

prostate matters

the voice of prostate cancer patients and their families

Newsletter of the Prostate Cancer Support Federation  Issue 20 Spring 2013

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Worried or concerned
about prostate cancer?

National Help
Line

0845 601 0766

Prostate Matters Editor: Hugh Gunn
email: editor@prostatematters-uk.org

You can download this newsletter
direct from our website. Go to:
[www.prostatecancerfederation.org.uk/
ProstateMatters_latest.pdf](http://www.prostatecancerfederation.org.uk/ProstateMatters_latest.pdf)

The Federation email address is:
info@prostatecancerfederation.org.uk

This newsletter is published 4 times per 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

Prostate  Cancer
Support Federation

the voice of prostate cancer patients and their families
Reg. Charity No. 1123373

Annual Conference: "Clinical Trials, what, why and how" Tuesday 14th May 2013

The Federation will be holding its Annual Conference and Annual General Meeting in The Friends House, near Euston, London on Tuesday 14th May.

This year the topic is Clinical Trials, what they are, why you might want to get on one, and how to enrol. We have engaged a number of top speakers, including Professor Johann de Bono (one of the masterminds behind Abiraterone), from the Institute of Cancer Research, and Professor Mark Emberton from University College London Hospital. The full programme, which commences at 10:30 (registration from 10:00), and will be complete by 16:45, can be found on the Federation Website.

As in past years, the middle section of the day will be taken up with the Annual General Meeting. There will be some significant constitutional matters to be agreed, so it is important that member groups appoint a Delegate.

As usual, attendance, including lunch, is free to members of support groups. To book a place, send an email to: bookings@prostatecancerfederation.org.uk, stating the following information:

Name(s)

Contact phone number.

Support group of which you are a member

If you are that group's Delegate for the AGM (see Clause 7 of the Constitution)

Any dietary requirements.



Janssen sponsored the print production of this newsletter. Control of editorial content was retained by the Prostate Cancer Support Federation.

Setting up a Prostate Cancer Support Group

Doug Badger - South Warwickshire Prostate Cancer Support Group



Pictured Left to Right, Bill Mathews(secretary), Jo Platt (Treasurer) and Doug Badger

My prostate cancer was picked up in January 2004. I was 55, in good health and with no symptoms of prostate problems but my PSA kept rising. After the usual investigations my consultant told me I was a good candidate for a radical prostatectomy and in May I had the operation. Through that period I greatly appreciated the information pack provided by The Prostate Cancer Charity, the support of the specialist urology nurses and regular phone calls from a friend with prostate cancer. In January 2009 I retired and soon after was elected as a public governor for our local NHS Foundation Trust. A conversation with a fellow governor revealed that he also had prostate cancer and we agreed that we should approach the trust about setting up a support group. I met with the Urology Specialist Nurses who supported the proposal and offered to attend meetings whenever possible.

My wife and I had attended a meeting of the Solihull support group run by Mike Ince and were impressed by how it was organised. Mike provided me with a check list of key things to plan for. I looked in Stratford and found a place in the middle of the town. We chose Thursday afternoons, a time and day when the specialist nurses were generally available. The Trust created and distributed leaflets to all the GP surgeries in South Warwickshire and for the Urology Department to give to patients. The Communications Manager also drafted a press release.

It was impossible to know what sort of group was needed until potential members had met and even then it was

not very clear! However at our first meeting on 21st June 2012, which was attended by 16 people, it was agreed to meet every two months and to have time for discussion and for a speaker on an aspect of prostate cancer. Since then we have met four more times and our lowest attendance was 8. Our speakers have included David Baxter-Smith (Diagnosis and Treatment Options), Graham Fulford (The Promotion of Screening) and Ann Moore (Erectile Dysfunction). An increase in the cost of hiring our meeting room prompted a search for a new venue. An approach to our local day hospice was warmly welcomed and so our February meeting was held at the Shakespeare Hospice just outside Stratford. Our speaker was Bev Ballinger, Director of Clinical Services, who with a colleague gave a brief history of the hospice and the range of services available.

We now have a committee and a constitution (thanks to the Kettering and District Group). We have been supported greatly by the Federation and are delighted now to be proper members. We seem to be a group that will concentrate on supporting each other through the many and varied challenges of living with Prostate Cancer. Wives, partners and one daughter (so far!) make up a substantial and valued minority of the group's regulars. Communications are mostly by e-mail (some snail mail!). For me the greatest satisfaction has been to find that we have so much to talk about and especially to offer to those struggling with being newly diagnosed. I was well supported when I was diagnosed but I didn't have a group like this to share things with. Enough said!

