 8222.

SURVEY RESULTS

Section 1 Regional Meetings

The majority of returns (72%) were in favour of Christie Hospital as the venue for the meetings. In the main the 6% that favoured an alternative location did so because they had to travel from outside the immediate Manchester area (e.g. Liverpool, Yorkshire, Stoke-on-Trent). The format of the meetings – times, speakers and refreshments – had a 64% approval and only 3% against. Similarly 69% approved of the topics chosen although 14% said that they would like to have other subject areas covered. Suggestions included more presentations by patients covering their own experiences (including but not limited to less common treatments e.g. HIFU); pros and

cons of Active Surveillance; and the effect both socially and economically on a patient’s family. The idea of helping to organise a Christie meeting was clearly of concern, as no returns showed a positive response!

Section 2 Local Support Groups

The response to statements in this section ranging from importance, locations and times of meetings was very similar - 65-69% in favour, 3-6% against. 53% liked the format of their local group with no dissenters, but only 47% of responders actually attended a group. Comments were generally supportive, but ranged from “Of great help!” to “Not attended my local group as I have never felt the need”. A few gave suggestions of locations to where a group would be good (included Altrincham/Sale and Sheffield).

8% said that with assistance from PCS they would like to establish a support group in their area.

Section 3 Communication

Information Provided

75% said they found it easy to obtain information from PCS and 83% said they found the office and volunteers to be responsive and caring. Comments in this area were especially encouraging relating to the importance of being able to talk to other patients when needed, the help and experience of other patients given at most appropriate times and the speed with which information was sent following a request. The quality of postal information was also praised.

Helpline

A little less than half (44%) had used the Helpline, but of those there was overwhelming approval of the value of the information given and of the value of the service. 42% of patients said they would like to be added to the list of patients willing to talk to others. One person who had previously offered their services, had not been used as a helpline volunteer. *Calls to the Helpline are initially handled by the office and by a very small number of volunteers. According to the nature of the call, a further volunteer will then contact the caller. This second volunteer is chosen because of his personal experience as a patient (perhaps he has experienced surgery or brachytherapy, or has been treated in the same hospital as the caller,*

etc). Over time familiarity has probably caused us to rely on too few volunteers for this service and therefore we shall be reconsidering this area.

Newsletters

The UsToo newsletter received a 64% approval rating, but the *Prostate Matters* received a massive 95% approval. The UsToo is easy for us to provide, as it is produced by the American organisation of the same name. We are affiliated with this organisation and therefore can receive complimentary copies to pass on to our members. We will continue to do this as a majority of members do value it.

The fact that the *Prostate Matters* is held in such high esteem pleases us greatly, but it does highlight one of our problems. We are a very small editorial team and writing the articles and editing the newspaper is a major task – one that has to be shared with other activities. Help in this area would be of utmost value – the provision of articles, reports on group activities and patient experiences—just letters to the editor would be helpful. Articles by the medical profession would be particularly welcome (thank you Mr Parr, for your article in this *Prostate Matters*, see page 9). Many areas were suggested for future articles and we will take notice. Given the raw material we can edit an article to make it suitable for the newsletter.

Website

Only a small number used the website (17%), many people stating that they didn’t have access to a computer. We would welcome a volunteer in this area who is interested in IT, and who may be prepared to manage the website. We have noticed that a number of our first contacts come through the website.

Section 4 Raising Awareness

The first group of questions in this area was about the importance of PCS representing patients’ interests to Health Professionals and Government Bodies and our involvement with various groups (e.g. Patient Trials steering committees, Dept of Health Steering Groups, Government Conferences on Cancer, Hospital Patient Forums, etc). This received another massive 92-100% approval. Other less specific groups such as BME, or Cancer and Sexuality forums received a fifty-fifty

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During this past year, it has been noticeable that we have had a number of calls to our helpline regarding incontinence. Also it is a subject that has been raised at a number of our Support Groups. It is evident from patient feedback, that different hospitals prepare their patients in different ways for a potential side effect of prostate cancer treatment (particularly, but not confined to, surgery). Pelvic exercises are the common approach, but some hospitals give these to patients beforehand, some immediately after treatment and others only if a patient has a problem. We like the idea of patients being encouraged to exercise in advance, building up the strength of the pelvic floor muscles prior to treatment.

We decided to approach Tena, the supplier of incontinence products. Their website (www.tena.co.uk) has good information about this subject and their description of the pelvic exercises has been followed successfully by a number of our members. The following article contains much information from Tena reproduced with their permission.

