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0845 601 0766

Federation plans to tackle prostate cancer

By Rowena Bartlett and Sandy Tyndale-Biscoe

As was announced at the AGM in May, we have embarked on a “branding” exercise, designed to get the Federation recognised as THE Independent Voice of prostate cancer patients. This was identified by Trustees and Members as one of our chief priorities at the Autumn Workshop last November. To help us with this, we were lucky to recruit the pro-bono services of Paul Gray, a PR consultant with long experience in the property market.

Paul explains that “…it was apparent that applying the same criteria to the charity sector as I had done in the property market would not only be productive but actually essential in order to compete in the increasingly demanding voluntary arena.”

Due partly to the economic climate and partly to how marketing-savvy the 21st century is, the same principles pertain – whether to a small charity’s fundraising campaign or to a FTSE 100’s investor-relations initiative. Nomenclature and terminology will vary depending on which trendy consultant or agency you use but, essentially, marketing, communications and business development in any sector is predicated on:

• Target audiences
• The organisation’s values, i.e. what it stands for and the principles it holds
• Mission, value proposition (VP), organising thought or strapline, driven by unique selling propositions (USPs) and track record

• Vision for the future driven by the mission or VP – less tangible, more abstract, the ultimate destination and for internal consumption

Our challenge was how to sell and communicate a charity whose name, however fondly we are attached to it, is, it must be said, largely unmemorable. As Paul said at the AGM, “the Federation does great work and is well-perceived by its members. However for Rowena to be able to do her job and raise funds and your profile commensurate with your values, mission and vision a new, appealing corporate handle is essential.”

We are aware that our members appreciate the somewhat cozy, club-like, atmosphere conjured up by the name Prostate Cancer Support Federation, and we have no intention of changing that. To our members, we remain a club. But to the outside world we need something with more impact:

• The market is highly competitive, we need to stand out, we need to be noticed
• We need to look good so we can attract supporters
• We need to attract supporters so we can raise funds
• We need to raise funds so we can tackle prostate cancer

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Janssen sponsored the print production of this newsletter. Control of editorial content was retained by the Prostate Cancer Support Federation.
So a new identity has been born. The campaign 
tackle prostate cancer (“tackle” for short) is a campaign of the Federation, run by and for patients and their families, to do what it says. It is not our name; that will remain the Prostate Cancer Support Federation. It is what we do and may become what others call us. But to our Members we will always be the Federation.

tackle implies:

• tackling a problem
• a call for action
• energy
• getting to grips with something
• confrontation
• masculinity – physical action
• sport: rugby and football, of course, but also
• fishing (the most participated – and most dangerous sport in the UK!)

All of the above exemplify why the Federation was founded and what it stands for.

We are, of course, aware, that among certain of the more vulgar members of society, the word “tackle” has connotations connected with the male genitalia. Whilst such a connection was not our intention, (not half, Ed) it is by no means inappropriate; one of the reasons prostate cancer is so often regarded as the hidden disease is because of a tendency to be shy, even prissy, about it. This is a mistake. If we want men to look after their prostates they must fully understand its importance to a happy life, and never forget that it is a sex organ!

From reactions so far, we are convinced that Tackle is an inspired name for a campaign which will move our organisation to its next, crucial stage of growth and development. It will take a lot of hard work but, over time, we know Tackle will become as well-known and supported as many “household” charities. Through the Tackle campaign the Federation will embrace the whole gamut of marketing and communications, particularly digital channels including social media.

Prostate Cancer Support Federation AGM 2013

Clinical Trials, what, why and how

By Terry Garrigan SECHC

Our annual conference and AGM took place in London on Tuesday 14 May 2013 and the topic was “Clinical Trials, what, why and how”.

Dr David Boocock from the John van Geest Cancer Research Centre set the ball rolling with “Prostate cancer and the immune system, from research lab to the clinic.” He stressed the importance of obtaining human samples from various stages of the disease, ensuring quality samples and storing them correctly.

