PSA North of England

Prostate Matters

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FOCUS ON SUPPORT GROUPS

One of the many activities in which PSA North of England becomes involved is the establishment and running of Self Help support groups.

Not all patients and their families and carers seek, or choose to attend these. Many people think that they would find them embarrassing or an imposition, or that attendance at a group would keep prostate cancer at the forefront of their thoughts, when they would prefer to put it at the back of their minds. That's fine!

For others, the exchange of information and experiences, and the freedom to talk about ones concerns and issues to other people who understand totally their feelings and emotions is an invaluable part of their resistance to this disease.

Some feel that it is an opportunity, having experienced prostate cancer, to help others!

For many patients who are living with prostate cancer, it is necessary to feel that one is fighting this enemy. Not just receiving treatment, but being proactive against this disease. To do this many gain an understanding that is almost as strong as their doctors and specialist consultants. To reach this stage some patients carry out a tremendous amount of research through the internet or from medical documents and/or conferences. In the best of all worlds, this is done with ones own medical team; with ones family and with fellow PC survivors in the context of support groups and other forums.

From a personal viewpoint I can hardly believe that contracting prostate cancer could have opened up such a significant and interesting new chapter in my life and that I would gain so many new friends through the many support groups that I visit and the people that I have met through PSA North of England.

In this issue of *Prostate Matters* we focus on the support group. We provide coverage of those currently in existence in our region and mention one or two in other areas, which you may wish to be conscious of should you have friends in other parts of the country.

Mike Lockett.

Macmillan/PSA North of England Development Coordinator

CHOOSING THE MOST APPROPRIATE TREATMENT FOR YOUR PROSTATE CANCER!

In December 2004 Dr Nigel Parr addressed an audience of PSA North of England members along with other guests and visitors at the last Christie meeting of the year.

This was the first visit of Dr Parr to a PSA North of England meeting and there were many who were looking forward to his talk, which was reflected in a strong audience despite the date being so close to Christmas.

Many of our members on the Wirral had spoken very highly of both Dr Parr and the high level of treatment that they had received from the two hospitals that many attended - Arrowe Park and Clatterbridge. Those readers who received our first edition of *Prostate Matters* may remember the article about the efforts of Dr Parr and others to bring Brachytherapy and Cryotherapy to Clatterbridge.

A summary of Dr Parr's talk starts on page 2.

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

It affects men from all walks of life and often goes unnoticed in the early stages.

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

CHOOSING THE MOST APPROPRIATE TREATMENT FOR YOUR PROSTATE CANCER! - The Christie talk by Dr Nigel Parr

The purpose of the talk was to highlight the choices currently available in the treatment of Prostate Cancer.

Dr Parr started by setting the scene for Prostate Cancer patients. He stated that patients should not bear this disease or the decisions that have to be made alone.

There are many alternate routes to be taken and in order to choose the most appropriate treatment of YOUR P.C. you need:-

- A Urologist who will stand up and fight for you.
- An Oncologist just behind.
- A friendly Oncology Nurse Specialist.
- Family and friends.
- Information that is both comprehensive and understandable.
- Time to think about it.

The first choice should occur at Biopsy! It is not unreasonable for a patient to request some kind of sedation whilst the biopsy takes place, but it is unusual for more than 1 in 10 patients in the North West to have this offered to them as a choice. The choices are:-

- No anaesthesia - often very painful.
- With rectal or sublingual analgesia.
- With injection of local anaesthesia into the prostate.
- IV sedation or Entonox - which requires an anaesthetist.

The next choice is probably the most demanding choice of all – that is the treatment. This is clearly influenced by the stage of the tumour, principally - localised; locally advanced or metastatic tumour.

Firstly the choice of treatment for localised tumours: - What influences the Consultant (be he Surgeon or Oncologist)? Obviously his own experience is a major factor, but his experience will be determined by his training. And during training little, or no time will have been given to the other's specialty. Even with this bias, doctors will refrain from making a specific recommendation, as there will be a variety of factors to be taken into account - not all medical. Patients present at varying ages, with a variety of presenting features, including their own personal preferences.

To assist patients and their doctors to make a sensible choice of treatment a Consensus Conference was arranged in Liverpool in 2002.

Four expert speakers addressed 67 delegates (including urologists, oncologists, nurses, patient representatives and physicists) on their specific area of interest and how each of 11 additional presenting features might influence their management of the disease.

Following debate the delegates voted on which treatment they would opt for if they had an early tumour. Similarly they then considered patients who had already had initial treatment which had failed, and looked at their treatment options.

The Outcome from the conference is represented in the diagrams below (figs. 1 &2).

The conclusion was that the full collection of all 4 treatment options is necessary in order to offer the *BEST INDIVIDUAL OPTION* and to allow for patient preference.

All of these factors need to be taken into account by your team – and your team is the group mentioned at the beginning of the talk!

Dr Parr then went on to talk more about Cryotherapy, which was likely to be the least well known treatment for the audience present.

Cryotherapy:

As long ago as 2500BC Egyptians and Greeks used cold water to relieve pain. Forty years ago in 1964 the first human prostate was frozen. Hopefully the first Wirral patients will be treated at the end of January/early February 2005 at the minimally invasive prostate cancer unit at Clatterbridge.

Ultrasound scanning allows the probes, which are now much thinner; to be placed accurately through a grid and the actual iceball target can be conformed to the shape of the prostate.

The tissue is frozen, then warmed up and this process is repeated several times.

Water begins to freeze at 0 degrees C. From -7 to -10 degrees the fluid around the cells starts to freeze. At -15 degrees ice crystals start to form in the cells themselves and at - 40 degrees all metabolic processes just discontinue. This causes damage to the tumour cells and flow of blood.

