

Prostate Matters

March 2006

Prostate Matters Issue 5.1

helpline 0845 456 0678

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Locally Advanced and Metastatic Prostate Cancers - is Taxotere man's Herceptin?

In the last 60 years there has been no major advance in the cure of locally advanced and metastatic prostate cancers; and yet these are potentially lethal tumours.

In contrast, cure rates for breast cancer have increased in the UK from 60% to near 80% over the last 20 years. Death rates from cervical cancer have fallen by 50% in a similar period of time, whilst improvements in adjuvant chemotherapy for

bowel malignancies have led to the prospect of a 10% to 20% improvement in survival prospects.

While Chemotherapy is used to treat many cancers, there seemed to be no benefit from this approach for prostate cancer patients until 1996, when clinical trials showed, for the first time, that chemotherapy might have a role to play. Mitoxantrone with low-dose steroids became the standard therapy for patients with progres-

sive prostate cancer, and this offered a chance of symptom control but no improvement in survival.

In the autumn of 2004, the conclusions of two publications in the New England Journal of Medicine changed the views of oncologists as to the benefits of chemotherapy in prostate cancer. The results described led very quickly to approvals from the US Food and Drugs Administration (FDA) for the use of Docetaxel in recurrent prostate cancer, and the granting of a licence by the European Medicines Agency (EMA).

This cause for optimism was dampened when in November 2005 the Scottish Medicines Consortium (SMC) announced that it would not recommend the use of Docetaxel (Taxotere) for men with advanced, hormone-resistant prostate cancer on cost grounds.

Fortunately following pressure from many quarters, the SMC has now confirmed that it will follow the final guidance of the National Institute for Health and Clinical Excellence (NICE) on the prescribing of this chemotherapy drug

What's it all about?

See page 11



John Dwyer and John Lancaster obviously finding something very funny—and this was only the beginning of the evening!

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.

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Our Christie talks are intended to cover many areas of interest for our members and patients. These include all forms of treatment, from the conventional and well tested surgery, radiotherapy and hormone treatment to newer treatments such as HIFU and Chemotherapy, and future treatments that are likely as a result of current day research.

We receive many requests to cover other subjects that are only touched on by our medical teams such as diet; or ignored totally such as holistic treatments and homeopathy.

As a result we invited Dr Valerie Hayhurst to come and talk to us at our October 2005 meeting. Dr Hayhurst is both a practising GP and a qualified practitioner in homeopathy at Liverpool's NHS Department of Homeopathy.

She told us that while training as a doctor in Edinburgh she worked in infectious diseases and saw how well homeopathy worked for HIV patients. Homeopathy is much bigger in Scotland than England and 25 per cent of Scottish GPs have completed foundation courses. She took a course in homeopathy before she had completed her GP training.

She explained that her father used to travel abroad on business and always used homeopathic remedies, so she had accepted the concept while still a child. Often people criticise homeopathy because of the lack of reproducible scientific evidence, but how do you know when you're a child that paracetamol helps a headache? Usually because somebody has told you! Then, when you have seen the effect of something, you use it. There are so many different uses for aspirin which weren't dreamt of when it was first developed but the effects of using it have been observed over the years.

As a homeopath in the NHS she is able to give 45 minutes at the first appointment and 15 minutes at follow-ups, allowing enough time to talk through the issue and to get to know the essence of the patient in order to give them a tailor-made remedy. Although a GP may know someone well they often feel hassled because of the next appointment.

Dr Hayhurst said that they have particular success with hay fever, eczema, premenstrual and menopausal symptoms, arthritis, cold sores and skin conditions in children and adults. She saw a boy whose hay fever was so bad that he had to stay inside and take antihistamines all summer. He took homeopathic remedies and by the

end of the summer he was out playing cricket.

Homeopathy is a useful tool which also works well with some problems which are difficult for GPs to deal with such as chronic fatigue, attention deficit hyperactivity disorder, depression, anxiety and arthritis. "I find it very satisfying."

What is Homeopathy?

Homeopathy is a therapeutic system. Its principles differ from those of conventional medicine, as does its approach to the patient and to the concept of ill health. However, it cannot replace all other forms of health care. It can be used as the treatment of first choice in a wide range of conditions and can be a useful addition, or "complement" in other situations, for example, to support good recovery after operations.

The concepts of disease and healing which are described in homeopathic books are quite similar to modern scientific concepts. Homeopathy emphasises the importance of treating individuals as individuals and of understanding the whole person as opposed to only understanding a single "diseased part".

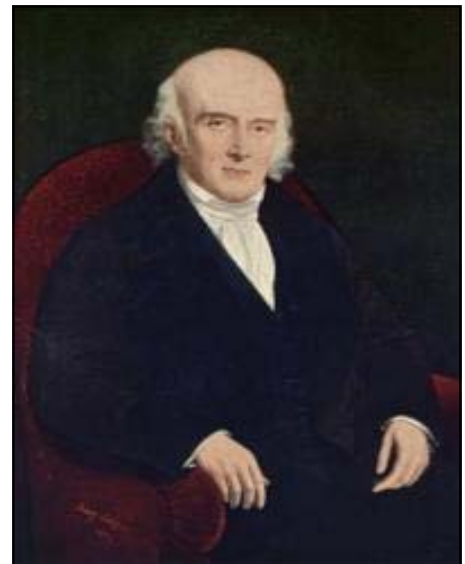
The body has many complex health-maintaining defensive mechanisms. The immune system is an essential part of this, but other factors also have a role to play. If these mechanisms fail, then we sustain damage or wounds which then have to be repaired. Homeopathy works by stimulating both the health-maintaining and the repair mechanisms.