Unfortunately, after treatment for prostate cancer, either surgery or radiotherapy, some men find they don't have complete control over their bladder. This incontinence (the medical term for losing control of your bladder) covers a range of situations, from occasional dribbling or leaking of urine to complete loss of control.

What causes urinary problems?

Incontinence may be caused by

- Your cancer - for some men urinary problems may have been the cause of initial concerns leading to a diagnosis of cancer.
- Surgery
- Radiotherapy

Sometimes men have temporary incontinence after prostate surgery or radiotherapy. So the problem may get better with time. But you will still have to manage it in the meantime.

Permanent incontinence after radiotherapy is quite rare these days, but it can happen. It is more common to have problems passing urine because of a narrowing of the tube carrying urine from the bladder. Up to 1 in 12 men (8%) need a short operation to stretch this

narrowing after radiotherapy treatment for prostate cancer.

Permanent incontinence may happen after radical prostatectomy. It is thought that about 20% of men have minor long term problems with incontinence after this type of surgery. Whereas about 5% have more major long term incontinence problems.

Managing urinary incontinence and prostate cancer

Recently there has been a lot of progress in dealing with incontinence and there are many ways of managing the problem. Discuss any worries with your doctor or nurse. They may be able to refer you to a continence advisor at the hospital or in the community. The community continence advisor is usually a district nurse with specialist knowledge of incontinence problems who will be able to visit you at home.

There are also other organisations where you can also get helpful information (we have listed two at the end of this article).

The most commonly experienced type of bladder weakness by men is a continuous dripping. This is often caused by a swollen prostate impeding the passage of the urine when urinating. As a result the bladder is not completely emptied.

Obesity can also lead to urine loss as it places undue strain on the abdominal and pelvic muscles.

Smokers cough can also be an indirect cause of leaking as the coughing is frequent and often more violent. The greater risk of contracting the circulatory diseases that smoking causes and the subsequent prescription of diuretic medicines will also increase the risk of leaking.

Nerve damage, some medications, constipation or even an infection can also lead to bladder weakness.

The most common type of bladder weakness amongst men is *overflow*.

These are the different types of bladder problems that exist:

Overflow and drip

When your bladder does not empty completely urine builds up and in the end may begin to dribble out. An enlarged prostate can also impede the flow of urine leading to continuous dribbling.

Stress

Unexpected leaking when you laugh, cough, sneeze or do some kinds of physical training. Weakened pelvic floor muscles are the usual cause.

Urge

You experience a strong and sudden urge

to pass urine. The bladder tries to empty despite your efforts to restrain leaking.

There is a lack of co-ordination between impulses the brain gives to the bladder and what your bladder does.

Mixed symptoms

It is fairly common to have more than one type of symptom.

Training programme

The following exercises could help to improve the situation for some men with bladder weakness. Please talk to your doctor to find out what would be the best solution for you.

Choose the best position for you

Lie on your back in one of the following positions:



with your legs pulled up



with a cushion supporting your legs



with your legs resting on a chair

Relax your back, buttocks, abdomen and legs as much as possible. Put your hand on the lower half of your abdomen and make sure the muscles are not tensed. Breathe easily.

Find the right muscles

Now you should concentrate on locating the right muscles. Slowly contract the sphincter. Squeeze the muscles around the urinary tract - imagine that you need to go to the toilet but can't get to one. Continue squeezing upwards so that you feel the pelvic floor being sucked inward and upwards.

Repeat this contraction using moderate effort for about 2 seconds and then rest a further 2 seconds. Do this a number of times.

By consciously interrupting the flow of urine next time you visit the toilet, you will be able to ascertain whether or not

Incontinence problems

A Guide for Men

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you have found the right muscles. But remember this is not part of the training programme - just a way of checking.

Another way to check is by placing a finger between your scrotum and the anus and feeling the muscles contract.

The 'strength' contraction

When you are sure that you have located the right muscles, you can squeeze harder and longer. Squeeze as hard as you can for 5 seconds and then relax for 5 seconds. Repeat this 5 - 10 times.

The 'endurance' contraction

Do the same but hold for anything between 30 seconds and one minute. After a while you will feel your strength ebbing but don't worry! Still try to contract the muscles for up to one minute. Do this exercise just once a day.

The 'resistance' contraction

When you have mastered the 'strength' contraction, you are ready to try this combined with abdominal pressure. For example:



- Squeeze at the same time you do sit-ups
- Squeeze when you cough
- Squeeze and jump at the same time
- Squeeze when you're out running

Squeeze next time you lift something heavy

As this training programme only takes a few minutes of your time, it would be a good idea to repeat it as often as possible, preferably 6 - 8 times daily. No injuries will result; it's extremely beneficial and is also an excellent precautionary measure!