The results of salvage cryotherapy, in patients who had failed to fully respond to external radiotherapy, showed that over

OUTCOME	MODERATE or SEVERE OUTFLOW OBSTRUCTIOMN	LARGE GLAND	WISHES TO AVOID BLOOD TRANSFUSION	WISHES TO RETAIN POTENCY IF POSSIBLE	HIGH GRADE TUMOUR	HIGH RISK CAPSULAR PENETRATION	PREVIOUS DVT OR ON ANTICOAGULANTS	AP R ESECTION or OTHER RECTAL DISEASE	BILATERAL HIP PROSTHESES	LIMITED HIP FLEXION	GENERALLY LESS FIT MEDICALLY
EXTERNAL BEAM RADIOTHERAPY (EBR)	O	+	+	O	O ★	O ★	+	O	-	+	+
RADICAL PROSTATECTOMY (RP)	+	+	-	+/o	+	-	+	+	+	+	-
BRACHYTHERAPY (BRA)	-	-	+	+/o	O △	-	+	-	+	O	+
CRYOTHERAPY (CRY)	O	-	+	-	+	+	+	-	+	O	+

+ = RECOMMENDED OPTION O = POSSIBLE TREATMENT - = AVOID

★ = POSSIBLY IN CONJUNCTION WITH HORMONE MANIPULATION

△ = IN CONJUNCTION WITH EXTERNAL BEAM RADIOTHERAPY

Fig. 1

MANAGEMENT OF RECURENCE / INITIAL TREATMENT	EBR	RP	BRA	CRY
EBR	-	+	-	+
RP	o/-	-	o/-	-
BRA	o/-	-	-	-
CRY	+	o	+	+
HORMONE MANIPULATION	+	+	+	+
OBSERVATION	+	+	+	+

Fig. 2

25% of these patients had tumours which were outside the prostate and some had very advanced local disease. After cryotherapy there was a 7 year disease free survival. There was a 77% success rate in patients with a T1 or T2 disease and even in patients with T3 and T4, there was a 50% salvage by cryotherapy.

This is a day case procedure and involves an overnight stay, but needs a catheter for two or three weeks. 4.3% experience incontinence afterwards and almost all patients who undergo cryotherapy will be impotent afterwards.

Conclusions:

Modern cryotherapy is a minimally invasive treatment which *should be offered* but *carefully audited* in patients with high risk tumours and those with relapse after external beam radiotherapy or brachytherapy.

Do I need treatment?

The question most frequently asked by people with early P.C. is: - Do I really need this treatment?

The most useful data in this decision making process comes from the Finnish Cancer Registry from 1965 to 1993, where 11500 men were presented with localised P.C (although it is probable that some were not localized, particularly prior to PSA era), and very few had received radiotherapy or radical prostatectomy. The treatment at that time throughout Finland was observation and hormone treatment. The strength of this paper was the 30 year follow up. Nothing else approaches that in the prostate cancer field.

Findings:

Half the individuals died of other causes, 1/6th had benignly behaving tumours, whereas 1/3rd who presented with early P.C. succumbed to the disease. It was always thought that the risk of dying with P.C. increases with time, but this study clearly shows that after 10 years the risk actually decreases. Most of the men who succumbed did so within 10 years, whilst only a small proportion did so after 10 years.

Working from the above data - how should the disease be tackled? We need to identify those tumours which are not ever going to cause the patient any harm and could be classed as insignificant, but treat those who are at high risk of dying of P.C.

The question in all P.C. patients' minds must be "What are my chances of dying from other diseases eventually?" Between the ages of 65 and 70 the risk of dying from other diseases is approx. 3% per year.

A computer program currently being developed is providing a lot more data from the files of insurance companies and should enable us to give patients a much more realistic expectation of their lifespan, but this needs to be validated.

The insignificant P.C. cancer definition is: A tumour that is not destined to metastasise or threaten the life of the host. The Epstein criteria will pick out 74% of insignificant tumours, which may be suitable for active monitoring..

Diet

If active surveillance is chosen rather than radical treatment is there anything the patient can do to assist e.g. change of diet? Certainly Selenium, soya, lycopene, low animal fat etc. may protect against *developing* P.C. but is it like closing the gate when the horse has bolted?

There is encouraging data from Quebec. 384 men diagnosed with cancer progression (CaP) between 1990 and 1992 enrolled in a study. Follow-up 5.2yrs later showed that 32 had died of further progression. The third with the highest fat in their diet had three times the mortality from CaP compared to those in the third with the lowest dietary fat. Encouraged by this a very low fat diet clinic has been set up at Arrowe Park. 24 patients (10 on active surveillance, 14 hormone manipulation) took part. All had had at least 2 PSA rises showing disease progression.

Conclusions:

A very low fat diet is well tolerated and safe in patients with P.C. and patients often feel "better" on this. It may decrease disease progression in those with well/moderately differentiated tumours. Larger studies are needed. Also patients feel they are doing something for themselves instead of just following instructions.

Locally advanced or Metastatic tumour:

Should the patient be placed on immediate treatment or just be observed? Results of all the studies are inconclusive, but overall results favour immediate hormonal manipulation with regard to *survival* but the *quality of life* is inadequately assessed. Testosterone withdrawal reduces tumours, but duration of response to it is variable.

Treatment options:

Orchidectomy:- This is emotive. Sugery can have complications, and it is irreversible! This is not offered very often, but perhaps it should be!

LHRH-analogues (e.g. Zolodex): - Local anaesthesia available for injections (if requested). Advanced cancer patients can develop osteoporosis.

Anti-androgens (e.g. Casodex):- Patients prefer tablets to surgery or injections, but more expensive and can produce painful breasts!

Controversies:

Intermittent therapy

Maximum androgen blockade.

All the above options have pros and cons which should be considered prior to making a choice.

Osteoporosis in advanced P.C:

Fractures resulting from the treatment of P.C. are more common than fractures from the disease alone.

All men with advanced or metastatic P.C. should be offered bone densitometry measurements before they undergo any form of treatment, so that a logical choice can be made as to which form of treatment they should undergo.

They are now getting an idea of how patients should choose their drugs in advanced P.C. and who should be given supplementary medication.

