Autumn Workshop
Thursday 22nd November 2012
Warwick Medical School

www.warwickconferences.com

The Federation's all-day workshop
FREE to representatives of Member Organisations
Lunch will also be provided

Please bring this important event to the attention of your members and please do try to attend.

The Speakers are:

Ann MacEwan, Support Group Development Manager, Prostate Cancer UK

Kara McDonnell, Involvement Coordinator/Community Development Officer, Macmillan

John Anderson, former Chief Executive, Prostate UK

Rob Banner, Director of PROSTaid and Trustee of the Prostate Cancer Support Federation

Mike Harrison, Chairman of Prostate Cancer Support North West and Trustee of the Prostate Cancer Support Federation

Roger Bacon, Chairman, PCaSO

Gary Steel, Chairman, Leighton Hospital Prostate Cancer Support Group

Graham Fulford, Chairman of the Graham Fulford Trust

"Making support groups more effective - patients working together"
The recent merger of The Prostate Cancer Charity and Prostate Action to form Prostate Cancer UK raises the question “What is the role of the Federation now and where is it going?”

To this end the Federation’s Trustees, together with some invited representatives from other groups, met at a workshop on 17th October to explore and agree an outline strategy for the charity, in the context of the overall objective of it being the only patient-led organisation that offers resources to and speaks for the very numerous prostate cancer patient support groups across the country.

After much debate, and many cups of coffee, the Trustees agreed in the first instance that despite the creation of Prostate UK, there is a continuing need for an independent, UK-wide, patient-led organisation to speak for patients, and that the Federation intends to continue to be that organisation. The Trustees considered that in order to best help the prostate cancer patients and their families, the three priorities for the Federation should be

- to continue and improve the direct support offered to patient groups;
- to promote education of health care professionals, so as to improve the patient experience, making the results of the latest research available at all centres;
- to campaign for early detection.

We intend to develop these themes over the next few months. Your chance to have your say on where the Federation is going will be at the upcoming Autumn Workshop, “Making support groups more effective - patients working together”, on Thursday 22nd November at Warwick Medical School (www.warwickconferences.com).

The Federation is grateful to Alderman Fiona Woolf and CMS Cameron McKenna for their kindness in hosting the meeting free of charge at their lovely offices.

Changes at the top in the Federation

These are changing times; the merger between our chief supporter, Prostate Action, and the Prostate Cancer Charity, to produce the major charity in the field, Prostate Cancer UK* has changed the scene and the Federation has responded by appointing a number of key people to roles in the Charity.

First of all, we welcome two new Trustees, co-opted by the current Board of Trustees in accordance with the Constitution.

Dr Frank Chinegwundoh (he has views about the title “Mister”), is a very distinguished urological surgeon who sits as a member of the Prostate Cancer Advisory Group and is Chair of the charity Cancer Black Care. He was a trustee of Prostate Action, and when we heard that he is ‘available’ (he did not join the board of trustees of Prostate Cancer UK) we snapped him up pretty quick.

Frank says: “I was delighted to be asked to join the board of Trustees of the PCSF. Such groups have an important role in offering peer support. Furthermore, the voice of those affected is powerful in improving prostate cancer services. I chair the charity Cancer Black Care, so appreciate the value of the voluntary sector. This trustee role will enable me to ally my voluntary sector experience with my consultant urology role and lobbying credentials, to move the agenda forward for prostate cancer sufferers.”

Secondly, to replace the probably irreplaceable Mike Lockett, we invited Mike Harrison, chair of both High Peak Prostate Cancer Support Group, and of Prostate Cancer North West to join the Board. Mike, who will be speaking at the upcoming Autumn Workshop (see page 1) is a welcome addition to the Trustees and will be able to bring to the Board the experiences of running a very diverse group.

Finally, it is with great pleasure that the Trustees announce that our Development Director, Rowena Bartlett, has been appointed as Chief Executive of the Charity. The role of chief executive is by no means new Rowena; she served two separate terms as chief executive of the very successful breast cancer charity, The Haven. After six months in the role of Development Director, she has shown a firm grasp of the essential issues facing the Federation and is rapidly licking the charity into the shape it needs to be if it is to continue to be the only independent, patient-led, UK-wide organisation that will speak for prostate cancer patients.