PROSTaid Awareness Event 2013

Kate Gunn - PROSTaid

We held our latest and most successful PROSTaid Cancer Awareness Event at Leicester Racecourse on March 6th. Over 200 people attended and were educated and entertained by Mr. Ben Challacombe, Consultant Urological Surgeon & Honorary Senior Lecturer at Guy's Hospital & King's College Hospital London, on robotic prostatectomy surgery, using the Da-Vinci Machine. Our second speaker was Grand National winner, Bob Champion, telling us about his life as a champion jockey and how he overcame testicular cancer. To complete the evening, our final speaker was Dr. Julian Barwell, Consultant and Senior Lecturer in Clinical Genetics, University Hospitals of Leicester.



Mr. Ben Challacombe

Mr. Challacombe led us through the state of the art robotic treatment for a radical prostatectomy and we saw a video of the challenges of working remotely from the patient, but also what a difference it is making to damage limitation carrying out surgery in this way. Mr. Challacombe also pointed out jokingly, that the next generation of surgeons will adapt to this method far more readily, because of their dexterity in the use of computer games.

Bob Champion talked about his colourful life as a jockey, but also about how he beat the odds when he developed testicular cancer and how his determination drove him on to win the Grand National on his horse Aldaniti. He also set up his cancer charity at the Royal Marsden Hospital to carry out research into testicular and prostate cancers. His charity has raised £15,000,000 for research and they are going to open a new laboratory in Norwich.

Dr. Julian Barwell explained the highly complex world of genes and how they are trying to unlock the genetic information they are gathering, in particular with the BRACA 2 gene. Dr. Barwell also appealed to anyone with



Bob Champion

a familial history of prostate cancer to contact his unit, to help further their understanding of inherited cancer and to identify inherited risk.

Everyone had a thoroughly enjoyable and informative evening and PROSTaid would like to thank Leicester Racecourse and especially events manager, Tracey Chapman for making the event such a huge success.



Dr. Julian Barwell

Cancer and the Immune System

Dr David Boocock - John van Geest Cancer Research Centre at Nottingham Trent University

Our world is dominated by bacteria and viruses, which make you ill if they penetrate your body's defences. Once they do, we have to depend on our last line of defence – the immune system, for protection. Once activated, “defensive” cells (white blood cells) seek and destroy anything that is potentially harmful. There are many types of white blood cells that do different things – some will “eat” foreign invaders, others target our own cells that have become infected and others can release certain proteins called “antibodies” that mark cells for others to destroy.

Most people will have been vaccinated against common diseases at some point. The reason that vaccinations (or immunisations) work is that they replicate the process of infection by exposing the immune system to harmless components of invading organisms. The immune system has a good memory and once exposed to an ‘invader’, it can respond to it much faster the next time it encounters it, even if this is years later.

Cancer cells begin life as normal cells in our body, but for some reason they become abnormal and start to grow uncontrollably (due to damage, infection or a genetic problem). Our immune system is usually able to recognise these abnormal cells and keep them in check before they can develop into “cancer”. We know that if the immune system is suppressed, such as when drugs are given to stop “rejection” after organ transplantation, the chance of cancer occurring significantly increases.

One approach for treating cancer, which shows great promise, is the development of vaccines that can activate the immune system to attack cancer cells. These can be given when cancer has already been diagnosed, an approach called “immunotherapy”. Activating the immune system by showing it a part of the cancer cell to which it can react to (a fragment of protein for example) will train it to fight the cancer and provide long-term protection against it. This approach also has far fewer side-effects than chemotherapy.

An example of immunotherapy in prostate cancer is Provenge (Sipuleucel-T) that was approved for treating hormone-refractory disease. The treatment involves removing immune cells from a patient, manipulating them in a laboratory and injecting “primed” cells back into the patient. Current research at the John van Geest Cancer Research Centre in Nottingham is developing new vaccines for prostate cancer which would involve a course of injections that are similar to those which you would receive for tetanus or ‘flu. The aim is to develop vaccines that will kill the cancer and protect against it coming back. This work needs us to identify new ‘target’ molecules against which we can develop these protective immune responses in a range of patients. Although we have already found a number of potential molecules, more work is required in order to demonstrate their effectiveness. Importantly, some of these molecules might also be used to better diagnose disease.



Dr David Boocock

There are benefits of immunotherapy. Other treatments such as radiotherapy and chemotherapy, kill, burn and poison cells. They are unable to distinguish cancer cells from non-cancer cells therefore healthy cells are destroyed and can leave the patient with a weakened immune system plus many more unwanted side effects. Immunotherapy could also be used in addition to surgery, as it can to attack cancer cells that have spread and/or are too small to be removed by an operation alone.