The optimum regime for hormone manipulation in P.C. may be anti-androgen first unless the PSA level was very high. If it started to escape hormone control, then have an LHRH analogue added in as soon as it started to relapse and if the patient was also osteopenic then add zoledronic acid. If a second relapse occurred, then have oestrogen patches.

Patient factors which govern choice:

Advice given

Response/cure rates

Effects on lifestyle

Effects on employment

Side effects

Doctors factors which govern choice:

Response/cure rates

Benefits v side effects

Continued page 12, col. 1

Nutrition and Prostate Cancer

In our first edition of *Prostate Matters* we included an article on Nutrition based upon information produced by the Prostate Cancer Foundation.

In clear response to many requests from our newer members (as well as existing ones) we shall reproduce the same recommendations at regular intervals.

In the last issue we looked at the first two headings below and gave more detail on how one could achieve the first two items - reducing red meat and reducing farm-raised fish. Alternatives to both were given, and we stressed that it is "farm-raised" fish that is the issue. Fresh wild fish is highly recommended.

Nutrition Goals

Nutrition researchers recommend striving to reach the five nutritional goals shown in the panel.

Nutrition Goals

- Decrease percentage of dietary fat to 15 to 20% of total energy intake
- Increase vegetable servings to 3 to 5 per day
- Increase fruit servings to 2 to 4 per day
- Increase dietary fibre intake to 25 to 35 grams per day
- Substitute soya protein for some animal protein so that you are getting 25 to 40 grams of soy protein per day

But how?

The following are simple ways you can achieve these five overall goals.

Reduce or eliminate consumption of red meat

Reduce or eliminate high fat, farm-raised fish

Minimize or eliminate consumption of cheese

The problem here is the high fat dairy content. Most of us have enjoyed cheese on its own, and it is a common flavour enhancer. Especially when eating out! But it's just not practical to eat cheesy foods. There are so many delicious alternatives, that you can still melt and dip away, without the fat!

Try dipping your vegetables or pitta in tomato salsa or hummus. By the way if you normally add mayonnaise to tuna, try a little hummus instead!

Use soya protein meat and cheese substitutes, tofu, soya milk, and soya protein powders, bars or drinks

There are a variety of ways to increase your daily soya protein intake to the recommended 25-40 grams - don't get bored!

Try the following:

- Make a breakfast of high-fibre cereal, fruit and soya milk (the unsweetened is just like natural milk).
- Put soya milk in any recipe calling for regular milk, although it does tend to separate in coffee, if too hot.
- Use soya cheese as you would regular cheese - if you like it!
- Try miso soup (delicious) and edamame at Japanese restaurants, and bean curd in Chinese restaurants.
- Make up your own marinades to create delicious tofu stir-fries. Your favourite meat, fish or chicken marinades will work great. Marinate tofu for at least a few hours or overnight.

Limit or eliminate salad dressings made from oil and minimize use of cooking fats

Hold the mayo, butter and margarine

See the hummus tip above.

Minimize or eliminate consumption of ice cream, frozen yogurt, cakes and pastries

Minimize or eliminate consumption of peanuts, chips, and other high fat snack foods

Use garlic, spices and flavouring rather than cooking oils whenever possible

Cover half to 2/3 of your plate with steamed vegetables

(Include fruits and vegetables with every meal)

Eat beans, peas and lentils more often than refined breads and pastas, and white rice

Get in the habit of reading food labels

Watch the portions you consume in order to control your calorie intake and your weight

Roasted Tomatoes and Red Peppers with garlic

The following is based on a Spanish dish (the name of which I cannot remember) that I first encountered in a restaurant in Madrid. The dish was placed on the centre of the table with bread while we were left to choose our meals from the menu.

Since then my wife Beryl has worked on the dish and it has become a favourite with friends and family. It can be served hot or cold as an appetiser with French bread; as part of a buffet; with salad or on a picnic. If you have still got some left over, you can add it to virtually any dish as an accompaniment. When we have friends in, we find that our kitchen is where most people gather and this dish on the table provides a great dip.

It is a magnificent Mediterranean red colour (steeped in Lycopene), and the aroma (especially when hot) from the roasted tomatoes, peppers and garlic is fantastic.

Originally, Beryl used to skin the peppers and tomatoes, but this is not really necessary. And, in our opinion, leaving the skins on doesn't detract from the dish and makes it even more simple to prepare!

Ingredients :

2 large red peppers - sliced

3 large beef tomatoes or 6 large vine tomatoes - sliced

2 to 4 (we like 4) cloves of garlic

1 tbsp dried oregano

Approximately 3 tbsp Olive oil (quantity left to your conscience)

Sea salt & freshly ground pepper

Method :

Slice the tomatoes and peppers and place in a large bowl. Add crushed garlic and sprinkle with the oregano. Drizzle 3 tablespoons of olive oil (less if you feel you need to) and salt and pepper. Mix well and transfer to an oven proof dish. If you have one that is not too deep that could be transferred straight to the table for serving, this would be ideal! Bake in the oven for 1 to 1½ hours, or until it is sufficiently well cooked for the ingredients and flavours to have blended together.

Serving :

As said previously, the dish can be served hot or cold. It can be kept in the fridge for about three days, so don't worry if you have produced too much!

Mike Lockett

Droylsden Support Group

The Droylsden Support Group had its first meeting on February 3rd at 6pm at Droylsden Football Club, Market Street, Droylsden, M43 7AW.

It was the brainchild of Les Ayres who went to the hospital in 2004 for a cataract operation and came out having been diagnosed with prostate cancer! By his own admission Les was devastated - convinced he only had a short time to live

When Les had completed his treatment, his first thought was how much he would have appreciated being able to talk to other patients. He knew support groups existed for other cancers; for example Breast Cancer – why not prostate cancer? He set about trying to start a group. At this point he came across PSA North of England and met Mike Lockett. With Mike's support and lots of help from Thameside General Urology department and other areas of the NHS he organised the first meeting.