We wish all three of these newcomers at the top the very best of luck, and look forward to the continuing success of the Federation under their guidance.

*Prostate Cancer UK have promised to continue the support for the Federation for at least the next 3 years, in the form of the Small Grants Awards (formerly Prostate Action Grants), the conferences and workshops, and most importantly, the grant to support development of the Federation.
In March 2012 I decided to do a walk to raise funds for charity, and discussed the idea with my wife Gail and with Noel Warner, chair of the Norfolk & Waveney Prostate Cancer Support Group (N&WPCSG). It became clear that to raise money for local charities, a local walk would make most sense. There is a suitable 240 mile circuit of Norfolk and Waveney on good paths, and thus the idea took shape.

We decided to raise money for Big C as well as N&WPCSG, partly because Big C has a need for funds, partly to avoid being gender-specific, and partly because the profile of Big C in Norfolk & Waveney would help secure support.

There is a tendency to concentrate on fundraising, but I was very keen to promote a positive message about exercise. Some people have a very difficult experience with cancer, but for others treatment is followed by a period of relatively normal life. There is evidence that lifestyle factors (exercise, diet, smoking, stress) make a big difference to the patient's prospects for long term survival with a good quality of life.

The lifestyle aspect of walknorfolk was the most difficult thing to tackle. It is also hard to measure the results. With Noel's enthusiastic and tenacious participation we courted the press and local radio and the media coverage has exceeded my expectations. We accepted that whilst we were promoting a message, the media were looking for a story, and the two things are not necessarily the same, but we got the message across.

Another aspect of walknorfolk was participation. I wanted people to walk with me, for an hour or two, a day or several days, according to their commitments and abilities. It didn't turn into the procession that some envisaged (which could have been a nightmare to manage) but I had company all the way, and thirteen people on the busiest day. This transformed it from a solo walk into a peripatetic social event which was fun for me and very much the celebration of exercise and the outdoors that I wanted. The oldest participant was 82 and the youngest was 8 and I think everyone had a good time. It certainly went better than I dared hope. I was ready for a rest at the end, but had a memorable experience. I won't attempt a detailed description of the route here, but you can find out more at www.walknorfolk.wordpress.com.

The fundraising was hard work, and very time-consuming. However people have been universally supportive, and very generous. I am confident that the final sum raised will reach £8000 including Gift Aid.

I will forego the pleasure of producing a list of thank-yous as there are too many people to thank. The support and help I have received, and the enthusiasm shown for the undertaking has been amazing. Walknorfolk has been an emotional experience for me at times, and certainly one I will never forget. My heartfelt thanks to all of you.
Most of us given some plasticine, might manage to make something simple and recognizable, but few of us would have the ingenuity to think up endlessly amusing characters, one of whom never speaks and turn them into wonderfully funny animation. Such was the brilliance of Wallace & Gromit, made by Nick Parks, Steve Box and Cinematographer, David Riddett.

David attended a PROStaid Gala Evening at the Odeon Cinema, Leicester and brought along the original Wallace & Gromit figures, including the rather scary Warerabbit. He gave a fascinating talk about how the films are made and brought along rare archive film showing what a painstaking business it all is. We were then treated to a special showing of ‘The Curse of the Warerabbit’, this being the last 35mm film to be ever shown in this cinema.

When Ardman first started, four people made ‘The Wrong Trousers’ and a half hour film took fourteen months to make. With the advent of digital production, they now employ four hundred people and make full length feature films.

Most People could not resist having their photo taken with Wallace, Gromit and the Warerabbit and also enjoyed a glass of bubbly, provided by Everards Brewery and nibbles provided by The Odeon Cinema let us use the cinema for free and also added to our enjoyment by provided Ben & Jerry’s ice-cream.

It was a great family evening and raised over £1000 for PROStaid.

Apart from raising awareness locally, PROStaid is funding a Prostate Cancer Nurse Specialist, at the Leicester General Hospital. It also funds a Palliative nurse who works in the community, for patients who have advanced prostate cancer and need care at home. This is the first such post in the country.

This year PROStaid has started holding talks for local GP’s to educate them on the various facets of prostate cancer and the need for testing. We are assisted in this by senior urological consultants from LGH.

