FEDERATION AUTUMN WORKSHOP

Prostate Research - Patients Lead

We, as patients, can have a significant say in what research is done, so that it concentrates on the needs that we feel strongest about. We are putting together a very interesting programme which will cover:

- a detailed update on progress on the Risk Based Screening Trial which by then will be well under way, thanks to the generosity of a large number of Federation Members (to date we have over £25k committed to this important research);

- results of the James Lind Alliance Prostate Cancer Priority Setting Programme which will have just completed its work;

- insights into a number of areas of research that are known to be at the top of patients’ priorities, such as diet and improved diagnosis techniques.

to be held at

The University of Warwick,
Coventry
on
10th November 2010
from 10.45am

Attendance (including lunch) will be free to accredited members of Federation Member Organisations. The venue is about 3 miles from Coventry Station, and we will run a bus service to and from the venue. Full details of the programme and the venue will be available in late August, at which time formal booking will commence. For more details go to:

www.prostatecancerfederation.org.uk

Worried or concerned about prostate cancer?

National Help Line
0845 601 0766

PM Editing Team: Roger Bacon
email: editor@prostatematters-uk.org

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

www.prostatecancerfederation.org.uk/
ProstateMatters_latest.pdf

The Federation e mail address is:
info@prostatecancerfederation.org.uk

It is intended to publish this newsletter 4 times a year

If you would like to comment on an article, or publish a report of your event in Prostate Matters, please contact The Editing Team
In the UK about 10,000 men die from prostate cancer each year and some 40,000 new cases are diagnosed. At present prostate cancer can only be cured if it is detected whilst still confined to the prostate gland and is asymptomatic. To identify such cases, men over the age of 50 years must be screened for the disease, using the PSA blood test and a digital examination of the rectum. If either or both tests suggest the presence of prostate cancer, the diagnosis may be confirmed or refuted by biopsying the prostate gland using transrectal ultrasound scanning.

If localised prostate cancer is diagnosed and is of the intermediate or high risk types, patients may be offered potentially curative treatment in the form of radical prostatectomy or radiotherapy (conformal external beam or brachytherapy seed implants). Surgery can be performed by an open technique or using laparoscopic or robotic procedures.

Whatever technique is used, about 2-4% patients suffer from post prostatectomy incontinence which may be severe, requiring 4 or more pads a day to keep the patient dry. In up to a further 6% of patients, less severe forms of incontinence may be bothersome with pad usage of between 1-3 pads per day. At 6 months out from surgery severe incontinence (4 or more pads a day) rarely improves spontaneously.

As with radical prostatectomy itself, results from AUS 800 implantation are best if performed in units with a high throughput of patients with post prostatectomy incontinence. It is unlikely that the UK needs more than 12 centres specialising in the usage of the AUS 800.

The current interest in managing post prostatectomy incontinence concerns the surgical management of mild to moderate pad usage patients and a number of novel surgical slings and compressive devices are undergoing cohort trials.

Stuart Berry of PROSTaid gives a patient’s experience of an Artificial Urinary Sphincter on Page 3

PCSF does not promote any treatments. Treatments should be tailored to the individual and both this treatment and Chryotherapy, mentioned later in this issue are one of many that could be appropriate.
Despite the impact of Iceland’s volcanic eruption on the travel industry, the 25th Anniversary EAU Congress in Barcelona turned out to be a considerable success with the five-day conference opening on 16 April.

Most of the meetings, sessions, courses and technical exhibits proceeded as originally planned, although organisers sometimes had to make adjustments to, in particular, the scientific programme when the flights of invited speakers and participants, particularly those coming from North America and Europe were cancelled. Main speakers found themselves rushing from one session to another covering for absent colleagues. 12,000 delegates were booked into the event and I am led to believe that almost 40% were unable to travel.

The congress is, of course, primarily aimed at Urologists and includes:
- An International day (Urology beyond Europe).
- A Scientific Programme
- Video sessions
- Workshops
- A trade exhibition
- Presentations of new drugs and equipment by pharmaceutical and manufacturers.