Modern homeopathic doctors work in the same way as their conventional colleagues. History taking, examination and investigation are all important in establishing the diagnosis - in understanding just what is wrong. However, homeopathic doctors consider a wider range of aspects of the patient's condition - personality traits, physical features, the effects of a variety of environmental influences, patterns of disease within families, and family and social relationships.

Dr Samuel Hahnemann

Homeopathic medicine was first described by Dr Samuel Hahnemann (1755 - 1843). Hahnemann was a German physician who was dissatisfied with the medical therapies and theories of his day. Hahnemann was translating a scientific paper by William Cullen, a Scottish physician, on his theory of why Cinchona Bark, a source of quinine and a popular drug at the time, was successful in treating Malaria. Hahnemann found that he disagreed

entirely with the findings. In his youth, he had been personal physician to the Prince of Transylvania, a position which had entailed his travelling in a particular part of Hungary where Marsh Fever or Malaria had been rife. He had used the herb, Cinchona Bark, but his experience did not support the conclusions of the paper. He decided to carry out some experiments of his own. Firstly, he took a dose of the herb himself and he found that he devel-



Dr Samuel Hahnemann 1755 - 1843

oped all the symptoms of Malaria except Pyrexia (fever or increases in body temperature). He realised that the cure of the disease could cause the symptoms of the disease. He tried it on his family, friends and volunteers and they all developed the same sort of symptoms. He experimented with this one drug on many people and the majority of them told the same story.

Hahnemann's observations

1. "Like cures like"

This caused the development of the principle that a small amount of something which will create the symptoms of a disease in a healthy person will actually cure that disease. Hahnemann called this principle "Similia, similibus curentur" or "let likes be cured by likes".

Although this is quite the opposite of the way conventional doctors use drugs, there are some modern drugs which work on exactly this principle. Digoxin, for example, can both cause and cure heart irregularities.

2. The minimum effective dose

His second observation arose from his desire to minimise the harmful effects of the drugs which doctors were using. He

did this by repeatedly diluting and succussing (shaking) each medicine to reduce its potential to poison and cause harm. What surprised him in his use of these preparations was that the more stages of dilution and succussion the drug had gone through, the greater its potential to cure quickly and harmlessly.

This latter observation is still the most controversial one. How can a medicine be more effective in a greater dilution? Indeed, many homeopathic preparations have been subjected to so many stages of this process that it is highly unlikely that any single molecules of the original substance remain.

Current research is focusing on the ability of water to retain an imprint of substances which have been dissolved in it. Whatever the mechanism, there is a substantial growing body of evidence that homeopathy works, is safe, effective and cost-effective.

The place of homeopathy in clinical care

Homeopathy can be used to treat a wide range of conditions. It can help to repair any damage which the body has the potential to repair, and help restore the balances and mechanisms involved in recovery and health. It is widely used, for example, in conditions such as asthma, eczema and premenstrual syndrome. Despite the differences in approach, homeopathic and conventional treatments can work very well alongside each other. Consulting a homeopathically-trained conventional doctor allows the individual patient to

receive the best of both worlds, with the most effective treatments being tailored just for them.

Dr Hayhurst briefly covered some of the homeopathic remedies used for patients with prostate cancer. These included Conium, Sabal serrulata (saw palmetto berry), selenium, Sulphur and Thuja.

There was also some discussion about Iscador, which had been used previously, or at least considered for use, by some patients present. This is a treatment based on the principles of anthroposophy (Anthroposophic Medicine), developed by philosopher and spiritual scientist Rudolf Steiner, PhD (1861-1925); this medical system takes into account the spiritual and physical components of illness. A treatment regime may include herbal and homeopathic medicines as well as dietetics, art and movement therapies, massage and hydrotherapy. Iscador is an extract from European mistletoe and contains compounds called lectins and viscotoxins. Mistletoe preparations are used to stimulate the immune system, to kill cancer cells, and to help reduce tumour size. It may also help improve the quality of life and survival of some cancer patients, especially those using chemo and radiation, and may help reduce pain and side effects of these treatments. A typical treatment course can last several months to years. The doses are gradually increased and adjusted depending on the patient's general condition, sex, age, and type of cancer. Mistletoe is typically given by subcutaneous injection.

A number of the audience asked how they could be considered for Homeopathic treatment. Dr Hayhurst said that the first

port of call would be the GP who acts as 'gatekeeper' to the full range of treatments available to patients. It is therefore necessary, as with most other treatments, to ask a GP for a letter of referral. Referrals are subject to the service agreements the individual Primary Care Trust has with providers of NHS homeopathy. If your Primary Care Trust does not have a service agreement with a provider of homeopathy it may still be possible to access NHS homeopathic treatment through an arrangement known as OATS (out of area treatments).

Homeopathy has been available on the NHS since the Health Service first began in 1948.

There are five NHS homeopathic hospitals in the NHS and qualified homeopathic doctors work in many other settings such as community-based clinics, general and private practices.

According to a recent survey, nearly 40% of GP partnerships in England now provide access to some form of complementary therapy for their NHS patients. However, if you find you have to convince your doctor that homeopathy is right for you, don't let this put you off. Experience shows that those patients who do persevere in asking their GP for homeopathic treatment do get a referral.

The Department of Homeopathy in Liverpool is one of five NHS hospital centres in the UK which accepts patients on referral from GPs. British Homoeopathic Association, 0870 4443950;

www.truhomeopathy.org

Locally Advanced and Metastatic Prostate Cancers

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(Taxotere) for men with advanced hormone resistant prostate cancer, when it is published later this year (expected July 2006).