**Please Check Your Details**

Please would all affiliated members check on the PCSF website, that their details are correct on both the map:

http://tinyurl.com/429ee7f

and the contact web page:

www.prostatecancerfederation.org.uk/membershipList.htm

If there are any alterations, please contact:

Sandy Tyndale-Biscoe
Email webmaster@prostatecancerfederation.org.uk

**DO YOU HAVE PROSTATE CANCER?**

**ARE YOU NOW OR HAVE YOU IN THE PAST RECEIVED HORMONE THERAPY TREATMENT?**

M3 Global research will be conducting some online research with prostate cancer patients

**WE ARE PAYING £40 AS A THANK YOU FOR TAKING PART IN A 25 MIN ONLINE SURVEY**

If you are interested please email me on

S Morrison@eu.M3.com

Or call me on 07932 997432

Regards Sue Morrison
Dear Hugh,

I hope that you won't be upset if I tell you that I don't find Prostate matters very people friendly. I find the technical papers very hard to read and I wonder if it would be better to have a summary of what is happening in "prostate cancer" written so that laymen can understand. It would also be good to focus on a Support Group in each edition. We are struggling for new members at the moment, so not a good time to focus on us. As you know, we come under the umbrella of the Prostate Project and I am copying in our Chairman, Colin Stokes, in case he wants to say anything about the work of our charity. I think that you have had something about one of our members, Nigel Lewis-Baker recently?

We are also working quite closely with Uni of Surrey Faculty of Health and Social Welfare - Prof Sara Faithful - who are doing some interesting work on "Coping with PCa". They have produced a video showing how (I think) 6 patients had coped with prostate cancer and the side effects after treatment, mainly incontinence and sexual relations. You can view it on the Support page of our website www.prostate-project.org.uk. From my experience, these issues are not given sufficient prominence in the field of prostate cancer. Happy to send you Sara's contact details if you don't have them.

I appreciate that you see a lobbying role for the Federation, but I would suggest that most of our members are looking for support and not a more active involvement. I put out Prostate matters at each meeting, but the takeup is very low, so in order to save you money, please reduce our order to 20 copies.

Regards

Peter Seaton
Prostate Project

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What do YOU think....... does Prostate Matters need to change?

Having received the following letter, it raises a very important point. It is vital that Prostate Matters reflects the views of our members (YOU) and has content which they find both interesting and informative.

Prostate Matters is YOUR newsletter, does it need to change and if so, in what way. I am trying to include more content from our membership and all of our groups have been asked if they have anything they wish to be included. Please do get involved and if you have any suggestions, please would you email them to me at treasurer@prostatecancerfederation.org.uk

Also, please do consider coming to our Autumn Conference to be held on November 22nd at The University of Warwick. The subject is Support Groups and How Can we Help Them. An ideal opportunity to have your say. The conference is free and lunch will be provided.

Hugh Gunn
Editor Prostate Matters

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APPLE Helps at The “Giving time for others Campaign”

In August, The Association of Prostate Patients in London (APPLE) took part in the “Giving time for others Campaign”, organised by the Mayor of Redbridge, Councillor Muhammed Javed and held in the Ilford Town Hall.

We had a stand and leaflets on Prostate Cancer and part of the day was networking with groups to make aware of the problems of the disease. We are now making arrangements to have a women speaker to talk to other women in the support groups and give them information.

This was part of the European Prostate Cancer Awareness Day (EPAD) which was held on the 19 September and another one will be held in November.

Chairman of APPLE, Ken Mastris & the Mayor of Redbridge, Councillor Muhammed Javed
On 7 March 2005 I joined the world of prostate cancer. Working with the inspirational Sir Clive Bourne (who founded Prostate Cancer Research Foundation) I was employed as the first full time member of staff to take an organisation that was raised £300,000 a year from an annual Gala Dinner to the first aim of £1 million. No mean feat for a girl with a great deal of knowledge about music, but none about the prostate. To say it was a challenge is an understatement. Sir Clive and his friends and family had done an incredible job of getting the charity to this point, but there were only paper files and no method in place for raising money from other areas. The Forum was going strong, with the 7th meeting about to take place and the charity had already established an annual grant round, one of the first prostate specific ones in the country. It really was a baptism of fire, get the files on the computer, start a newsletter and look at where else money could be raised from. Also, try and find out as much as possible about prostate cancer – no mean feat. How different things are now! We’ve achieved a huge amount. Brought Bob Monkhouse back from the dead; professionalised the grant making; made the Forum The prostate cancer meeting; funding some of the best research – Abiraterone was something Sir Clive was adamant should be funded, we did; merged once to create Prostate Action; given a voice to patients of all three diseases; fought for them with NICE; improved our GP training; joined the Prostate Cancer Support Federation as a trustee and continued the vital funding that John Anderson and Prostate UK started and now we are merging again, to create The voice for prostate disease patients in the UK.