On the first evening there was a welcome evening and award ceremony, with the EAU recognising particular individuals. The UK figured strongly with the most prestigious award for Urologists under the age of 40 given to Prof. James Catto, Sheffield Hallamshire Hospital, who is already recognised internationally as an expert in the field of bladder cancer. Prof. Louis Dennis, Secretary of Europa Uomo, who presented at the Federations Inaugural Conference in 2008, was given a lifetime honorary award.

The EAU, in recognition of the importance of working together with patients, now provides Europa Uomo with a stand at the exhibition and a meeting room where we can hold our own meetings, which normally involves a full Board meeting and a programme of visiting speakers from the congress. Unfortunately we suffered with a decimated attendance at the meeting through the volcano. On the other hand our stand, which was manned mainly by my wife, Beryl, representing a patient’s partner, and a representative of the European School of Oncology, Milan, was in a prominent position and received visits from most of the passing delegates and other exhibitors. I took a large amount of Federation material which was very popular, particularly the Patient Information Booklet, the PCRMP and the Role of the Clinical Nurse Specialist.

Media coverage at the conference focused on the press event which discussed controversies in mass prostate cancer screening. A media forum was held which focussed on “Prostate cancer screening in Europe – the debate continues”. Europa Uomo, urological professionals and the European Union were represented and the debate was chaired by Prof. Freddie Hamdy. Unfortunately, as is often the case, mass screening for prostate cancer in Europe was still not recommended.

There was the expected diversion towards the end of the congress with delegates striving to find ways to return to their home countries. We had a delay of six days in our return which unfortunately caused me to miss what was clearly a successful AGM and Conference at Penny Brohn.

Mike Lockett

Post Prostatectomy Incontinence
A Patient’s Experience
Stuart Berry PROSTaid

“As one of 40,000 men in the UK each year I know what it is like being told you have Prostate Cancer.

I elected to have a Radical Prostatectomy, which was followed by External Beam Radiotherapy some 3 years later. I am extremely grateful to my GP and Consultants for the early diagnosis and for their expertise, which has prolonged my life. However the side affects of treatment CAN have a significant impact on your quality of life.

I experienced severe urinary incontinence, having to wear pads throughout the day and night. Other methods of controlling the condition had been unsuccessful and although I knew that the implantation of an Artificial Urinary Sphincter was an option I took some time to decide on the procedure but three years ago I had the operation.

After the normal 4 weeks or so of postoperative recuperation the devise was activated, from that day to this my continence has been restored. I have been able to have a Pee like any other man, standing at the urinals with the rest. I don’t wear uncomfortable pads, which are unhygienic and restrict your activities. This procedure has dramatically improved my quality of life and I feel fortunate that Mr Terry an expert in this treatment was able to perform the operation at the Leicester General Hospital.

As the coordinator of the PROSTaid Support and BE-Friending service a number of men have contacted me to explain their own continence issues and have subsequently gone on to have successful treatment. In trying to counteract the symptoms some men reduce their fluid intake and lack the confidence to stray far from a loo, this condition can affect your self-esteem. I would encourage anyone who experiences the condition to overlook their embarrassment and seek medical advice”

You can contact Stuart on - Tel No 01455 291752
The Great Drag Race
The reality

By Hugh Gunn

After months of choreography and make-up lessons, the day of The Great Drag Race finally dawned! The ten men chosen to lead the event travelled to London the day before and we had our final rehearsal in London Fields. Then two of us went off to the Ministry of Health to deliver a letter to the new Health Minister, Andrew Lansley.

The day was rounded off with us and our wives being taken to an Italian restaurant for a very welcome meal. Everyone was upbeat and excited about the next day.

It was a very early start for me, as I was taken at 6am, to the BBC 5 Live Studio to do a little bit of last minute publicity for the race. Then off to London Fields and our HQ, The Cat & Mutton! Under the watchful eye of the film crew, we dressed and made up - luckily, no ladders or holes in tights - and then we were fit to go. You have never seen an uglier group of ladies in your life!!

We were introduced to legendary Blue Peter presenter Peter Duncan, who came to run with us, in gold evening dress (unaware that he had it on back to front). He turned out to be a thoroughly super person and very supportive of our cause.

The atmosphere on the park was lively, although everyone seemed hesitant to get ‘dragged up’, but as soon as the first one braved it, everyone got into gear. There were one hundred and twenty-eight runners and they all made a fantastic effort with their costumes. It really was great to see so many young men and their families supporting us.