Les and his wife Anne are used to running clubs – they run an over fifties club and an art class – but had no idea whether this new venture would attract people.

Twenty eight turned up at the first meeting!

Les has an easy way with people; he put them all at ease and all present had some input to the evening. There was a very varied range of cases and treatments – from active monitoring through hormone treatment and all the other conventional treatments to Orchidectomy. Les's GP Dr Crook also attended to give his support and medical experience, which was very much appreciated.

There was a unanimous vote to continue these meetings and the standard meeting time is now set at the first Thursday each month from 6-8pm in the football club lounge.

Les is a natural entertainer, but visitors thought he had exceeded all expectations when at the second meeting the club lounge contained in the order of a hundred people, some dancing to a disco. It wasn't the support group - it was a 90th birthday party.

Retirement to the members' bar became the option and the meeting was held to background music from the disco in the adjoining room! The Droylsden meetings have so far been very eventful! It is fair to say that few people are likely to leave the meeting feeling anything but uplifted by attending - there is a tremendous friendliness and camaraderie.

On the medical side, there were two very significant comments by attendees at the second meeting.

One couple had attended Christie hospital for a consultation. They had taken with them a booklet, which they had acquired from PSA NoE following the first meeting, giving them some background to the disease. As a result the Christie consultant used the booklet to help describe the specific cancer of this patient and recorded the stages in the booklet - PSA reading, Gleason score, etc. They thought this was invaluable to them in understanding their particular situation!

Another gentleman commented that he had learned more from his single visit to the first meeting than he had learned in many years from his consultant. We should say that most patients have an excellent relationship with their medical staff, but on occasion there is a lack of doctor/patient rapport - especially if the patient is elderly or has limited options. In this case hearing other peoples' stories, and how their relationships were conducted with their medical teams, had given him renewed hope and resolve.

Another patient commented that he sometimes found it difficult to raise issues, being made to feel that he was questioning the professional knowledge of his doctor. Dr Crook made a very pertinent comment - he said that doctors would prefer a patient to talk openly and genuinely about their concerns. This saved miscommunication between doctor and patient and enabled issues to be addressed.

If you would like to attend the Droylsden Group, just turn up on the night or contact Les Ayres on 0161 370 7015 or The PSA NoE office on 0161 474 8222 or 0845 456 0678.

Les and les girls push it out for Prostate Cancer

Les Ayres with Mary Linney Page and Melanie Hopkins

Other Support Groups

In this issue of Prostate Matters we mention the most active of our local support groups. However, there are others that have not attracted so many patients. It may be that there is not a demand, although one of these areas is Trafford (served primarily by Trafford Hospital) which has many new patients each year.

We know that there are other areas where a support group would be welcome and we are working to establish groups in these areas. They include Chester, Stoke-on-Trent and Cumbria, as well as more local areas in Greater Manchester. If you identify with these areas and especially if you would like to help establish a group, please contact Mike Lockett through the PSA NoE office.

Finally, there are of course other areas of the UK that have support groups and we shall be establishing links to these via our website. Most of these offer services nationwide, although their main activity tends to be stronger in a particular geographic area. Two prominent ones with whom we have close relationships are PCaSO and PCSA(CE). PCaSO is administered from the Central South Coast of England (Help Line 0845 650 2555. or email PCaSO at info@pcaso.com). PCSA(CE) - Central England (http://www.psatest.co.uk or contact Brian Atkins, Secretary, 01455-448040).

Bolton Support Group

The Bolton branch of PSA North of England has now been in existence for just over a year. The group meets on the second Wednesday of every month from 2pm to 4pm at St Luke's Church, Chorley Old Road, Bolton.

While there are members who have been part of the group from the beginning, almost every meeting welcomes new faces.

The Urology department of Royal Bolton Hospital has been very supportive of the group, displaying information leaflets and sometimes recommending that a particular patient may benefit from visiting the group.

The group offers help, advice and support to anyone; whether the patient, wife, partner or carer of those affected by this increasingly common form of male cancer.

Bolton prostate cancer patient Ian Jackson, a founder member of the Bolton Support Group says: "When I was diagnosed with prostate cancer at Easter 2003, I experienced shock and bleak feelings of isolation and fear. I desperately wanted to talk to someone who had been through what I was about to face….I was able to talk to other people who knew what I was going through. The information they gave me was of great value and that convinced me of the benefit that support and a support group could be to new, and established patients alike."

A Bury member said: "If you are living with prostate cancer you are not alone. We can tell you how to find out more about different treatments. It is also important to remember that the majority of prostate problems may not be cancerous."

A quote from one meeting was: "A very humorous exchange of experiences took place and we were convinced that if anyone heard the laughter they would not believe we were a group of prostate cancer patients".

The wife of one patient said: "The meetings have provided a tremendous lift for me. I feel so good when we have been, that I have only missed one meeting in the last year."

People handle cancer in their own ways, and not everyone finds group meetings to be right for them, but these are typical reactions – many people talk of the camaraderie that exists and of new friends that are made through something that had such a negative start.

The group also has a helpline which enables people to talk in complete confidence to somebody who has been in a similar situation and understands how they might be feeling. The Bolton group helpline is 0845 456 0678.

On average 200 men in the Bolton and surrounding areas are diagnosed with Prostate cancer each year. It is suspected that less than 20% of these are diagnosed sufficiently early to receive a complete cure. Fortunately, many patients live normal lives for many years receiving containing treatment! But the group wants to change this ratio by raising awareness and encouraging men to be conscious of this increasingly common form of male cancer; just as women are aware of breast cancer.

As a result members took part in an awareness campaign in the Bolton Market Hall on 26th March – part of the Prostate Cancer Charity awareness week. They were joined by Bolton Oncology Sister, Dorothy Sugden and Ian reported that "as well as handing out hundreds of leaflets, a great time was had by all and they even attracted a visitor from another planet! Or was it Ken McCreesh in disguise?"