It really has been an honour and a privilege learning and helping all those with a prostate problem; from meeting all the researchers we fund; all the Forum attendees and all those patients and their families, you have all made it so easy to ask people for money and to do the best that we can to make your lives better. The memories that will stay with me forever all involve patients, from the elderly gentleman at a Lodge talk I gave who asked me if I thought he ought to get his wife to check his prostate for him – I said I wasn’t sure she would know what she was feeling for!! To following Hugh Gunn on his journey from stunning drag queen to doing well on Abiraterone, I can’t put into words how much knowing you all has made doing my job so much easier.

So now it’s time to say goodbye, I wish the Federation the best of luck, Rowena and the trustees I am sure will continue fighting for all patients, and I will be thinking of you all.

Emma

John Dwyer

We are sad that John Dwyer has retired from active involvement in managing the Federation. John was one of the very first architects of the Federation and helped steer it through the early years to see it become the organisation it is now.

He was also instrumental in setting up the PCS North West support group and has worked tirelessly on research developments in the area on prostate cancer treatment. At the age of 84 he has earned a very well deserved rest.

John is shown with Mike Harrison, Chairman of PCS, being presented with an engraved tankard in appreciations for all of his hard work.

Thank you from us all John!!
First of all, a huge thanks to Emma and her team at Prostate Action for the hats and T/Shirts which all the helpers and collectors wore to stand out in the crowd which is extremely important.

The main reason for the event was to continue to promote the “Get Checked” Campaign and to encourage men to listen to our positive messages.

We touched a lot of men and, because we had held a similar event back in March (Prostate Cancer Awareness Month) this year at the OUFC Club we were also overwhelmed by the stories of men we had spoken to on that occasion. They had listened to us and have been to their doctors to get checked. (That made us all feel good.)

One man told me that as a result of our previous awareness day, he had been to see his doctor. His PSA was 5.7 but his doctor has not referred him for any further tests. (Well should I have said nothing - what would you have done?)

I advised him to have another PSA test in 6 months and told him to keep a note of the date and number of his last test to see if it has changed. I gave him our number to call us at any time if felt the need to.

We had our Gazebo, Banners, Balloons and Support Team ready and in place by 1pm and the OUFC Management Team rounded up some of the OPCSG Team and took them to different places where they felt it best location to shake the tins.

As soon a 3pm came we packed everything away and all the helpers had lots of stories to tell about people who had spoken to them and the outstanding number of men that had Issues. As usual, many men did not want to know anything about Prostate Cancer for reasons best known to them. Again, many of the ladies were very keen to donate money and ask searching questions.

The other news is that we have suggestions and statistics to share that may well help other Support Groups collecting in the future.

1. Have a Team with a Stand and /or Banners at the Main Entrance where people who want more detailed information can be directed to. Try to get collectors at all of the entrances in a ‘pyramid’ formation – one out front with two or three further behind.

2. All to wear matching clothing (looks professional). We have our own T Shirts as well as those from Prostate Action.

3. If possible, have one (bucket) collector to every 500 expected at the game.

4. Be armed with a useful leaflet to give out.

5. In our case, 6,900 people attended the Match and we collected £856.00 which equates to 12p per person. This should give you an indication of how much you are likely to collect if you have events in the future like this one.

**NICE Refuses Denosumab for Prostate Cancer**

NICE has compared Denosumab with bisphosphonates (Zometa) for treatment in bone disease from metastatic cancer.

As there is no recommended treatment pathway for prostate cancer which includes treatment for bone health, there was nothing to compare and therefore, Denosumab has been passed for all cancers, with the exception of prostate cancer.