We ten performed our dance routine (I say that loosely) to a rapturous reception from a very supportive audience and then all the runners joined in and we succeeded in doubling the world record for the longest line of dancing ‘drag queens’. Our fabulous choreographer Lisa Lee led the way, ably supported by pop star Chico, and it was a great warm up.

Afterwards, there was a party and the crew from Montambanco were presented with some very well-deserved flowers and Champagne. They must be congratulated for their effort and commitment in pulling this off.

Then, somewhat exhausted, I went for a meal with my family and home to bed.

The months of preparation, the frequent trips to London, sometimes with quite serious health problems, have been exhausting, but a wonderful experience for us all. We have all admired each other’s bravery, both physical and mental. None of us found it particularly easy to don women’s clothing and perform in public. I think that part was the biggest hurdle, but it certainly attracted attention. The Great Drag Race generated around 50 stories in the press and on radio, and has received hundreds, if not thousands, of additional mentions on various websites.

More importantly, the documentary will be great and looks like shaping up into something really big. The event itself is on target to raise £20,000. Not bad for the first year. This will now become an annual event and will grow into a giant fundraiser with thousands of participants, generating huge amounts of publicity and awareness.

One only has to look at the dozens of comments on the Facebook group to see how much fun was had by everyone involved and what potential the event has for the future.

On a personal note, I haven’t laughed so much for years, I have met some very dedicated, brave people and to my absolute amazement, I loved every minute of it!

Next year I urge you all to give it your greatest support!
**Prostate Cancer Support Association Kent**

By Graham Edwards

**We are an acorn of an association** in Kent that is slowly growing and generating interest in other parts of the county. As PSA Kent, a charity in our own right we have been in existence for just over a year, having originally been a branch of the former national Prostate Cancer Support Association (PSA). We have a membership of 60 with groups in Canterbury, Maidstone, Tunbridge Wells and PSA Kent (West) based in Orpington.

Since our initial inception in 2006 we have raised over £120,000 enabling us to donate 11 multi-scanners to Kent Hospitals. These portable machines help monitor kidney bladder and prostate cancers.

In order to use all the money donated for our projects, we have applied over the years for grants to cover running costs. We have been successful in the interim period with a lottery grant, a local benefactor foundation trust grant and twice with Macmillan cancer support funding.

The Macmillan staff at the hospitals have given us and continue to give us enormous support. Information leaflets on prostate cancer called ‘hit below the belt’ are included in patients packs. On the back page are printed contact numbers for the area groups, as well as a hospital staff member contact for each hospital.

Our Treasurer Gerry Costa created our web-site, and another member Mick Brocklehurst produces our Newsletter. It is a light-hearted network of news and views with a few anecdotes which helps to keep us focussed.

Gerry and I give power-point presentations to local groups, Lions, Rotarians and Masonic Lodges to promote this male only cancer. Because we have had so much support from these associations we invite them whenever possible to attend the presentations at a hospital near them. In this way it helps to develop a network of interest in what we do.

Members have come up with novel ideas about posters for prostate cancer which we distribute to hospitals and doctors surgeries as well as the leaflets. One member Lionel Corrall has a regular pitch on a shopping mall concourse and enlists another member who is a saxophonist to play for a captive audience. Martin Cox also raised money from his band concert to give to the association.

Our Treasurer Gerry Costa created our web-site, and another member Mick Brocklehurst produces our Newsletter. It is a light-hearted network of news and views with a few anecdotes which helps to keep us focussed.

Gerry and Mick and their wives have each organised social fun day events in their beautiful gardens, giving so much of their time to raise funds for our charity.

Gerry and Viki’s son Marcel took part in a 10k run and raised a substantial amount of money for us. So did Jane the daughter of our members Rex and Veronica Morley when she dived in at the deep end by getting 14 of her friends to do a swimathon in eleven London open-air Lidos starting at he crack of dawn in the bleak midwinter, raising hundreds of pounds.

Charlie, a young woman whose father had recently died wanted to fund raise for a year in his honour. She named it ‘Dad’s Quest’, we called her ‘Little Miss Dynamite.’