Other sources of help and information

The Continence Foundation offers support and advice through publications, their web site and a confidential helpline

THE NEED TO REDUCE PATIENT DISCOMFORT DURING TRANSRECTAL ULTRASONOGRAPHY-GUIDED PROSTATE BIOPSY: WHAT DO WE KNOW?

Copy of a letter to the BJU by NIGEL J. PARR and JOE PHILIP, Department of Urology, Wirral Trust Hospitals, Merseyside, UK

Dear Sir,

We read with interest the important review by Marco de Sio et al. [1], together with the results of a randomized prospective study carried out by Fink et al. [2] of transrectal lidocaine administered by both gel and suppository, in the same issue. However, we feel that readers should also be aware of two studies recently presented, both comparing i.v. sedation with the more commonly used periprostatic infiltration of local anaesthetic. Turgut et al. [3] found that visual analogue scale (VAS) scores of >4 (moderate to severe pain) occurred in 3% of those given i.v. sedation, 29% given periprostatic infiltration and 80% with neither. Sarvis et al. [4] reported, in their poster at the last AUA Annual Meeting, a trial of i.v. sedation vs periprostatic infiltration, but with no control arm. Their results are remarkably similar (for a VAS score of ≥ 5 , 4% of patients for i.v. sedation vs 23% for periprostatic infiltration). Furthermore, 44% of patients given i.v. sedation had no pain, compared to only 10% of those administered periprostatic infiltration. Overall satisfaction scores were also significantly better in the i.v. sedation group. In com-

parison, Fink et al. [2] reported a VAS score of ≥ 5 in 32% of their placebo arm, with 36% for lidocaine gel, 16% for lidocaine suppository 1 h before biopsy, and in none of those given a lidocaine suppository 2 h beforehand experiencing this magnitude of pain.

We have offered i.v. sedation to our patients undergoing biopsy for the last 3 years.

Furthermore, we have now inserted gold marker seeds transrectally under i.v. sedation in 47 patients as part of a radiotherapy trial, and using a 14 G needle (broader than normally used for biopsy). These patients have all previously had a biopsy in other hospitals throughout our region, mainly with the administration of periprostatic lignocaine. The radiation oncologist involved in this study informs us that when these patients are seen before radiotherapy, they frequently volunteer, without prompting, that the second procedure was much better than the biopsy in their local hospital.

The question must be asked whether it is reasonable in 2006, to inflict moderate/severe pain to such a significant proportion of patients undergoing biopsy, at a time when they are often particularly anxious and upset due to the possibility of harbouring a cancer? We photographed part of the poster by Sarvis et al. [4] and showed it during a talk to a local prostate support group attended by over 100 members, the vast majority having previously had a biopsy. These patients were unanimous that all men should be offered the choice of sedation for TRUS-guided biopsy. Perhaps we should now add to this the option of a lidocaine suppository administered well beforehand.

In summary, we think that the extent of pain associated with biopsy is often not fully appreciated. Patients are also not made adequately aware of this risk beforehand. Strategies are now available to limit significant pain to just a very small proportion of patients, and this should be discussed as part of informed consent.

Article references can be provided.

Helpline: 0845 345 0165

Web Site:

www.continence-foundation.org.uk

Email: continence-help@dial.pipex.com

Write to: *The Helpline Nurse at the Continence Foundation, 307 Hatton Square, 16 Baldwins Gardens, London EC1N 7RJ*

InContact offers support and advice, and represents the interests of people with continence problems.

Helpline: 0870 770 3246

Web Site: www.incontact.org

Email: info@incontact.org

Write to: *InContact
United House
North Road
London N7 9DP*

Reflection

EATING OUT ON A PROSTATE CANCER DIET: A GEM IN STOCKPORT

In the past we have focussed on survivors of PCS with the intention of covering features that will be uplifting or of value in combating prostate cancer. However, at the request of our members and readers, in future we will reflect on those members of and contributors to PCS who can no longer be with us.

During the past year we have lost a number, including

Laurie Denton, who chaired the Cheadle group for a time and was our charity's secretary for a number of years. Laurie was a big man with an enormous personality and sense of humour. He had boundless energy



and great compassion for his fellow man. Laurie was a "doer" who was first in line when an action needed to be taken. He was a regular attendee at PCS events, often with his son Dave.