If you would like to attend the Bolton Group, just turn up on the day or contact Ian Jackson through the PSA NoE office on 0161 474 8222 or 0845 456 0678.

Top: Joan Cowley, Mary McIntyre, Mike McIntyre, Peter Fitzsimmons, Ken McCreesh. Middle: George Cowley, Robot Man, Ian Jackson.

Bottom: Olwyn Fitzsimmons, Mary McIntyre, Joan Cowley.

Ian also said that there were a number of patients and/or partners, especially those newly diagnosed or perhaps with advanced cancer, who felt unable to face a group of people at their particular stage. In this case Ian is happy to talk with people on a one to one basis in complete confidence. Please contact Ian through the PSA NoE office on the helpline listed above.

Oldham Support Group

The Oldham support group is just at its inception.

When a new support group is being arranged there are a number of approaches that can be taken. One is to broadcast the group high, wide and handsome in the hope of attracting as many people as possible from a particular area. In advance of this a number of planning meetings are likely to have taken place by an organising group.

Another is to be more modest in an attempt to gauge reaction and to feel that whatever happens the numbers are manageable. In this case the planning is likely to be less onerous, and the first meeting is going to help form the pattern for the future. This was the approach taken at Oldham.

Jane Tunstall and Lisa Buckley, both Urology Nurses at the hospital, worked with PSA North of England to assess the demand and arrange this first meeting. Just twenty invitations were handed out by the nurses to a cross section of patients of the Urology department.

A first meeting was held at the Oldham Royal Hospital at 6pm on 28th February. The weather that evening was typically Oldham winter, but that did not keep people from attending - all but two of the invitees attended, some with their wives.

Two of those invited gave their apologies and said that they would attend a future meeting.

All present had an opportunity to talk about their particular circumstances, and the fact that Jane and Lisa were present was extremely valuable, as they were able to address a particular situation that had occurred at Oldham that week – the hospital was in the process of introducing a new appointments system. The system would enable patients to have much more choice regarding time and date, but unfortunately teething problems had caused some concern among patients. Jane and Lisa were able to address these concerns.

There was generally a positive response to the evening and two patients volunteered to find an alternative venue for future meetings (the hospital only being appropriate for the first meeting).

With this encouragement, the task now is to establish a home for the group and to promote its existence to other patients in the area.

If any readers would like to attend or assist in the development of this group, please contact Mike Lockett through the office (0161 474 8222 or 0845 456 0678) or Jane/Lisa at Oldham Royal Hospital.

North East Cheshire

The North East Cheshire Sub-Group of North of England Prostate Cancer Support Group

We are a small group all members of the PSA North of England, who meet generally at The Bulls Head Hotel, Prestbury Road, Mottram St. Andrews.

We operate in more of a social than an educational format, in that approximately every three months we meet at the above venue for a meal together, including our wives/partners. We are fortunate in that they have a room that we can reserve that gives us a certain amount of privacy. We are able then to discuss more personal matters, if we so wish, but do not have a specific agenda. For that we prefer to give mutual support to each other when needed. We prefer to consider ourselves as a group of friends not just fellow cancer patients.

Usually in each year we have a men only meeting to discuss more personal matters that will be at a different venue. If any other PSA members living within a convenient area for our meetings wishes to join us, they would be most welcome. Please contact either Robin or myself at the telephone numbers shown below or by e-mail to daviesjandbm@aol.com.

John Davies

Robin Pritchard 01625 585753

John Davies 01625 250257

LEIGHTON HOSPITAL PROSTATE CANCER SUPPORT GROUP

The Leighton support group, at Crewe, meets approximately bi-monthly. There is usually a speaker on a subject of relevance to the group, and the audience is a good mix of patients and carers.

Gary Steele is the Chairman of the group and, as our article in a previous edition of Prostate Matters showed, he works tirelessly to raise the profile of prostate cancer. The following is just some of the activity in which Gary and his group have been involved.

They have been busy of late arranging a programme of events for the "Round-Winsford-Event" on Sunday 26th June 2005, in which Gary has "encouraged" Businesses to advertise.

Gary has also arranged a campaign of awareness with the sponsoring of the MG class F, with Martin Wills and the BMW Endurance Team of L VC MotorSport. Both have commenced racing and PC awareness has been mentioned in programmes at Thruxton Park and Silverstone as well as being placed on several Web sites including dailysportscar .com which is one of the main and most popular ones in motor racing.

They have been invited to have a stand in the MG Owners club Marquee at Brands Hatch for the main meeting on Sat/Sun' 14/15th May 2005 as well as having some tickets in a "Box" in the main stand for one of the two days.

Gary is also arranging with Martin Wills to be part of the procession with the car and have a stand at the Maidenhead Carnival" on Saturday 11th June, which usually attracts some 60,000 people.

Most of his Saturdays will now be taken up in being at the various meetings with the cars promoting their campaign and hopefully fund raising at the same time.

They will be designing a special leaflet which will include photographs of the cars and relevant information and have advertising on the back from which companies will provide the funding.

The next Crewe meeting is their 5th AGM, which is on Saturday 7th May in the Post Graduate Centre, Leighton Hospital.

If interested please contact the PSA Office for further information about this group.

Wirral and North Cheshire Support Group

The new group on the Wirral has been a long time in the planning, but all indications are that the effort will have been well worth while.

First conversations took place between PSA North of England and Beverly Rogers, Macmillan Urology Nurse at Arrowe Park Hospital, Wirral, in 2003. A survey form was created and posted or handed to patients of the hospital to gauge their demand and expectations. This was quite extensive covering areas such as preferences for group or one-to-one; demand for drop-in centres; willingness to become involved with establishing/running a group; topics to be covered, etc.

A large number of patients returned the forms and a number said that they would be willing to help or attend. Unfortunately, due to a change of personnel at PSA NoE there was a major delay at this point. But, some months later Mike Lockett met with Beverley and they restarted the activities again. People were re-contacted and a number of planning meetings took place. Two patients emerged as the driving force behind the group - Lance Yates and Calvin Wood; Lance had previously been involved in the raising of £260,000, for the Clatterbridge prostate cancer fund, referred to in the first issue of *Prostate Matters* and in the article on Dr Nigel Parr in this issue.