Unfortunately NICE reviews have become very lengthy, leading to unacceptable delays in the availability of treatment. Many hospitals are not giving treatment with Docetaxel as a result of the unavailability of the conclusions of the NICE review.

And yet NICE has made preliminary recommendations that Docetaxel (within its licensed indications) is recommended as a treatment option for those men with hormone-refractory metastatic prostate cancer that meet a

specific criteria (see criteria and notes at the end of the article).

These preliminary findings are positive and we welcome and look forward to them being confirmed in due course.

Unfortunately until that time too many men will still be subject to the same problem that recently faced the breast cancer patients with Herceptin (at the whim of the local trust), where an incomplete recommendation by NICE allows a decision to be taken on cost grounds.

Confirmation is urgently required from NICE to enable men to access Taxotere treatment on an equitable basis.

Selection criteria:

- Basically that men should be able to care for themselves and can carry out normal day to day activities.

Within the recommendation treatment with docetaxel should be stopped:

- at the completion of planned treatment up to 10 cycles,

- or if severe adverse events occur,

- or in the presence of progression of the disease.

Repeat treatment with Docetaxel following relapse after initial successful response is not recommended.

Personality - Eva Lomas

In the past we have featured articles on a number of men as our personalities. On this occasion we are delighted to be able to feature a lady who is a very active supporter of PSA NoE – Eva Lomas.



Eva and her husband Norman are members of the Bolton Support Group and will also be familiar faces to regular attendees of the Christie meetings.

Members who have been unable to attend the Christie meetings have often asked if we could provide a summary of the presentations. This is not as easy as you might think - many speakers do not have notes that can be passed on to us! At some point in the future Christie will have a recording facility, but this is not currently available. When she heard of our problem Eva offered to take shorthand notes - for someone without medical training this is an onerous task. She then types her notes and, after a little “doctoring” and approval by the speakers, they are included in *Prostate Matters*.

While being grateful for this assistance, we at PSA NoE were unaware of the many other activities in which Eva is involved!

Eva was born in Leigh and lived, until her marriage to Norman at the family home which was situated on land now incorporated into *Pennington Country Park*, the famous nature reserve. She was educated locally and began her working life as an administrator for a local firm of Wholesale Grocery Distributors.

At Bolton Palais she met Norman and

they married a few weeks before he began his National Service in the RAF. After his demob they moved to their own house in Over Hulton, midway between both sets of parents. They have a son, a daughter and a grandson.

Later Eva became an employee of a local Estate Agent and when the owner announced his retirement she bought the business. Before retiring she had expanded the agency and held office as National President of the *National Association of Estate Agents*. In this role she was a frequent commuter to its headquarters in Warwick, and a guest of the President of the *National Association of Realtors* at their 1994 Convention in Anaheim, California, where she met and spoke with the keynote speaker, President Bill Clinton. She is currently Chairman of the Association’s “College of Fellows”.

Worldwide travel and mixing with the powerful have not corrupted Eva’s sense of genuine service. Since 1981 she has been a member of Soroptimist International of *Leigh and District* holding the position of President in 1990. She also took on the role of Buildings Convenor of the Soroptimist Residential Club in London, when much restoration and refurbishment of this “listed Building” took place. Soroptimist International is a worldwide organisation for women in management and the professions, working through service projects to advance human rights and the status of women. Members are women of all ages, cultures and ethnic groups, who join their local clubs to give service to others. Each club identifies the needs of its community, then establishes specific projects to address those needs.

Eva is also a founder member of the Inner Wheel Club of Astley - Norman has been a member of Rotary for many years. Eva’s professional experience and well-judged contributions were welcomed at their early meetings as fledgling members became acquainted with the ways of Inner Wheel. The network of friendship established then has been extended by Eva at District meetings, at both Rotary and Inner Wheel Conferences and at Inner Wheel Conventions in Stockholm and Florence. For the year 2005-06 Eva is the District Chairman of the Inner Wheel District 128, which covers the Isle of Man with parts of Cheshire, Greater Manchester, Lancashire, Merseyside and West Yorkshire. As Chairman she has chosen

to raise funds for Macmillan Cancer Relief, our current sponsor.

Eva is clearly someone who takes action where she sees need, relates what she has accomplished rather than stating her intention, she has devoted many hours as a volunteer receptionist at Wigan and Leigh Hospice.

One may wonder that she had any time available to fit in hobbies, but many have been the delighted recipient of her exquisitely handcrafted cards and bookmarks.

Despite all of her achievements, Eva is a very unassuming lady. In fact much of the above only came to light because Norman



Eva and Norman starting the dancing at Eva’s 70th birthday.

proudly told the guests of her achievements at Eva’s seventieth birthday party!

Due to the extremely heavy work load that Eva currently has, we have not benefited from her assistance for the last two speakers. However, Eva hopes to be back

The Good, the bad and the Ugly

The Christie Meeting held on 17th December was very successful with an excellent buffet sponsored by Workplace Centres. This provided a great opportunity for interaction. Unfortunately, due to a failure in our recording system, we are unable on this occasion to provide a summary of the enjoyable talk by Alison Birtle entitled the good, the bad and the ugly!

Survey of Members Views

Accompanying this newsletter there is a survey asking members of PSA NoE for their views on the running of the association. If you haven't received a copy please contact the office!