Jim Glennon, was one of the founder members of the Wirral Group. He had been a golfer and enjoyed walks with his wife Mary. He was a great believer in the strength of the association and represented the Wirral group on the Executive Committee.

Walter Finlayson was one of only two black members of PCS, the other being his brother Hugh who has now returned to Jamaica. As you know, prostate cancer is more prevalent among the Afro-Caribbean race and there are fond memories of Walter, John Dwyer and myself at a very busy and colourful Afro-Caribbean Club in Moss Side attempting to raise awareness of this disease.

Derek Robinson was a regular attendee at both the Cheadle Group and the Christie meetings. He was one of those very well read patients who shared his knowledge with other members of his group.

Sandy Foot made a unique contribution to our charity. He was a prostate cancer patient who decided to help in the most appropriate way that he could. As an accountant, Sandy had been our auditor every year since we became a charity.

John Taylor was a member who despite travelling from Breadsall in Derbyshire, rarely missed a Christie meeting with his wife, Christine. Christine has stayed a member and is actively raising the subject of Prostate Cancer awareness in her home area.

Other men who I'm sorry to say I did not know well include **Derek Bell**, **Frank Carroll** and **Alan Terry**.

Inevitably there may be others of whom, for a variety of reasons, we are unaware - they may be members who keep a low profile, or we may simply not have been informed of their passing.

Nevertheless, our thoughts are with all those members who can no longer be with us, and of course, with their families.

Mike Lockett

How often have you been out wishing to enjoy a good meal only to discover that it was difficult to find one that suits your requirements? You want to avoid red meat or anything else containing animal fat, but have the impression that someone ordering a vegetarian meal necessarily requires lots of cheese, something you really do not want. Also, however much you may like fish, you feel that there should be a viable alternative. Does this sound familiar?

This has been my experience in the past and that is why I am so pleased to discover a Mediterranean restaurant in Stockport that includes the most delicious and nutritious dishes which happen to be suitable for someone on a prostate cancer diet, as well as offering a good variety to those who do not share your preferences. This place really deserves to be more widely known.

Rozafa is the name of the place (telephone number 0161 477 4849) next to the Stockport Arms on St Petersgate, through the white door and up a flight of stairs. It is a most friendly restaurant with a small staff who are dedicated to providing what I consider to be excellent food and service at modest prices. Also, the "house" wine is delicious. There is a lunchtime menu and if you go early in the evening, you may be offered a special value-for-money "early doors" menu, which has tempted me back many times over the last year. When some friends and I had a special celebration dinner party for 17 there recently, the staff provided all that we could have wished for to make it successful and memorable.

I believe, as I am sure many of you do, that a good diet is most important and I felt that I must share my experience with others on a similar diet.

Chris Cotton

Support Groups - Meeting dates and times

Bolton Support Group - the second Wednesday of every month from 2pm to 4pm at St Luke's Church, Chorley Old Road, Bolton.

Droylsden Support Group - the first Thursday of each month at 6pm at Droylsden Football Club, Market Street, Droylsden, M43 7AW.

Cheadle Hulme Support Group

The second Monday of each month at 1pm at the Hesketh Tavern, Hulme Hall Road, Cheadle Hulme. Just turn up on the day or call the PCS office first if you prefer. If you arrive early you can have lunch before the meeting!

Leighton support group, at Crewe, - approximately bi-monthly on Saturday morn-

ings at 10am. Next meeting scheduled for November 3rd.

North East Cheshire Please contact John Davies 01625 250257 or Robin Pritchard 01625 585753 for details

The North Staffs Support Group This group meets on the third Wednesday of every month from 6pm to 8pm at The Joiners Square Community Centre, Cor-

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Donations



Richard Lockett in the second part of the triathlon, the bike ride.

Last year, the PCS Chairman's son, Richard, competed in the Salford triathlon to raise funds for Prostate Cancer Support.

The triathlon consists of three events to be completed immediately, one after the other – a swim of 1500m, 40km cycle, and 10km run. The course that was used was the one established for the Commonwealth games in 2002 and which is now a regular event for the Triathlon World Cup.

The event was doubly significant for Richard because not only was he able to raise funds for prostate cancer (£1474, which was donated to PCS), but only two years previously he had undergone surgery on his neck that could have left him paralysed had it not been successful. The operation was a success and to celebrate the good news that he was fully fit, he took on the triathlon.

There were many spectators enjoying fine weather and a great day out.