The approach taken was to promote the group extensively. Local hospitals displayed posters and leaflets; the first meeting was covered in a number of local newspapers and on local radio; the PSA NoE office also sent out letters to patients in the Wirral and North Cheshire area informing them of the meeting.

Responses indicated that there could be up to forty people attending the first meeting, which was to be held at the Healthy Living Centre, Civic Hall, Civic Way, Ellesmere Port CH65 0AZ (0151 356 6970 or www.lhlc.co.uk for directions) on Saturday 26th February.

Approximately 60 people attended the first meeting!

There was an agenda of speakers including introductions and explanation of the aims of the group by Lance and Calvin. Mike talked about PSA North of England. Jimmy McGannon who was the supervisor of the Plumbing department (seriously!) at Arrowe Park hospital talked about an awareness campaign that they were carrying out as part of Prostate Cancer Charity awareness week and Beverley talked about the approach to prostate cancer by the medical staff at Arrowe Park and Clatterbridge and of their support for a support group. Beverley then took lots of questions from the floor and where relevant took it upon herself to pick up issues that affected individuals. This represented a major commitment on her behalf, but at the second meeting it was clear that she had responded to all the issues!

Responses were requested from the audience as to their view of the morning and the demand for future meetings. It was unanimously agreed that the meetings should be held at the same time (10am to 12 pm) on the last Saturday of each month.

Since the second meeting was Easter Saturday, it was expected that the numbers would be less. There were in excess of sixty attendees and the programme included a talk by Richard Silvioli a Senior Dietitian from St Catherine's Hospital, Wirral. There was much discussion around diet and nutrition, and it was clear that this is a subject that will be revisited on future occasions.

At the meeting volunteers were invited to form a committee and to help with future organisation – there was a very good response to this and it is clear that the Wirral and North Cheshire group is going to have a strong future.

If you would like to attend the Wirral Group, just turn up on the day or call the PSA NoE office on 0161 474 8222 or 0845 456 0678.

Pictured from the top: Beverley Rogers and Richard Silvioli; Jean Yates and Barbara Wood providing refreshment; Calvin Wood (far left) and Lance Yates (far right).

Readers letters

- Donor wanted.

Now that we have produced a few issues of *Prostate Matters*, we hope to attract letters from our readers. The first we have received is from Ian at Bolton. Ian says that he is missing his prostate!

He wonders if anyone out there has a prostate to donate?

Cheadle Hulme Support Group

A Personal View

Why do I attend PSA North of England branch meetings?

I first consulted my G.P. in 1997 and by 2000 I had had prostate cancer confirmed.

As all of us have experienced, when informed that a serious condition has developed, I was scared as to what the future would hold. I worried about my wife and family, and I did not know what to do.

I had heard of the prostate support association from Macmillan nurses and I asked my urologist what he thought of such a group.

The response I got was a negative one. "I shouldn't go there. You will be scared out of your skin"

As I was not too impressed by the reaction of my urologist to my condition it seemed to me that I had nothing to loose and possibly something to gain from going to a meeting.

When I learnt that the most convenient branch to attend was the one in Cheadle Hulme and that it met in a pub at lunch time, I couldn't keep away!

What did I find when I got there?

A group of men and their wives who had been through exactly what I was going through.

A wealth of experience of the cancer/the treatments on offer/opinions of various hospitals and consultants. That all was not lost and you can survive and lead an active life. And the sheer optimism and above all the good humour of those present.

Now you can't keep me away. I have certainly gained more than I have put in.

So my advice is seek out your nearest branch and enjoy!

Laurie Denton

Ed: The Cheadle Group meets on 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 if first you prefer. If you arrive early you can have lunch before the meeting!

Donations

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

- RUNCORN ROTARY - £50
- HORWICH ROTARY - £50
- THE SALVATION ARMY (OLDHAM) - £442 & £300
- SWINTON AND PEDLEBURY - £200
- WHITEFIELD HEBREW CONGREGATION - £24
- SALE & DISTRICT LIONS - £1000
- MARKS & SPENCER - £200
- LEIGHTON SUPPORT GROUP - £1500
- DOUBLE COLUMN PRESS GROUP - £100
- DONATIONS FROM PSA NOE MEMBERS - £785

The PSA North of England charges an annual membership fee of £12 - less than the cost of the material and information that is communicated to members on an ongoing basis. This fee is set at a modest level so as not to present a barrier for any person who would benefit from becoming a member. As a result we are dependant on external funding and very grateful to all who give donations.

Any member who would like to help in raising funds should contact our office, as there are many fund raising events available.

Vitamin E

The Foundation for Cancer Research & Education, who's Prostate Cancer Prevention Plan we publish from time to time, has modified its recommended daily dosage of Vitamin E. Their original recommendation (400 IU daily) was largely based on a randomized controlled trial (Heinonen, et al) that showed a 40% reduction in prostate cancer death rate among men taking vitamin E.

Unlike most supplements, vitamin E has been tested as a treatment against a range of diseases. Many of these are well designed randomized controlled clinical trials, which provide extensive information about both the benefits and toxicity of the

Continued page 11, col. 2

Fighting male cancer killer

by Charlotte Percival

The following article has been reproduced courtesy of Evening Press, York, and was first published on Monday 21 March 2005.

EVERY hour at least one man dies from prostate cancer. As Prostate Cancer Awareness Week gets under way CHARLOTTE PERCIVAL talks to a North Yorkshire man who has fought the disease for nine years.

BRYAN METCALF had been suffering from urinary infections for ten years before a urologist suspected he had cancer.

His urethra was sore, he had difficulty urinating, and he was starting to suffer aches and pains all over his body.

But it was not until his prostate was examined that tests revealed the news that Bryan, 58, and his wife Maureen had feared.