Obviously we are only able to post the survey to registered members and recipients of the *Prostate Matters*, but if you would like to pass an opinion about PSA NoE and are not a member (perhaps you attend a support group but have chosen not to join the association) we would still like to hear from you. In this case please contact the office or visit our website where there is a copy that can be downloaded.

Our previous survey was conducted a little over two years ago and the committee believe that it is now time that we undertook another survey.

40% of the members responded to the last survey, which is a high percentage, as surveys go! However we would like to better this on this occasion, so we do ask in advance for you to reply so that you have a say in shaping PSA NoE.

Why do we conduct member surveys?

- While we are guided by the aims of the association, we recognise that our or-

Aims of PSA North of England

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.

ganisation has evolved.

- We wish to develop an organisation that meets the needs and expectations of patients and carers and is therefore valued by its members.

- We receive many comments from a small cross section of our members, but we would like to understand the views of a wider cross section.

- Also there are some members who don't become involved in the associations activities. That is fine – it is purely down to each person to benefit from PSA

NoE in the way that suits them most. Even so, we wonder if there are members who would like to become involved if the opportunities were available.

The previous survey

By way of introduction to this year's survey, and to show that your views do matter, we thought that it would be appropriate to remind members on the actions taken following the previous survey.

At that time views about the "Regional meetings" and "providing information to members" dominated the responses. The headline messages from that survey indicated the following:

1 Location of the Regional meetings is important. Christies was perceived to be the most appropriate location (by over 60% of responses), but we should not ignore other places (e.g. centre of Manchester) for those who travel a distance, or by public transport.

In the past two years we have held ten meetings at the Christie hospital on Saturday afternoons at regular intervals. Attendance varies a little depending on the subject matter, but generally they are well supported and feedback is good.

2 Christie facilities are generally good (theatre, sound, etc.) but we should look at making the meetings more time efficient by reviewing the need for refreshments at the start of a meeting. Nevertheless it is important that people should be

allowed time to mix at a mid meeting interval.

We have experimented with the timing and the latest approach is to have refreshments at the beginning of the meeting with plenty of time for members to mix prior to the formal presentation. The mid-meeting interval has been omitted in the interests of time (and cost).

3 The main thrust of the meetings (Medical presentations) was strongly supported, but other subjects, such as diet or

alternative treatments should be included from time to time.

We have covered a wide spectrum. Medical presentations have covered "understanding prostate cancer", "making the treatment choice", "patient experiences" these have been very well received by attendees. We have also covered treatment for advanced disease. Our presenters have visited us from all over the UK and even the USA. We have had presentations from researchers, drug manufacturers, dieticians and homeopathic practitioners.

4 Additional locations for local support group meetings were asked for by those members who were not located on the south side of Manchester. This was one of the aims of the Development Project put in place with the support of Macmillan Cancer Relief.

As a result we have helped to start new groups at Bolton, Ellesmere Port (for the Wirral and North Cheshire), Droylsden and Oldham. We have had our first three meetings in Stoke-on-Trent and are still talking to medical staff in the Preston/Cumbria area. Getting a new group off the ground is a significant task, but we are pleased with the progress in this area. Nevertheless, we would like to achieve more. Sadly, we have failed to develop the Trafford Group, but will be taking a fresh look at this in the near future.

5 In general it was felt that members' contact details should be made available to the wider membership, but only if individual members approved

Despite this comment, we have not circulated a list of contacts. In response to various specific requirements we have passed contact details on, but only after first obtaining specific approval from the relevant individuals.

6 Communication with the members and the provision of useful information (e.g. about the disease; diet; travel insurance) was of paramount importance. In excess of 80% of responses indicated that the reestablishment of a newsletter would be welcome.

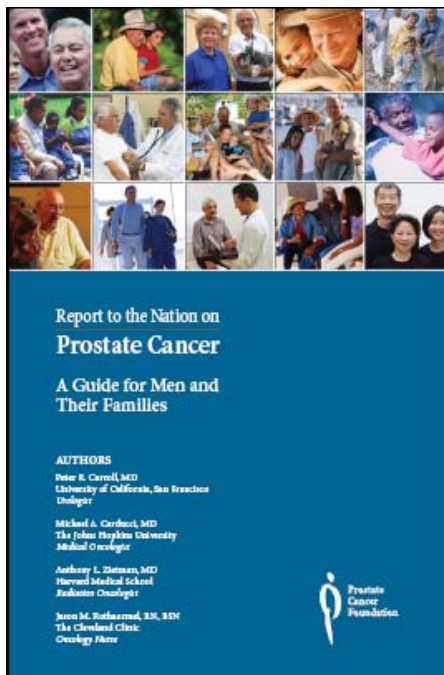
We believe that we have made significant progress in this area. The UsTOO

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Report to the Nation on Prostate Cancer 2005

A Guide for Men and Their Families

from The Prostate Cancer Foundation



In our last edition of *Prostate Matters* we provided information and a summary of the Nutrition and Prostate Cancer Guide from the American organisation “Prostate Cancer Foundation” (PCF).

Since then another document has been published by this same organisation which is very impressive. The “Report to the Nation on Prostate Cancer: A Guide for Men and Their Families”. Although this report has been produced in the USA and obviously draws on information, statistics and experiences of prostate cancer in that country, it is totally appropriate to patients and families in the UK.

Receiving a diagnosis of prostate cancer typically raises numerous concerns and questions about how to best treat the disease and how it will impact the future. Can I be cured? What is my prognosis? How will the treatment that I choose affect my lifestyle? What questions should I be sure to ask my doctors? How do I make treatment choices for a disease I know little about? Every day, hundreds of men are diagnosed with prostate cancer, and they and their families start looking for answers to complex questions such as these.