The immune system in the body cleverly attacks and destroys harmful viruses and bacteria. White blood cells are defence cells and do different things. An antigen is any foreign substance, such as viruses, bacteria, bits of protein, in fact anything not meant to be there, which stimulates an immune response. Self antigens are meant to be there and do not trigger the immune system, whereas non-self antigens should not be present and activate the immune system. Vaccines are biological preparations that can improve immunity.

A vaccine may be formed from a weakened version of a microbe, which then stops you getting the disease in later life. An example of this is cervical cancer caused by a virus, now being treated by a vaccination programme.

When the immune system is not working, cancer will form and the body is constantly fighting it off.

Dr. David Boocock

In the development of cancer immunotherapy, just the antigens are collected in the lab, in a test tube. Animals are the pre clinical models and problems may occur when it’s actually trialled on humans as they do not always respond in exactly the same way. Peptide based vaccines – amino acids in long chains are present as proteins and it’s these proteins which need targeting. A tiny fragment of the protein can be used without being removed from the body, making it possibly cheaper and NHS friendly. HER 2 / Neu receptor targeting could be a promising new approach for prostate cancer patients.

Professor Mark Emberton from UCLH continued the morning session with the topic “A quiver of trials for men with early (organ confined) prostate cancer”.

The professor works with men who have curable, organ confined disease. Those deemed as low risk, would present with a Gleason score of 3+3 or below, intermediate risk Gleason score of 3+4 and clinical
Continued From Page 2

significant disease, Gleason score 4+3. It is thought a true Gleason score of 3+3 probably never killed anyone! Professor Emberton asked “In fact is it prostate cancer at all”? So where to draw the line? Do aggressive cancers evolve or do they begin as aggressive? Active surveillance studies have failed to answer this question. TRUS biopsies are only a random test. Could we perform fewer biopsies? What makes low grade prostate cancer progress? Possibly changes in the immune system? Older men, in 75-79 yr age bracket are now presenting with aggressive disease, the reasons are unknown. Men in the 48-50 yr age group with non-aggressive cancers pose a huge dilemma; To live with it or to get it treated. The potential for benefit is not great. Biopsies are known to often cause harm such as infection, sepsis, e-coli etc. It is thought that biopsies will become a thing of the past. Ideally, men should have an MRI before a biopsy. MRIs are cheap, non-invasive, 98% accurate and can be done in any hospital on their usual machine.

The PROMIS trial is Government funded, £2.5 million pilot study of 50 cases. This is an MRI followed by a precise biopsy. Professor Emberton finished his talk by suggesting that no man should agree to a biopsy without having had an MRI beforehand!

The afternoon session began with Professor Johann de Bono from the Institute of Cancer Research. His presentation was “Improving Outcomes from Advanced Prostate Cancer”.

The Institute has had four new treatments up and running in five years! He is part of the Abiraterone team. He explained that prostate cancer is not just one disease but about twenty different ones. The aim of the trials is to minimise the over-treating of indolent disease while treating the aggressive strains.

Abiraterone is usually administered after chemotherapy treatment, although it is possible that it may be used to better effect if used pre chemotherapy. Slow progress is being made, but four new drugs are improving survival. There are exciting new drugs in trials, but men are still dying from prostate cancer! It is now known that hormone therapy drugs seem to work better the sooner they are administered and combination drugs appear to be the way forward. It is also known that steroids can fuel cancer cell growth so have to be used with caution. Professor de Bono finished with a note to all men, to think for themselves and not expect their doctor to think for them!

The last session of the day was delivered by Matthew Sydes a senior scientist, MRC Clinical Trials Unit. He spoke on “How randomised controlled trials allow for evidence-based decision making.”

Advanced prostate cancer is caused by genomic changes in the cells. Each normal cell has a life and then is programmed to die, but a cancer cell carries on multiplying forming a tumour. Drugs have been invented to turn these cells off. As recently as 2003 the UK was known as a desert of prostate cancer research, but is now regarded as a field leader. The lab team, consisting of 25 staff test drugs on patients, taking samples from them and sequencing the whole genome. The genome is our individual make up. The buzz word is Precision Medicine which minimises risk while maximising outcome. Prostate cancer is driven by genetic changes in cells. Abnormal hormones drive the genetic switches which are different between aggressive and non aggressive disease (tigers and pussycats). It is not only genetic changes but also the immune system. The jury is out on whether to treat Gleason 3+3 cancers. Cancer occurs where there are breaks in the DNA structure, which don’t repair properly. They then re-join different chromosomes together. Cancer cells learn to adapt and drug developments can be slow and costly. It is the responsibility of the research team to accelerate matters. Combination drugs are the way forward and have proved to be successful in the treatment of Aids. Much still needs to be done as eventually cancer outsmarts all known drugs, cells start to make their own hormones. Abiraterone doesn’t work for everyone. For example on a patient with a cell that cannot be switched off but multiplies continually.