Hormone treatment for prostate cancer causes osteoporosis and skeletal related events. The fact that there is no recommended treatment pathway for bone health is not only morally wrong, but condemns men to bone breakages and great pain when it could be so easily avoided.

This is something which hugely impacts on quality of life ought to be corrected very quickly.
The PSA argument continues to sway in each direction, to the frustration of most patients, who feel, possibly intuitively, that all the talk of “harm” arising from a simple test must be wrong. The argument recently took a very firm step in the wrong direction, when the US Preventive Services Task Force recommended against PSA-based screening for prostate cancer. This met with considerable criticism from the urology profession, but their argument is inevitably weakened by the suspicion that theirs is special pleading; they make money from screening.

The on-line journal OncologySTAT, published by Elsevier, recently interviewed Dr James Eastham, MD, Chair of Urologic Oncology at Memorial Sloan-Kettering Cancer Center in New York about this. His reply gives a good clue as to how the profession will react to the Task Force recommendation, which, although it is only applicable in the US, is being used over here by medical professionals who are against the test (and who seem to be for the continuance of the death rate of 10,000 men per year – but of course we’re not allowed to think that). Dr Eastham had a number of important points to make.

As we all know, the difficulty with prostate cancer is that not all prostate cancers are lethal, but current screening practices are based on the assumption that they are. If there’s any abnormality, the patient gets a biopsy, and if the biopsy shows any kind of prostate cancer, he generally gets treated. It is believed that results in a significant amount of over-treatment, as many prostate cancers are irrelevant and don’t represent a threat to the length or quality of life of the patient. In such cases the patient only experiences the negative aspects of treatment. He won’t die from prostate cancer, but he never would have. Screening in his case has done nothing but harm.

Dr Eastham felt that clinicians, rather than the Task Force, by effectively saying we shouldn’t do PSA testing, had missed an opportunity to take into account some of the important points to make.

Dr Eastham suggested that a more rational fashion of screening is that a man has his risk assessed based on his baseline PSA value. That baseline value will determine whether he should get more or less frequent PSA testing. So, rather than treating every man in the same way, i.e., a PSA every year regardless of risk, one can get a baseline PSA, establish risk at that time, and men at very low risk may only need one more PSA assessment several years later just to confirm that they are very low risk.

The men at highest risk, however, can then be followed more closely and, if they do meet the threshold to undergo a biopsy, they can have that; but, if cancer is diagnosed, their risk is reassessed. So, based on the biopsy and how many biopsies contain cancer and what the cancer looks like under the microscope, they may still just be observed; not all prostate cancers diagnosed need immediate treatment.

The goal of PSA screening should be to establish the risk that a man will develop a lethal prostate cancer. Based on that risk, a recommendation can be made: for men at low risk, it may be just following them less closely and for men at higher risk, following them more closely.

The strength of the evidence to support prostate cancer screening is that death rates from prostate cancer have declined markedly with the advent of PSA testing. So, there is evidence based on just that epidemiology: death rates from prostate cancer in the United States have dropped substantially.

Dr Eastham said that in many ways, those at Memorial Sloan-Kettering Cancer Center agree with the Task Force findings (about benefits and harms of PSA-based screening) in that the current screening practices do need to be modified. However, he felt that the Task Force, by effectively saying we shouldn’t do PSA testing, had missed an opportunity to take into account some of the things mentioned above: we should use more selective and targeted screening and treatment based on risk.

From his answers it is apparent that Dr Eastham felt that clinicians, rather than rejecting the Task Force recommendations out of hand, will acknowledge that they had brought out some very important points and modify their approach, adopting a more risk-based strategy.

Resources available from the PCSF,

please fill in the number required in the boxes, cut out the form and send to:
Prostate Support Federation, Mansion House Chambers, 22 High Street, Stockport, SK1 1EG

Postage and Packaging will be charged

Setting up a support group
Role of a Clinical Nurse Specialist
Clinical Trials
The Real Prostate Cancer Risk Management Programme
Understanding Cancer Waiting Times
Knowledge Empowers, Treatment Information Booklet
It’s A Man Thing, Awareness Card

Name:________________________________________________________
Group:_____________________________________________________
Address:_____________________________________________________
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Post Code:___________________________________________________
phone:______________________________________________________
Email:______________________________________________________

Page 8