In preparing this guide the goal has been to arm you with as much relevant information as possible about prostate cancer and its treatments so you can work with

your doctors to choose the path that’s right for you. In doing so a balance has been achieved between being too comprehensive (such that only a few would be interested in reading it) and too brief (such that the guide did not explore the subtle differences between certain treatment options). As a result the guide does its best to highlight the key issues that you’ll face over the years, to focus on how the results of tests or scans might affect the way your cancer is managed, and to emphasize the importance of working together with all members of your health care team at every step of the way.

There can be many stages to prostate cancer. Fortunately, there are a variety of treatment options at every stage, but new decisions about each option will be required at every step along the way. Because different therapies are offered by different specialists, the guide encourages you to discuss your situation with a team of specialists, including a urologist, a radiation oncologist, and a medical oncologist with whom you can discuss the different treatment options and find the path that’s right for you.

The authors have divided this guide into three sections (see the index accompanying this article), each representing a different stage of disease progression, and have included a set of tear-out sheets and wallet-sized cards for each stage that you can carry with you, summarizing key points to consider and questions to ask your doctors. The final section gives you an opportunity to look ahead to the future, to see what the new research is focusing on, and to learn about whether enrolling in clinical trials and joining in the fight against prostate cancer might be right for you.

It is our hope that this Guide will enable you to hold meaningful, regular dialogues with all of the members of your health care team - the doctors, nurses, and pharmacists - to find the treatment path that’s

right for you ensuring that you and your fellow prostate cancer survivors will live longer and better lives.

If you or someone you love has been diagnosed with prostate cancer and would like to receive more detailed information about the available treatment options, you can download a copy of the guide from the PCF website www.prostatecancerfoundation.org.

Alternatively a free copy can be ordered from PCF, but outside of the USA a \$10 dollar shipping charge is made for each

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Prostate cancer action plan urged

Patients with prostate cancer, which kills 10,000 men in England every year, are treated unfairly and are seen as a low priority, MPs have said.

The government has been urged to improve services across the NHS by the House of Commons Committee of Public Accounts.

MPs also said that while there had been improvements, many patients in England



Ministers acknowledged improvements were needed

with suspected cancer were still waiting too long to see a specialist.

Report to the Nation on Prostate Cancer 2005

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copy. Therefore to make this document more easily available to our members, PSA NoE will be obtaining a large quantity direct from PCF which will enable us to achieve an economy of scale on shipping costs.

These will then be made available to members for just the UK postage charge.

The Prostate Cancer Foundation, which is based in California, claims to be the world's largest philanthropic source of support for prostate cancer research. Founded in 1993, the PCF has raised more than \$230 million and provided funding for prostate cancer research to more than 1200 researchers at 100 institutions worldwide.

Ministers said work was being done to "maintain the momentum of improvement".

Committee chairman Edward Leigh MP said: "Prostate cancer... is regarded as a lower priority than other common cancers when it comes to the provision of specialist care.

"The inequitable treatment of this group of NHS patients is entirely unacceptable."

The committee urged the government's cancer tsar (Professor Mike Richards) to publish an in-depth report on the standard of prostate services in England and the reasons for any deficiencies.

Action plans for improvements should be set in motion where there are problems, MPs added.

Sir Nigel Crisp KCB, permanent secretary at the Department of Health and Chief Executive of the NHS (recently resigned) denied prostate cancer was a lower government priority, saying it was just that NHS guidance came at a later time.

"We are currently working very hard towards establishing specialist teams for prostate cancer, each with a nurse specialist to provide the care and support that people need."

Waiting times

The committee was responding to National Audit Office research on progress in cancer services between 1999 and 2004, which also found 40% of cancer patients waited more than two weeks to see a specialist.

The public accounts committee said waits should be no more than two weeks and that GPs needed to improve their ability to identify patients with cancer symptoms.

MPs also singled out:

- The uneven spread of palliative care beds
- The lack of information given to patients on drugs' side-effects and pain linked to their condition.
- The lack of information on financial benefits on offer to cancer patients

A spokesman for cancer support charity

Macmillan Cancer Relief said the officials must ensure every patient gets specialist benefits advice.

'Momentum'

"The government must address these issues by producing a new National Cancer Plan which goes beyond tackling waiting lists and death rates," the spokesman added.

The calls that we receive at the PSA NoE helpline (and the concerns expressed by

"We are currently working very hard towards establishing specialist teams for prostate cancer"

Department of Health

some patients at support meetings) indicate that the treatment of prostate cancer patients is very varied. Many are worried about the length of time they have to wait for their diagnosis and treatment, or the fact that they haven't been given enough information. The best can be very good the worst is appalling.

The committee has identified a major problem and we urge the government to act quickly.

Health Minister Rosie Winterton said the report acknowledged improvements in services between 2000 and 2004.

"More lives are being saved ... death rates have fallen by 14% since 1996"

*Rosie Winterton
Health Minister*

She said patients were seeing the benefits of more staff, modern equipment and shorter waiting times.

"More lives are being saved as a result - death rates have fallen by 14% since 1996.

"The report also recognises that there is more work to be done. We acknowledge this and have put actions in place to maintain the momentum of improvement."

If you feel that prostate cancer is receiving a lower priority than other common cancers, we urge you to write to your MP and express your concerns at the inequality that exists.

Wirral & North Cheshire Group AGM launches £15,000 campaign at its AGM

article by Brian Webster



The photo shows distinguished guests and the groups co-chairmen (standing). It was the Group's first AGM having been formed on 01/02/05.