Dr David Boocock is one part of a large research team at the John van Geest Cancer Research Centre at Nottingham Trent University: <http://tinyurl.com/JvGCRC>

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

DUCTAL PROSTATE CANCER

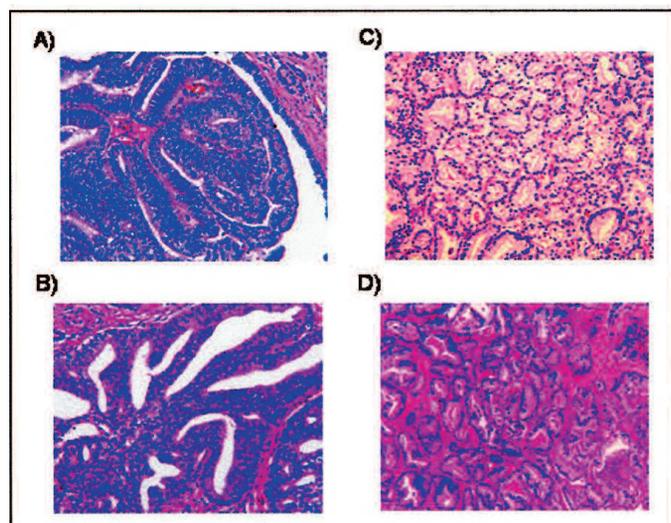
Ian Graham-Jones - PCaSO

When I first heard of this, as a result of a help line enquiry by one of our members of PCaSO who had been diagnosed with ductal carcinoma of the prostate, my reaction – I suspect like most of our readers – was “Eh, what’s that?” As a result of some research, and with much thanks to helpful responses from our three medical advisers, I thought it would be appropriate to give an account of what I have gleaned about this very rare variant of our ‘normal’ prostate cancer.

What follows, I must stress, is purely a layman’s account, so clinicians and others with expertise please forgive any errors.

Less than 1% of men are diagnosed with ductal prostate cancer. Unlike ‘normal’ prostate cancer (which technically a US paper calls ‘acinar’ prostate cancer) which generally starts in the area towards the outer edge of the prostate, ductal cancer starts in the ducts close to the urethra and is therefore found in the central area of the prostate. It is therefore unlikely to be detected early by the usual DRE, or digital rectal examination. It is often an aggressive form of the disease, and can spread to the urethra and other surrounding tissues. Unlike ‘normal’ prostate cancer, which in its early stages usually has no symptoms, and the first indication may be a raised PSA level, the early symptoms of ductal prostate cancer may well be pain on urinating and other urinary symptoms such as urinary obstruction or blood in the urine. These symptoms may well be confused with one of the other prostate diseases such as prostatitis or BPH (benign prostate enlargement), and so treated by the GP with antibiotics or other conventional drugs. Again, unlike standard prostate cancer, the pure ductal variety is not PSA responsive, so there may well be no rise in the PSA. (Some prostate cancers may combine the two types, so in this case a PSA rise can be expected.) Because of its potential for aggressiveness, however, it does need to be seen by a specialist consultant as soon as possible.

The only clear diagnosis can be made with a biopsy, where the structure of the cells is unmistakably different from the ‘normal’ variety.



The pictures show what the pathologist will see under a microscope after a biopsy: a typical standard Gleason 3 pattern cell structure (as shown in C & D) compared with the ductal variety (as shown in A & B) which, even to the layman, appear totally different. Thus the pathologist cannot identify it with any of the standard Gleason patterns, so it is usually graded as a Gleason 4. (You can find a diagram of the five Gleason patterns and a picture of a typical Gleason 3 sample in PCaSO’s Information Book in sections A3 and A4, which may be downloaded from our website www.pcaso.org). Sometimes, because it constricts the urethra, it can be revealed by a cystoscopy – an examination of the bladder.

Prompt referral to an oncologist rather than a urologist is recommended by all three of our medical advisers, as it is more responsive to radiotherapy if caught early enough. The pure ductal variety often does not respond well to conventional hormone therapies, and some specialists suggest that early chemotherapy treatment may be advantageous. However, consultants see so few cases of this variant that there is no clear evidence of the best route for treating this seemingly rather unpleasant form of the disease.

Royal Shrewsbury Hospital given Prostate Cancer Scanner

Christine Bolingbroke



Campaigners in Shropshire have raised £11,000 for a new scanner to detect prostate cancer.

The ultrasound machine was donated by the Shropshire Prostate Cancer Support Group to the Shrewsbury and Telford Hospital NHS Trust.

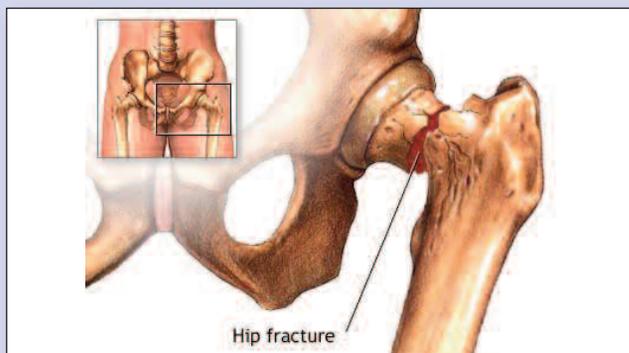
Andy Elves, a consultant urologist from the trust, said: "Without the support it is unlikely we would have been able to buy this."