One noticeable aspect was the many teams that were competing to raise awareness and money for charities, many of them containing TV celebrities and representing their TV programmes (Emmerdale, Coronation Street and BBC Newsreaders) as well as commercial and medical organisations, such as Leukemia Research and BUPA. The teams operate a relay and complete a half distance course. The first person swims 750m, the second rides 20km and the third runs 5km. For some charities there was more than one team, and this made the charity particularly noticeable.

Anyone interested in forming a PCS team (the more the merrier)?

Listed below are some donations received since our last publication, for which we are very grateful. This does not include recent donations which will be listed in our next issue.

	£
Ashworth Charitable Trust	2000
Buffaloes	1300
Christadelphian Samaritan fund	200
Daniel Thwaites Trust	650
Droylsden Support Group	
fundraising day	261
Ferguson Benevolent Fund	2500
Hoover Trust Fund	1250
Laspen Trust	250
Leighton Support Group	180
M Lakin	500
Mainwaring Probus Club	30
Manchester Guardian Charitable	
Trust	500
Manchester Historic Vehicle Club	34
MG B Promotions	165
Morrison Awareness Day	27
Pennington M	30
Rainford Trust	500
Richard Lockett -	
Triathlon Sponsorship	1474
Roger Vere Foundation	500
Stretford Rotary	250
The Childwick Trust	5000
Rotary Club of Eccles	300

There have also been some very generous individual donations from PCS Members amounting to - 308

Additionally under the banner of our charity, a number of individuals have raised funds for specific causes.

These include

Roy Fisher, who has raised money for the Clatterbridge Scanner appeal	1350
John Burston - Bolton	
Sponsored Cycling	150
Mike McIntyre - Bolton	195

Support Groups - Meeting dates and times

nes Street (off Leek Road), Stoke-on-Trent.

Oldham Support Group - the last Tuesday of each month at 6pm at the Pennine Lounge, The Bus Depot, Oldham. The Bus Depot is off Walshaw Street near to Mumps Roundabout. Cars can be parked on the staff car park.

Wirral & North Cheshire - the last

Saturday of each month (excl. summer break) at 10am at the Healthy Living Centre, Civic Hall, Civic Way, Ellesmere Port CH65 0AZ.

Lancaster Meetings of this brand new group will be held CancerCare, Slyne- dales, Slyne Road, Lancaster, LA2 6ST. Contact 01524 381820 for details.

PROSTATE CANCER SUPPORT

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

Phone: 0161-474-8222
Website: www.prostatecancersupport.org
Email: info@prostatecancersupport.org

We're on the Web!

www.prostatecancersupport.org

● Prostate Cancer -
Information and Support

helpline 0845 456 0678

Aims of Prostate Cancer Support

To provide help, support and information to men who have Prostate Cancer, and to their families and carers.

To give a voice to all those affected by Prostate Cancer by raising awareness and by making representation to appropriate bodies

-The public, Health professionals
and Government.

**European Prostate Cancer Awareness
day**

14th September 2007

Followed by

**Worldwide Prostate Cancer Awareness
week 17th—22nd September 2007**

Survey of Members Views

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response - yes, or don't know – only one dissenter!

Local support groups were seen to be effective at raising awareness, and the Wirral group was complimented on its (then) new leaflet. 22% said they would be happy to assist in promoting PCS to the medical profession. This is an area (local group awareness activity) that has seen significant development since the survey was conducted.

Section 5 Management of PCS

This section was about the effectiveness of the committee and of the development project that had been carried out over the previous two and a half years. 69% felt that the committee effectively managed PCS. 50% felt that the project had been very effective, but 44% didn't know. There were a number

of comments recognising the hard work that had been put in by committee members, but also a recognition that there was so much more to do! There was a promising number who said that they would be willing to be involved in PCS activities, but only 6% would consider membership of the executive committee.

We would like to thank all those who responded to the survey. It is very important for us to obtain your feedback. With this in mind, please feel free to comment at any time on any aspect of PCS through the office or with a Committee Member.

As before, we shall take notice of your comments and attempt to address those areas requiring attention.

Committee members and volunteers

At the Prostate Cancer Support AGM held earlier this year, a request was made for PCS members to consider putting themselves forward as volunteers or as members of the Executive Committee.

To ensure that the organisation stays democratic and always fairly represents the membership, all Committee members must resign each year, although they may stand for re-election. To ensure vitality in the function of each Office, Committee members should not (normally) hold the same Office for more than three years, after which they should stand down for a minimum period of one year.

Very importantly, we are always looking for volunteers to assist in PCS activities – awareness days, helpline volunteers, etc. – and would welcome hearing from any interested members.