The Wirral & North Cheshire Prostate Cancer support group met at the Healthy Living Centre, Ellesmere Port on Saturday morning 28/01/06 from 10.00 am to 12 noon. About 70 members attended and our guests were the Lord Mayor and Mayoress of EllesmerePort, Andrew Miller MP, Dr I.Syndikus, Consultant Oncologist at Clatterbridge Hospital, Mr Ashdown and his wife, from the Berwick Masonic Lodge and Mike Lockett from PSA North of England.

At the meeting our new publicity leaflet was officially launched into the public domain. Apart from the leaflet giving details of our Support Group, it is also intended to raise awareness among

men to offer themselves for routine screening for prostate cancer. The aim is for our leaflet to be available throughout the area from hospitals, doctors' surgeries and other channels such as Public Libraries etc.

The primary aim of our Group is to give support to fellow prostate cancer sufferers and their carers, but a further aim is to raise money when we can for the Hospitals, for equipment they cannot obtain from the NHS. To this end, at our meeting we officially launched our campaign to raise £15,000 for some equipment required by the new Brachytherapy and Cryo surgery unit which opened at Clatterbridge Hospital in February 2005. In this respect, it was extremely

pleasing to receive £300 from Mr Ashdown as a donation from the Berwick Masonic lodge and also to receive a £50 personal donation from Mr Andrew Miller.

Dr Syndikus addressed the meeting explaining in some detail the specific nature of the equipment required by Clatterbridge and both Andrew Miller and the Lord Mayor addressed the meeting with considerable words of encouragement to us and wished us well in our future endeavours.

As a Group we also intend, whenever it is possible, to lobby the powers that be to start a screening programme for men to test for prostate cancer. It is a fact that despite the number of prostate cancer cases diagnosed annually being not that far short of the number of breast cancer cases, the financial resources put into prostate cancer by Government, falls well below the resources put into breast cancer screening and treatments. Obviously we would not like to detract from resources for the ladies but we would like to see some broad equivalence for men given the almost equivalent prevalence of both diseases.

The meeting concluded with refreshments and a raffle which was well received, from which the Group made £163, prizes having been donated by the Committee.

Brian Webster--Treasurer for and on behalf of the PSA North of England Wirral and North Cheshire Support Group.

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 and also the fourth Wednesday of each month at 7pm at the Doffcocker Inn, Chorley Old Road, Bolton, BL1 5QE..

Droylsden Support Group - the first Thursday of each month at 6pm at Droyls-

den Football Club, Market Street, Droylsden, M43 7AW.

Leighton support group, at Crewe, - approximately bi-monthly on Saturday mornings at 10am. Meetings scheduled include May 6th, July 8th, Sept 2nd and Nov 4th.

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.

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

Wirral & North Cheshire - the last Saturday of each month (excl. summer break) at 10am at the Healthy Living

The Federation of Prostate Cancer Support Organisations - FPCSO

With regard to health, it is often said that men are too quiet about health issues and don't influence decisions taken at national government level or in the NHS. As a result we know that a disease such as prostate cancer is a "poor cousin" when compared to many other cancers (witness the report on page 7 of this issue).

There are many patient-led support groups around the country (a relatively recent development) which provide excellent local services to prostate cancer patients and their

carers, but there has been no central point to develop a patient-led voice that is representative of the wider community of prostate cancer patients and carers.

The "Prostate Cancer Support Federation" seeks to remedy this omission by establishing a forum for patient-led charities, from different regions across the country. This will facilitate co-ordination whilst allowing complete independence for member support groups. Most importantly, it will generate a national patient-led body from which patients speak for patients.

The Federation is already established as a non-registered charity but will be launched officially during the spring of 2006.

It has been helped and inspired by other organisations such as "Europa Uomo" (the European Coalition against Prostate Cancer) and "UsToo" in North America – an objective of both these organisations is to

increase awareness of prostate cancer. The Federation will provide a national interface to both these organisations as well as to health professional bodies.

The first example of a tangible outcome of the Federation is the Prostate Passport, which was originally developed at the request of Europa Uomo – its purpose is to serve as a memory support for patients as well as for the treating doctor. There is a copy included with this issue of *Prostate Matters*.



Patients often express concern that they feel they have to make the treatment decision when ill equipped to do so! When provided with so many different choices, and sometimes at so many stages of treatment, it is often difficult to know the kind of questions to ask doctors. The Prostate Passport contains a list of questions that you may feel you want to ask your doctors. The list is comprehensive and you will not want to ask all of these, so please be selective.

We trust that you will find the passport useful, and we would be very pleased to receive your views (and those of your consultants) on the value of the document. Additionally, we would be interested in any comments concerning possible future issues of the passport.

Further developments will be communicated to our members directly over the next few months, and we will report on progress in *Prostate Matters*.

Support Groups - Meeting dates and times

Centre, Civic Hall, Civic Way, Ellesmere Port CH65 0AZ.

Cheadle Hulme Support Group

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

Stoke-on-Trent Support Group

This group is in its formative stage and as such hasn't settled to a regular meeting night. To date there have been three meetings each held at 6pm at the University Hospital of North Staffs about the middle of a month. Please check with the PSA NoE office for the next meeting date.

Poet's Corner!

We are delighted to print contributions from readers in *Prostate Matters*, as we see this as "your" newsletter!

Recently one of our members and readers sent us a poem that he had written while receiving radiation therapy. This got us thinking!