"They said I could have surgery or radiotherapy, but as the cancer was close to the urethra, radiotherapy could cause lots of problems," said Bryan. "I was down to one choice."

Bryan, of Hambleton, near Selby, underwent surgery, but as the cancer was fibrous and close to the urethra, it was difficult to remove it all.

His condition was monitored for four years, before he tried hormone manipulation therapy, a vaccination trial and low-dose chemotherapy.

It was then doctors realised that one of his kidneys was not working properly and this year, after more tests, they discovered a regrowth of prostate cancer.

As Bryan prepares for a course of radiotherapy, he wants to warn other men to look out for the signs.

He said: "The thing about prostate cancer is some people don't have to do anything about it other than keep an eye on it for many years, which is called active monitoring.

"But other people need a cure and if that works then they might not have to go back for treatment ever again, just once a year for a blood test.

"People need to get the cancer when it's in the early stages, when you can monitor it, when you can get the option of a cure.

"If that's one possibility or if it's escaped from the prostate but still quite low, then perhaps you can put the brakes on it.

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IS THERE HOPE FOR PC-SPES?

J. Dwyer April 2005

PC-SPES, which is a mixture of herbs, was used successfully in the treatment of prostate cancer. Some batches were, however, reported to contain traces of synthetic drugs including diethyl stilbesterol, indomethacin and warfarin. One particular paper (Sovak et al. J. Nat. Cancer Inst. 2002) reported a negative correlation between the concentration of these 'contaminants' in batches of PC-SPES and their cytotoxicity (ability to destroy cancer cells). Consequently, they concluded that the contaminants were responsible for the clinical efficacy of PC-SPES. We have a copy of this paper, and their results, albeit based on limited data, do support the conclusion of the authors. Moreover, their analytical results show significant variation, in composition, between batches of the product.

Subsequently, the manufacturers of PC-SPES were forced to withdraw the product from the market, although there was, and still is, some controversy regarding this outcome.

A recent, and very interesting, paper (D. Sadava & J. Wineburg: Cancer Letters 2005) examined the role of PC-SPES in the treatment of small-cell lung cancer which is a particularly aggressive form of cancer. They considered two batches of PC-SPES, one of which was mildly contaminated and the other more heavily contaminated. They found no significant difference between them with regard to their cytotoxicity (i.e. no correlation with level of contamination). They then added the calculated maximum levels of contaminants (singly or in combination) to extracts of the less contaminated batch of PC-SPES and found no increase in cytotoxicity, as measured by a cell counting procedure. Additionally they investigated the mechanism of cytoxicity from measurements of the rate of cellular fragmentation. DNA fragmentation inside the cells provides a measure of apoptosis (programmed cell death). On the basis of these and other results in their report, they conclude that the traces of pharmaceuticals found in PC-SPES were not responsible for its cytotoxicity and pro- apoptotic activity on small-cell lung cancer cells.

Of course small-cell lung cancer is not prostate cancer, but this work, if validated by other researchers, could help to change attitudes. We have asked the author to keep us informed of progress, and we are also in touch with Sophie Chen, who developed PC-SPES.

XXTH EUROPEAN..UROLOGY CONFERENCE.

Istanbul March 2005

A Personal Comment

Following my retirement as Director of the Centre for Microporous materials at UMIST, in 1999, and discovering that I had prostate cancer, I initiated a study of prostate cancer cells using Fourier Transform Infrared Microscopy. Noel Clarke, at the Christie Hospital, supplied the cells and with the assistance of my remaining Post Doc we examined them. From early stages our intention was to evaluate the role of modern analytical spectroscopic techniques in oncology. The initial investigations focused on the examination of relevant cell lines and the spectroscopic diagnosis, grading and staging of prostate tissue. Subsequent investigations have considered the role of lipids in the progression of prostate cancer.

Early results, regarding diagnosis were promising and to strengthen the programme we invited other scientists from both Institutions to join in the collaboration (their names are listed in the references below). We were fortunate to attract an excellent graduate student (E.Gazi) who progressed the project extremely effectively. He has presented aspects of this work in UK and USA and made an oral presentation and also exhibited a poster at the above International Conference. Moreover, because the abstract was highly recommended by the reviewers a précis of the paper was included in the' Souvenir Session' presented by Prof. A. R. Zlotta, which was a summary of the best presentations made during the congress. Additionally, in the poster session, our poster received a top 'prize. Dr. Gazi is now a post doctoral researcher in the group headed by Noel Clarke at the Paterson Lab. (Christie) and is looking at the effects of lipids (fats) in the progression of prostate cancer. A comment on part of this proposed research is reported by Mr. Noel Clarke in the AICR newsletter (winter 2004).

It is too soon to know what effect this work will have on the diagnosis, grading and staging of prostate cancer etc. but for me this is a satisfactory outcome to an unfortunate beginning.

J. Dwyer April 2005

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CHARTER MARK PRESENTATION TO UROLOGY DEPARTMENT

On Friday 8 April 2005 Ann Coffey MP presented the Charter Mark to the Urology Directorate of Stockport NHS Foundation Trust and Tameside Acute Services NHS Trust at Stepping Hill Hospital.

Mrs Robina Shah, Chairman and Dr Chris Burke, Chief Executive, were present along with some 40 staff from the Urology Directorate and a number of patients who had helped the hospital in a number of ways. These included Patient Forums and patient involvement in a number of Projects. The awards were made to nurses from the Urology departments of each hospital.

Ms Coffey paid tribute to all who had contributed to this achievement; Doctors, Nurses, Management and Patients. Dr Stephen Brown, in thanking Ms Coffey, stated that it was very fitting that the awards were actually received by nurses from each hospitals Urology Departments

A Charter mark is awarded, by the Cabinet Office, in recognition of excellence in customer service and user involvement. Applicants must set and publish standards and then be accountable to clients for those standards. They must also demonstrate innovation and continuous service improvement. The award is made on a three yearly basis, and from this year successful applicants will have to undergo regular review leading up to their next application to ensure continuous service development and improvement.