Charlie rallied the troops, contacted the media, enrolled friends and family and even those standing by the wayside, to support her cause. At the college where she works she arranged a whole spectrum of activities involving the students. Among friends she organised ho-downs, parachute jumps, abseiling, and even walking on water! A tremendous achievement concluding the year long events with a Blue Ball.

We have social lunches in different locations throughout the year, and have an annual dinner-dance in December. Our valiant members collect outside superstores on high days, holidays and wet and cold days. They wear PSA visi-vests give out information leaflets, and where permissible fly the flag (well it’s really a banner) with the PSA logo. The banner was another idea from Anne-Marie, the daughter of our members John and Felicity Trinder. Their other daughter Katherine has been instrumental in providing funds from her office ‘dress-down days’.

Friends and families of our members are supportive with donations from birthday celebrations in lieu of presents or donations in lieu of Christmas Cards. It is particularly moving when we receive a donation from family members in lieu of funeral flowers.

Although we have raised an enormous amount of money over the four years, we have just as importantly raised the awareness of this male only cancer.

**We tell men that if they are in doubt, check it out, don’t delay, get a psa to-day.**

It’s only a little prick!
A letter from Doug Gray, a member of the Derriford (Plymouth) Prostate Support Group

Dear Members,

After reading the Spring Edition 2010 (Issue 8) of Prostate Matters I am seriously concerned that the ‘Prostate Cancer Risk Based Screening Trial’ mentioned in the lead article could set back any possibility of National Screening being introduced for a disease that kills more than 10,000 men a year in the UK.

This is especially the case at the moment as the UK National Screening Committee (NSC) is currently reviewing its position on screening for prostate cancer with plans to issue its report by March next year.

Also, a public consultation on the draft prostate cancer screening review has now started and runs until 21 September and all interested parties are invited to send their comments. Already, the Prostate Cancer Support Federation (PCSF) is listed as a stakeholder in the consultation process (see http://www.screening.nhs.uk/prostatecancer).

Why does the Prostate Matters article on the ‘Prostate Cancer Risk Based Screening Trial’ disturb me? The answer is simple. The article accepts the PSA test is not ideal and that a more sophisticated risk based approach for early diagnosis is needed. Although I agree the PSA test is not ideal, what the article fails to say is that PSA testing should continue in the meantime until a more accurate diagnostic test is available, even for national screening purposes.

What is more damning is that this trial announcement could be used as ‘ammunition’ by those against screening to delay the introduction of national screening, especially as the majority of the PCSF’s ‘grass roots’ membership are men who have, or have had, prostate cancer.

From my participation at one PCSF’s management committee meeting it appears to me that the committee either does not support national screening or has accepted defeat and have given up trying to lobby for screening. Either way this is not acceptable, especially as the majority of prostate cancer sufferers and their relatives do support the need for screening.

For example, the vote at the end of the Great PSA Debate last November indicated that 60% of questionnaire respondents were in favour of national screening, even after the revised motion “Every man at risk of prostate disease should be made aware of the PSA test, its benefits and limitations and should be able to freely exercise his right to have it” was unanimously agreed. Although the questionnaire results from the Great PSA Debate were published in Prostate Matters (Issue 10 February 2010) the screening vote results were not.

The support for national screening within patient led groups is also evidenced by the vote taken at the end of the Derriford (Plymouth) Prostate Steering Group Public Debate held on the 25th March 2010 to answer the question “Should national screening be introduced for prostate cancer?” which showed that 51% were for screening, 26% against and 23% undecided.

Based on this information, I strongly urge all member organisations of the PCFS to poll their membership to establish their position on screening and feed this information back to the management committee so that a consolidated PCSF position on screening can be fed into the public consultation already taking place.

If you wonder why I am so passionate about the need for screening please visit my website for additional information at www.loveyourprostate.com or alternatively contact me using my e-mail address dougray1@btinternet.com

Yours sincerely

Doug Gray

PS. Please note that I fully support the need for a more accurate means of diagnosing prostate cancer but this should evolve and not be used as a roadblock to prevent screening.

Will the Prostate Cancer Risk Based Screening Trial do More Harm than Good?