Poetry is recognised for its therapeutic value to the creator, and in some cases can benefit the reader through the offering of vicarious emotions, not the least of which it can sometimes result in a good laugh! So, please send us your contributions. If the response is significant, we thought that we might even introduce a prize for best entry on an annual basis.

Prostate Cancer Beam Irradiation Treatment

I was treated at Clatterbridge hospital over 8 weeks recently & wrote the following poem in appreciation of the Radiotherapists:-

"The Beam Team"

"Do just what the doctor says,
Shape a beam of hard X-rays,
These you carefully locate
O'er the poorly bad prostate.
No machine or system slack
Can arrest your beam attack,
Over two plus thirty days
Reach the target dose in G-rays,
O'er all two thousand miles
Greeted by your constant smiles".

I hope you like it!

Dr Michael Madden
29/11/2005

A Patients experience of HIFU salvage treatment

Chris Cotton

High Intensity Focused Ultrasound surgery (HIFU) for prostate cancer was first made available to suitable patients in the UK in 2004, following developments in Europe, especially the pioneering work in Lyons. Many PSA N of E members may remember the most illuminating talk given in June 2004 at the Christie Hospital by Stephen Brown, consultant urologist at Stepping Hill Hospital, the first in the UK to administer HIFU to prostate cancer patients. Copies of the summary of that talk, as reported in the September 2004 edition of "Prostate Matters", are still available to members by telephoning the office on 0161 474 8222 or by visiting the website at

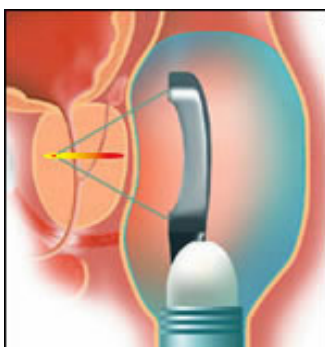
www.prostatecancersupport.org.

There is a reference in the summary notes to the application of HIFU to patients who have local recurrence after external radiotherapy ("salvage" treatment). Suitable circumstances for this to be tested in the UK arose last April, when two patients, including me, were given this opportunity as a part of a cancer research exercise.

This is a very exciting development because it involves a radical approach where tissue already affected by radical radiotherapy is involved. As successive increases in my PSA readings over many months had indicated the likelihood of cancer recurrence and as HIFU was considered to be a possibility, an isotopic bone scan, x-ray tests and MR scans were necessary in order to determine that there was no clear evidence of metastases (secondary tumours). A prostate biopsy was then performed, leading to a positive result. Fortunately, I was found to be a suitable subject for the project.

The operation for both my fellow patient and myself took place in April at Stepping Hill, following liaison with the team at Caen, from where Prof. Henri Bensadoun

came to work with the Stockport team for that occasion. An element of trans-urethral resection of the prostate preceded the HIFU in order to minimise the risk of complications and to maximise the effectiveness of the HIFU. In brief, the latter is administered by placing into the rectum a probe which emits short bursts of convergent beam high intensity ultrasound that pass through the front wall of the rectum to reach focal points in the prostate, creating, on each occasion, a sudden temporary increase in temperature.



This is repeated for each of the many focal points in order to destroy a volume including the tumour. As expected under the circumstances of tumour recurrence, my operation took approximately four hours, a longer time than that for some HIFU operations. The drainage of debris continued after the operation by means of a urinary catheter for a few days and thereafter "the natural way". Fortunately, subsequent re-catheterisation was not necessary for me.

As a "salvage" patient I was so pleased to be offered this opportunity that I was prepared to accept that some of the after-effects might be more pronounced than those experienced by certain other patients. Although the short-term effects were unpleasant, as expected, they proved to be manageable and I felt that I had been

very well briefed. For the benefit of other potential patients, it has been suggested that I go into some detail about these effects.

Understandably, the administration of a general anaesthetic for about four hours involved some time to recover from tiredness, minor forgetfulness etc. Urinary difficulties included initial pain and discomfort arising from swollen tissue in and around the urethra, also an element of difficulty with urinary control (minor incontinence). These were much improved after 6 weeks. As the surgery was administered to radiotherapy-damaged tissue, the passing of blood continued for a longer period than would otherwise be anticipated; 5 weeks in total, becoming more intermittent after 4. An intestinal problem (partly related to antibiotics) improved within two weeks. As expected, damage to the nerves which run alongside the prostate can have a serious effect on potency, especially for "salvage" patients.

The procedure is less surgically invasive than radical prostatectomy, but, as explained in the available HIFU literature, some of the long-term effects on the nerves may be comparable. As these vary from patient to patient and only time will tell, I far prefer to emphasise the fact that I am delighted to be generally quite fit and active, not to mention that I had the unmitigated pleasure of returning to full-time work only two months after the operation!

If you are concerned about HIFU and wish to discuss it with me, please contact PSA North of England by telephoning 0161 474 8222.

Chris Cotton

THE GREAT NORTH RUN

by Dave Denton

Well, what can I say about my Great North Run experience. Six months of hard training 3 times a week. I am not a runner, this half marathon (13miles) is the furthest I have run in my life.

Sun 18 September THE BIG DAY in Newcastle.

It all began at 5.30am that morning. I left my accommodation to take the car to the

finish area. From there I returned by train to Newcastle and the start area. What a site!

50,000 people all waiting to run. Chatting with everyone, but before you know it you are off. It takes 15mins to cross the start line and my journey of 13miles begins.

Everything went well, no cramp or pulled

muscles, but the mass of people made it difficult to run at my pace.

The whole route was lined with people cheering, especially the last two miles to the finish, where they were twelve deep on both sides of the road. It was very motivating!