Anyone can ask to go on a trial. They are safe and effective treatments. Randomised controlled trials are fair tests and very reliable. It is important to remember that new is not necessarily better than current.

In the setting up of a trial there has to be a design and a peer review, both with verbal and written information. A regulatory review involving ethics with the patient choosing to discontinue at any time, local recruits and patient consent. Knowing about research will make it more likely that men will join and remembering that research should not be regarded as special, but part of good practice. Questions: Can I
choose my own treatment? No. Not on a randomised trial. The patient must be right for the trial and the trial must be right for him. He must be willing to follow either treatment and be willing to commit. There may be difficulty such as surgery versus radiotherapy. It must be remembered that both private and NHS doctors have the same access to research data.

Unfortunately there is a high failure rate in new treatments and the typical trial period is 5 – 10 yrs! Clinical trials for men whose cancer has returned or has stopped responding to treatment is the way forward, extending their lives and relieving some symptoms. Hopefully in the years to come prostate cancer will be better understood and treated.

This conference was very thought provoking and it was amazing to learn how much research is going on all the time. Future generations will see massive changes in the treatment of this disease, hopefully reducing the misery of erectile dysfunction and incontinence suffered by many at present.

APPLE gets Involved in Local Review of Urology Services

Over recent months, expert clinicians representing all the hospitals providing urological cancer services in north central London, north east London and west Essex have been looking at how they can improve urological cancer surgical services, specifically complex surgery for bladder and prostate cancer and kidney cancer. This review is being led by London Cancer which represents NHS cancer care providers and the cancer Joint Development Group and also involves GPs, nurses, health professionals and patient representatives.

The review has led to London Cancer Board recommending that complex surgery be consolidated in one specialist centre for bladder and prostate cancer University College Hospital, Euston and one specialist centre for kidney cancer The Royal Free, Hampstead. If this goes ahead, surgery for bladder, prostate and kidney cancer would no longer be carried out at any other hospitals across north central London, north east London and west Essex this includes King George Hospital, Goodmayes/Queens Hospital, Romford. Importantly, patients would continue to receive the majority of their care at their local urological cancer unit. This would include King George Hospital, Goodmayes/Queens Hospital, Romford. (More information about London Cancer and the recommendations can be found online at http://www.londoncancer.org/cancer-professionals/urological/).

APPLE Secretary Jane Smith has been selected to sit on the Board of London Cancer as a Patient representative following our meeting the following was following was sent to London cancer as the views of its members

On behalf of APPLE and all our members, please find below our feedback and response to the proposed changes to Urology Services.

Firstly, we are not against the idea of centres of excellence. However... I would like to query the validity of the data (referred to in the Stratford presentation back in January) justifying the benefits of a one site urology team performing the bigger operations. As I recall, the data used to show the benefits of a one site urology team was based on data from the US over just one year. I do not think one year's data is suffice. Surely data over 5 to 20 years would be more legitimate? We have been presented with the reasons to move to a one site option based on these statistics. Are we sure the statistics can be relied upon?

The proposals given, only allow for feedback on the stated plans, with no consideration given to alternative options or evidences as to why other proposal should not be presented. This is in light of NICE Guidance, which suggests the current number of procedures carried out would justify continued provision at two centres.

Our Urology services at King George Hospital, Goodmayes and Queen's Hospital Romford are very good, and most of our members are served locally at these hospitals. Our BHR chief executive, Averil Dongworth, has confirmed the BHR trust would have liked to put Queens Hospital forward as the second site. (I have just forwarded her email confirming this to you.) Are you sure a two centre option should not be put forward for consultation as a viable option?