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Yours sincerely

Doug Gray

PS. Please note that I fully support the need for a more accurate means of diagnosing prostate cancer but this should evolve and not be used as a roadblock to prevent screening.
Dear Doug,

Thank you for your revised letter to the Prostate Cancer Support Federation Committee. I would like to answer your points one by one but before I do that let me state that the committee is not giving up the battle to ensure that men with prostate cancer are detected early in their cycle. That is our number one priority.

Yes we are going to be very much involved in the draft prostate cancer screening review and all our members have been notified and their views requested.

You state in your letter that the article in Prostate Matters doesn’t confirm the PCSF commitment to continuing with PSA testing. Whilst perhaps not explicitly stated, our commitment is real and proof of it is that two members of the Prostate Cancer Risk Based Trial (PCRB'T) steering committee, David Baxter-Smith, Consultant Urologist and Graham Fulford of the Graham Fulford Trust travel the country undertaking PSA testing. The trial is not a replacement for that or the advice that we are sending out to men of over 50 or less for those in the high risk group that a PSA test is their right.

You also state that the trial announcement could be used as ammunition by those against screening to delay introduction of a program. Those powers against screening already have enough ammunition from the recent European and American trials and the SCHARR report. There are other trials at a much more advanced stage than the PCRB'T that could potentially block screening if the government and the medical profession needed such ammunition; they don’t need it.

I reiterate that we are committed to ensuring every man at risk from prostate cancer receives a PSA test and a DRE. As you state at the end of the Great PSA Debate, a substantial majority accepted the revised motion. It was not calling for screening, it was calling for awareness that everyone was entitled to a PSA test after counselling. The committee has recognised that there are strong forces against screening and that we need to have a plan B to ensure that there is early detection of this dreadful disease. That is why we are supporting and involved in PCRB'T because this just might be something those powers cannot deny works as a valid screening mechanism. By the way your own Derriford group, who took a vote on screening at one of their meetings, didn’t exactly give a ringing (51% for) endorsement to it!

Finally we have polled our membership both on screening and the PCRB'T and they generously ‘put their hands in their pockets’ and provided funds to start the trial. Surely that is a sign of membership commitment to an early detection program.

Your Sincerely

Hon. Secretary
Prostate Cancer Support Federation
On behalf of the Trustees PCSF

The UK National Screening Committee

The UK National Screening Committee (UK NSC) has just started a national consultation on prostate cancer screening.

More details, including the draft evaluation of prostate cancer screening against the UK NSC criteria, can be found on our website at [www.screening.nhs.uk/prostatecancer](http://www.screening.nhs.uk/prostatecancer)

We would welcome your comments on the draft report. Submissions should be returned to Dr Anne Mackie, UK NSC Director of Programmes, by 21 September 2010. Her email is anne.mackie@imperial.nhs.uk

There is more information about the work and remit of the UK NSC at [www.screening.nhs.uk/about](http://www.screening.nhs.uk/about). Our policy review process is described at [www.screening.nhs.uk/policyreview](http://www.screening.nhs.uk/policyreview)

The PCSF is specifically mentioned as a stakeholder, so we need to put together a co-ordinated response. We have until 21st September to submit comments.

To this end, we are holding a meeting to formulate a unified response, on the 19th August, 2.00pm to 5.00pm at:

The Lord Leycester Hotel,
19 Jury Street,
Warwick,
CV34 4EJ

Spaces are limited, but anyone who would like to attend should email: s.tyndalebiscoe@btinternet.com giving names and the Member Organisation you represent.
Prostate Cancer Support Federation

22 High Street, Stockport
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Tel: 0161 474 8222
Charity No. 1123373

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Publicity/PR: - VACANT

Representatives on National groups

NCRI; PCAG; PCCA; NICE - David Smith / John Dwyer

Political Liaison
Dr Tom Stuttaford
Education/Research Coordinator
John Dwyer

Prostate Matters is published four times a year. It provides news, information, personal memoir and opinion about prostate cancer. It also reports, quotes and research findings about prostate problems. Anyone who wishes to embark on any dietary, drug, exercise or other lifestyle change intended to prevent or treat a specific disease or condition should first consult with and seek clearance from a qualified health care professional.

Prostate Cancer Cryotherapy: Effective minimally invasive treatment.