Before you know it you are at the finish and all that training for the last six

John & Julia's 60th!

It's hard to believe it looking at them, but those Lancasters celebrated their joint 60th birthdays at the Lowry Hotel in Manchester during January. This was a surprise party organised by their children John Paul, Clare and Anna.

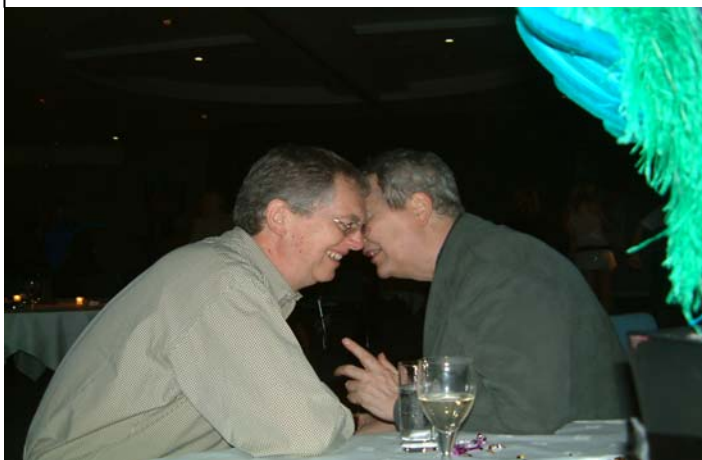
During the evening many people paid tribute to John and Julia recounting stories of their past. PSA NoE members and other patients would want to express their own tribute to John, who has been an inspiration and a great help to so many, and would want to express their best wishes to John and Julia for the future.

John's knowledge of this disease is second to none among patients.

John was diagnosed with advanced prostate cancer when he was 49 years of age and was given a very poor prognosis. He always demonstrates great determination;



John and Julia with their family Clare, John Paul and Anna.



John Lancaster and Mike Lockett photographed at John's 60th!

Captions to the office please.

an immense understanding of this disease; perseverance and a refusal to give in. Additionally, John would be the first to say that the love and support of his family have ensured that they, and we, were able to celebrate John and Julia's 60th in such grand style.

THE GREAT NORTH RUN

continued from page 10

months has paid off.

Into the finish area, collect my medal and collapse.

I understand the man that won the race did so in a New World record time of 59 min 5 sec. If he wants any tips or advice he only has to call me!!!!!!!!!!!!!!

It was a memorable day, very satisfying. I would recommend it to anyone. Do not be fooled though it is also very hard work!!!!!!!!!!!!!! Well I did it.

If anyone would like a challenge this year's race is on 1/10/06. I will not be there!!!!!!!!!!!!

Time 2 hours and 6 minutes,

Position 12,270

Congratulations Dave and many thanks for the £550 which you donated to PSA NoE !

Donations

Some recent donations, for which we are very grateful, are:

A J Burton	250
Brian Wilson Charitable Trust	200
D. Lennie	50
Dave Denton	550
David & Frederic Barclay	1000
Earnest Mee	200
Kennedy Leigh	250
Leeds Building Society	500
Leighton Support Group	400
Manchester Historic Vehicles	100
Marple Ring o'Bells Quiz Nights	300
Mary Webb Trust	250
Maxton G Beesley	165
Menorah Synagogue	200
Miller Beckett & J	500
Mr & Mrs K Murgatroyd	200
Oldham United Charity	300
Reuben Bros Foundation	200
Searchlight	25
Shell global Solutions	250
Sir Jules Thorn Charitable Trust	500
Souter Charitable Trust	1000
St Helen's Rotary	250
Tony Burling	100
West Derby Wastelands	500
Wirral and North Cheshire Group	250

There have also been some very generous donations from PSA Members which collectively amount to - 1056

Sadly, since our last newsletter, we have lost a small number of our members to this disease.

These include Wilfred Ball and John Taylor. Friends and relatives of Wilf and John have donated in excess of £500 to PSA NoE in their memory.

TOMBOLA

At a number of events Julia Lancaster runs a tombola to raise funds for PSA NoE. If any reader would care to donate a prize would they please contact Julia through the office (0161 474 8222).

PSA North of England

PSA North of England
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 PSA North of England

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.

Next Regional Meeting at Christie Hospital

We are aiming at the 27th May 2006

Subject to be announced

Tea and coffee at 1pm.

Survey of Members Views

continued from page 5

newsletter is circulated to all members on a monthly basis. *Prostate Matters* the PSA North of England Newsletter is circulated at regular intervals (we are aiming at four times a year). The office receives regular calls from people asking for information about both the disease and associated subjects such as insurance cover, to which we are able to respond! Many members have furnished us with their email addresses, and occasionally we communicate via this means to save cost, or when a rapid response may be required.

7 Although only a quarter of the (registered) membership had personal experience of the Helpline service, it was stated to be invaluable for those who had required help and in particular for newly diagnosed patients.

This is still in operation, although we will be reviewing the system in the near future. We have also called on a wider number of members than was previously the case (helped by the establishment of local contacts through the support groups).

8 There was an encouraging number of people who said that they would help in a number of areas, and this was to be followed up by the committee.

Some of this additional help has been forthcoming and it has been good to see a number of new faces at events. Even so help is needed from far more people to share the load.

We hope to have the results of this year's survey available by the end of April.

Committee members and volunteers

At the PSA North of England AGM held later this year a request will be made for PSA NoE 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.

Also, the committee are always looking for volunteers to assist in the association activities – awareness days, helpline volunteers, etc. – and would welcome hearing from any interested members.