Applicants are rigorously assessed on their ability to meet the requirements of six separate criteria;

- Set standards and perform well

- Actively engage with customers, partners and staff

- Be fair and accessible to everyone and promote choice

- Continuously develop and improve

- Use resources effectively and imaginatively

- Contribute to improving opportunities and quality of life in the communities you serve.

The Urology Directorate which provides services at Stockport NHS Foundation Trust and Tameside Acute Services NHS Trust, has been awarded this prestigious accolade in recognition of excellence in customer care for the 3rd time in succession.

ZOLADEX® (GOSERELIN) IS THE ONLY LHRHA THAT SIGNIFICANTLY IMPROVES SURVIVAL FOR MEN WITH PROSTATE CANCER

London, 4th APRIL 2005 - Men with prostate cancer receiving Zoladex long-term therapy in addition to radiotherapy benefit from reduction in progression of their disease and improved survival according to two key papers published in international journals this month.

The long term data in the *International Journal of Radiation Oncology, Biology and Physics* published by the independent Radiation Therapy Oncology Group (RTOG) confirm the survival benefit arising from Zoladex adjuvant therapy. The class effect in the management of prostatic diseases review in the *British Journal of Urology International* show that Zoladex is the only Luteinising Hormone-Releasing Hormone agonist (LHRHa) with such proven survival benefits in the adjuvant setting.

'The RTOG 85 31 study, is very important, because it confirms the significant improvement in overall survival for men when Zoladex is used as immediate, long-term adjuvant therapy with radiotherapy' says Mr Amir Kaisary, Consultant Urologist, Royal Free Hospital, London. 'Moreover, the 10 year data which demonstrate proven survival benefits, strengthen our belief in our current clinical practice using Zoladex long-term therapy for the appropriate groups of patients. Zoladex used as a neo-adjuvant therapy, adjuvant therapy or both, has been shown to be beneficial in prostate cancer patients when receiving radiotherapy.'

The RTOG study set out to determine the effectiveness of adding Zoladex as an immediate long-term adjuvant therapy in patients with unfavourable prognosis prostate cancer treated with definitive radiotherapy. The results show that after 10 years:

- A quarter more men were alive in the group given Zoladex in addition to radiotherapy compared to the group given radiotherapy alone (49% vs. 39%)
- The number of men remaining free of disease recurrence was 60% higher in the group given Zoladex in addition to radiotherapy (37% vs. 23%).

The RTOG study gives additional confirmation of earlier reports showing that Zoladex provides benefits both in delaying progression and improving survival. It is the only LHRHa for which this has been shown.

The proven clinical evidence and current NICE guidance on the management of prostate cancer support the role of combination treatment employing radiotherapy and hormone therapy (LHRHa or anti-androgen) in patients with locally advanced disease (when the tumour has spread outside the prostate gland) who can expect to be treated for several years. Long-term adjuvant therapy with the anti-androgen Casodex (bicalutamide) 150mg has also been shown to give a significant reduction in the risk of disease progression, compared with radiotherapy alone, whilst maintaining men's physical capacity, sexual interest and bone mineral density.

Where clinically appropriate, men should be involved in decision-making and be allowed to choose therapies less likely to cause side effects they would prefer to avoid. The role of the patient in treatment choice is recognised as essential to achieving acceptable and successful long-term management.

References for the above article are available from the PSA NoE office.

Vitamin E

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vitamin. In general, vitamin E is regarded as quite safe at a wide range of doses. But Miller, et al has recently challenged vitamin E's safety in an article published in the January 2005 issue of the *Annals of Internal Medicine* (especially alpha-tocopherol vitamin E, at doses of 400 IU or more).

Until the situation is clarified, FCRE recommend you take vitamin E in doses at or below 200 IU. Although you can easily find 800 and 1000 IU capsules, the most widely available supplement dose is 400 IU. If you have a supply of 400 IU and wish to change to 200 IU or less, consider taking the 400 IU every other day or every third day, which would give an average daily dose of 200 IU or 133 IU respectively.

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North of England

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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.

We're on the Web!
www.prostatecancersupport.org

- Prostate Cancer - Information and Support

helpline 0845 456 0678

The next edition of Prostate Matters will contain the following articles:

- General information on supplements
- Specific comment on Flaxseed oil
- The Christie talks
- Update from AGM

CHOOSING THE MOST APPROPRIATE TREATMENT FOR YOUR PROSTATE CANCER!

continued from page 3

Convenience

Cost

Effects on lifestyle

FUTURE OF CHOICE

The development of cancer services should be *patient centred and take account of patients' families' and carers' views and preferences* as well as those of *professionals* involved in cancer care.

This will only take place if:-

1. patients are made aware of all possible choices

2. patient support groups network and create *vociferous and powerful pressure groups* to lobby health service managers and politicians at local and central levels.

At present the overall standard of care for P.C. in the U.K. lags behind what has been achieved in other countries and in the treatment of other cancers in the U.K., but there is now promising data to suggest that there are effective tumour vaccines on the way.

In locally advanced P.C. which has spread outside the prostate, but is still growing locally, cryotherapy can be used, but once cancer tumours have floated off into the blood stream or gone to the lymph nodes this treatment is not effective. Cryotherapy is only available at Clatterbridge at present and there is a reluctance for consultants to refer patients to another area.

Fighting male cancer killer

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"The worst time for people to find out is when it starts to affect the bones or the brain, when they've got full blown secondary cancer."

Although Bryan is about to undergo more treatment, he is enjoying his work as a parish council clerk and runs a support group for other people affected by the condition.

"Life is good, I'm enjoying it," he said. "I've got a six-year-old granddaughter who is a great joy to us, and I really appreciate my life. There are little humps and bumps along the way, but the future is good."

For information about Bryan's email support service or the York Prostate Cancer Support Group, email bryan.metcalf@virgin.net or phone 01757 228394.