Galil Medical is one of the leading Cryotherapy companies in the world having the greatest involvement in the European and specifically in the UK market. Galil Medical combines the leading technology with support and resources to help and assist doctors at every stage, which is reflected in the support given to Galil, by the leading Urologists throughout the UK. Galil Medical is also the foremost company in the innovation of new equipment and treatment regimes, improving the treatment choices for doctors and patients.

Galil Medical cryotherapy systems use compressed Argon gas through the Joule-Thompson effect to produce extremely low temperatures. As the gas passes through cryoablation needles, the tip of the needle is cooled, forming an iceball, which engulfs the tumour and destroys the tissue.

The basic principles of cryosurgery for tumours are fast cooling of the tissue to a lethal temperature, slow thawing, and repetition of the freeze-thaw cycle. The application of lethal ice (-400°C or lower is the target temperature), combined with a slow thawing causes the maximum destruction to the targeted area. The ice can be “sculpted” to fit the individuals target lesions; prostates in the range of 10g/m to 120gm have been successfully treated.

Cryotherapy can be applied in primary prostate cancer, salvage prostate cancer (failure after external beam, brachytherapy, HIFU etc.) and is now also available (where applicable) to focally treat prostate cancer. Cryotherapy can also be repeated, if this is required. The versatility of cryosurgery makes the treatment of some prostate cancers possible, where other treatments may be contra-indicated; patients with co-morbidities can often still be treated. During the minimally invasive cryotherapy procedure, multiple cryoablation needles are inserted into the prostate through the perineum (the area between the anus and scrotum). This is mostly done with the patient under general anaesthetic (the treatment can also be offered under local or spinal block with sedation for those who cannot tolerate a general anaesthetic). An ultrasound probe is inserted into the rectum to view the prostate and the entire freezing process during the cryosurgical treatment.

While the prostate cancer cryosurgery patient is anaesthetised, a transperineal ultrasound is used to view and as a monitor to guide the insertion of the 17g (1.47mm) cryoablation needles through the perineum into precise locations within the prostate gland. The needles are guided through a special template placed above the ultrasound on a special stepping unit. A warming catheter (43°C) is used to protect the urethra from freezing since the urethra passes through the prostate gland. Thermal sensor needles are used to monitor the temperature within and around the prostate to ensure that the prostate is being frozen to temperatures less than -40°C while the adjacent areas of the rectum and other organs are not frozen. The use of the temperature sensing needles to monitor temperatures of the entire prostate and surrounding tissues dramatically lowers the chance of incontinence, rectal fistulae or other side effects.

When the cryoablation needles and temperature sensors are in place, ultra pure, high pressure (240bar) argon gas, is circulated through the cryoablation needles to create freezing temperatures of -40°C degrees or colder. Circulating the extremely cold argon gas through the cryoablation needles creates a lethally cold iceball that freezes the prostate and the cancer cells in it. Once the targeted area is frozen, the thawing is employed. The thawing process melts and kills the cells in the prostate gland. This is called the freeze-thaw process. This process is repeated to ensure all cancerous cells are destroyed and help stop future prostate cancer recurrence.

Throughout the cryoablation procedure, temperature sensors are used to allow physicians to determine when target temperatures have been reached. The cancer tumour and its blood supply are destroyed and the dead tissue is re-absorbed or remains in the body as harmless scar tissue.

When the freeze-thaw process is finished, the warming catheter is removed and usually a urinary catheter is inserted in place to help with any temporary urinary problems (retention may occur without the catheter due to the swelling of the prostate tissue). The urinary catheter is typically removed after two or three days; unless problems persist.

Because of its minimal impact on the body (no toxic substances, low anaesthesia etc.) patients are usually out of hospital after one night and returning to normal activities within a few days. Some centres are promoting the possibility of day case only treatments.

Galil Medical's advanced cryoablation technology allows for the rapid treatment of prostate cancer, either as a primary, salvage or focal treatment. The treatment is safe and uses ultrasound and is supported by 10 years of data. Galil Medical also promotes the science of cryoablation and now supports and sponsors 2 prostate registries for the collection of data to further increase the knowledge and science of Cryotherapy.

For further information please contact: Ms. E Bennett on 01293 459848
Or email to: eurosupport@galilm edical.com