Re the length of tim e for the ‘consultation’ period, this has been minimal. The first we heard of the changes was a week before the end of January meeting at Stratford. The deadline for all feedback is today. Is that really sufficient tim e for a consultation? I think not. Also, if the proposals go through as planned, it will see the end of prostate, bladder and kidney cancer surgery in North and North-East London, S Herts and W Essex, affecting over 2,000,000 people. The way the consultation has been handled few of these people know. I do not feel the consultation process has been carried out sufficiently.
Most of us have a dream in life and if we are lucky, we get the opportunity to realise it. That will be the case for Colin Peach from the Teeside Support Group.

Colin has always wanted to own a racehorse and he decided at the age of sixty six that the time had come. On 24th May 2013, Colin and Patrick Holmes (trainer) from Foulrice Racing Stables, went over to Ireland and watched about a hundred horses run over 3 furlongs. The following day Colin bought a 2 year old bay colt at the auctions and he has aptly named it PROSTATE AWARENESS.

Colin was diagnosed with prostate cancer in 2006 and had a radical prostatectomy. Unfortunately it had already spread outside the prostate and he has since been through various treatments; hormone therapy, 6 weeks of radiotherapy, 30 weeks of chemotherapy, Abiraterone, and currently Dexamethasone. As many men will know that is a hard road to travel, both physically and mentally and it is only natural to feel "the time has come" to live the dream.

Hopefully, PROSTATE AWARENESS will be having his first run at York on 28th July 2013. On race day the jockey will be wearing light blue and white with a dark and light blue chequered cap.

Colin obviously has high hopes for his young horse and we all wish him the best of luck and what a wonderful way to raise awareness!

Dr Jon Rees, a GP at Backwell & Nailsea Medical Group, is undertaking some work with the European Men’s Health Forum. He has sent us a flyer promoting a research project to allow men to ask questions about prostate disease. These will be answered within 48 hours by a urologist or clinical nurse specialist. They will then collated to try to find a pan-European assessment of the knowledge that men with prostate disease want and currently lack.

The online doctor always has time

What do Europe’s men want to know about their prostates?

The EMHF has launched a pioneering Q&A web-based service in English, Spanish and German to ask men what they need to know about their prostates—rather than what we think they need to know. Log on to:

www.yourprostate.eu

All questions are answered by specialist nurses and urologists within 48 hours. Our research to date has uncovered some very unexpected and surprising questions—especially lifestyle questions that doctors so often consider to be unimportant. Other languages including French and Italian coming soon.

Please help us to help men by publicising this service as widely as possible.

For more information please contact the EMHF’s project director Veronica Wray atveronica.wray@emhf.org, T +44 (0)20 8568 8546, M +44 (0)7710 624454, W www.emhf.org

Please Check Your Details

Unless otherwise requested, your details will appear on the list of groups on our website. 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

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Broccoli as a high-tech research tool? It seems improbable but 78 Norfolk men are being invited to include a range of broccoli soups in their diet. They are being recruited via the urology department at the Norfolk and Norwich University Hospital and are patients with low or intermediate risk prostate cancer who have opted for the active surveillance regime rather than treatment.

Professor Richard Mithen, leader of the research project at the Norwich-based Institute of Food Research, and one of his team, Dr Omar Al Kadhi, told the Norfolk and Waveney Support Group that, after 15 years of work to develop a better broccoli, the objective now was to study how well it worked.

The broccoli in question is not the standard, cultivated vegetable but Beneforte “super broccoli” which has been created by scientists at the institute and other research facilities on the Norwich Research Park, including the John Innes Centre, by interbreeding standard broccoli with a wild relative that grows in Sicily. Beneforte is becoming available in supermarkets but has been in short supply because of last summer’s bad weather.

The aim of the trial is to try to establish whether broccoli in the diet makes changes in our bodies and within prostate tissue to protect men from the emergence of new cancer cells. But rather than expect men to eat lots of broccoli the vehicle will be three different soups, such as broccoli and Stilton, with the broccoli content varying in strength.

The institute’s role is research into the relationship between food and health to enable society to achieve healthy and sustainable diets. The institute is a world leader in the study of pathogens such as salmonella and as a result of its work the shelf life of everyday food products has been extended.

Professor Mithen said that one of the reasons the Government provides 65 per cent of the institute’s funding through the Biotechnology and Biological Sciences Research Council was to support research into how we used diet and life style to ensure healthy aging.

Broccoli, tomatoes, oily fish and exercise in moderation were known to have a beneficial effect. The institute was looking into how these things interacted. The current project had received substantial funding from the Prostate Cancer Foundation (www.pcf.org), an American charity that was the most important body in the world in terms of prostate cancer research.

Dr Al Kadhi said that volunteers who took up the invitation to take part in the study would be tested by providing biopsy samples to check the effect of the soup diet and would also be asked to keep a food diary.

It has come to the notice of people on the Helpline and through the support groups, that information from the Federation workshops and the AGM, is filtering through to the group members, but it would be much better if group members could hear it first hand and in its entirety. These days are really stimulating and are a great opportunity to meet people from all over the country. They provide up to date information on the latest treatments, particularly relevant if you have advanced disease and provide information on the latest research.

The lunch is always extremely good and everyone who attends finds it really worthwhile. It is completely free and if you and your members are not keen to drive or come by train, you could consider hiring a mini bus. Partners are also welcome and it is an ideal occasion to learn more about the disease and to meet others who are in a similar supporting role.
This year’s Federation Autumn Workshop will be held at the Nicolson Building, University of Birmingham, on Tuesday 19th November.

In response to comments about the Annual Conference in May, we intend to make the event a much more interactive one, with an opportunity for members to network, exchange views and experiences so that they can better represent the needs of prostate cancer patients. Topics to be covered are to be finalised but will include: centralisation of prostate services – good or bad idea?; how to work with the new NHS commissioning arrangements; and new developments in the standard treatments.

If you have ideas for this or subsequent workshops, please email them to contact@prostatecancerfederation.org.uk.

Attendance, including lunch, will, as usual, be free for members of Member groups. Numbers are limited to 100 so to ensure your place, send an email to bookings@prostatecancerfederation.org.uk, stating names, affiliation (group of which you are a member) and any dietary restrictions.
The Bolton Group purchases Accuvein for local hospital

Stephen Gilbert

When Eva Lomas received a substantial collection in memory of her late husband Norman from family, friends and members of PCS North West, she wanted to put it to good use by purchasing a piece of medical equipment for the local Royal Bolton Hospital where her husband had been treated throughout his illness.

It was decided to purchase the Accuvein 4000, (an electronic vein detector used when taking blood samples and fitting cannulas).

However, excellent as the collection was, there was a substantial shortfall to reach the purchase price so members of the Bolton Prostate Cancer Support Group decided to make up the difference, taking into account that Norman and Eva had been active members of the Bolton group for many years. The money was raised and the instrument ordered.

The official presentation took place on the 14th May 2013 in the Churchill Unit, which is the cancer centre at the hospital. It was attended by several Churchill Centre staff and members of the Urology department. A good number of Bolton Support Group members attended including the Chairman, Mr John Burston, supported by the Vice Chairman and Secretary. Mrs Eva Lomas made the presentation on behalf of the group and donors to the collection. The medical staff involved are extremely pleased with the instrument which enables them to carry out their duties more efficiently and gives the patients a less stressful experience.

The local press and Medical Photographer were in attendance which will give Prostate Cancer Support some needed publicity.

Resources available from the Tackle Prostate Cancer Campaign

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 | Name: .................................................................................................. |
| Role of a Clinical Nurse Specialist | Group: ............................................................................................ |
| Clinical Trials | Address: .......................................................................................... |
| The Real Prostate Cancer Risk Management Programme | .............................................................................................. |
| Understanding Cancer Waiting Times | .............................................................................................. |
| Knowledge Empowers, Treatment Information Booklet | .............................................................................................. |
| It’s A Man Thing, Awareness Card | .............................................................................................. |
| ____________________________ | Post Code: ________________________________ |
| ____________________________ | phone: ________________________________ |
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