The machine is being used at the Royal Shrewsbury Hospital.

Bone Health – A Patient’s View

Hugh Gunn & David Smith

If you are unfortunate enough to be diagnosed with advanced prostate cancer, or your cancer has become advanced, the only treatment option available is Hormone Therapy. Although this will prolong your life, it will also cause osteoporosis, which in time can lead to Skeletal Related Events (SREs). It is therefore important to understand the particular problems surrounding advanced prostate cancer.



In every other cancer, NICE has laid out a treatment pathway which involves the use of bisphosphonate drugs and latterly, Denosumab for bone health. These drugs help to limit the damage to your skeleton caused by hormone therapy and therefore avoid SREs.

Not so with prostate cancer, as there is no such pathway laid

down by NICE involving bisphosphonates for bone health, so it is important that the patient knows about the issues involved.

Bisphosphonates

There are many bisphosphonate drugs and many are taken orally, once a week on a particular day. They are taken first thing in the morning with a full glass of water, on an empty stomach. The patient has to be either sitting or standing in an upright position and must not eat or drink anything for at least 30 minutes after taking.

The gold standard bisphosphonate treatment is Zoledronic Acid, marketed as Zometa. This is given as a monthly infusion into the patient’s arm and requires a visit to hospital. Blood tests have to be taken either on the day, or in the days immediately preceding the infusion. This treatment will involve spending most of a day in the hospital.

Denosumab

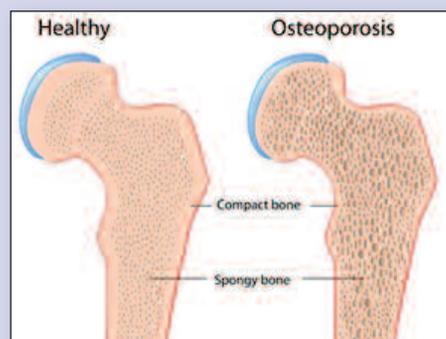
Denosumab is a new drug for bone health which has just been passed by NICE for all cancers, apart from prostate cancer. It works in a different way from bisphosphonates in that it is a fully human monoclonal antibody and instead of putting a coating on the bones, it prevents bone destruction. Denosumab is given by an injection every 4 weeks given by your healthcare professional.

All of these treatments are well tolerated, but as with all drugs, there can be side effects. The most serious of these is a condition called **osteonecrosis of the jaw**. The symptoms may include jaw pain, swelling, numbness, loose teeth, gum infection, or slow healing after injury or surgery involving the gums. In view of this, dental hygiene is of vital importance. To assist with this, there is a toothpaste called **Duraphat 5000**, which is available from your dentist on prescription.

Summary

Once again prostate cancer sufferers are being denied access to a therapy that could strengthen their bones; preventing osteoporosis and even fractures that can occur with weak bones. Hip fractures are common just getting out of bed and falling over. One can only surmise that the NICE decision is based on economics because there is no medical reason why men on androgen deprivation therapy (ADT) should not be prescribed this drug especially if a bone density scan shows adverse weakening of the bones.

We need men to appeal to their MPs to raise this issue so that it becomes a loud chorus both in the media and Parliament.



York and Selby Prostate Cancer Support Group

The group meets at York District Hospital at 6pm in the post graduate lecture suite about 4 times per year supported by a urology nurse specialist. There is also an opportunity to chat over a drink at Selby Bowling Club on the first Wednesday of the month at 7.30pm. There may be a few exceptions eg New Year’s Day, check with Bryan on 01757 228394.

Further meetings planned this year are:-

Monday June 3rd “How Macmillan helps in the area”

Monday Sept. 9th “To screen or not to screen”

J R Wilson Consultant Urologist

Monday Nov 25th “Updates on clinical trials”

Lisa Mole, Research Nurse.

The group welcomes partners, spouses, relatives, carers or anyone else interested in prostate cancer.

The core Selby members are planning awareness days at various locations during the year including Morrison’s and Sainsbury’s supermarkets.

At the last York meeting in February, the speaker had a problem that stopped him attending. All was not lost as patients and carers shared their experiences and concerns.

Bryan Metcalf

bryan.metcalf@virgin.net

01757 228394

Exploring the Needs of Gay and Bisexual Men Dealing with Prostate Cancer

By Sean Ralph



Martin Wells of The Lesbian & Gay Foundation, Manchester

In September 2012 Prostate Cancer UK and Stonewall held a one-day workshop in London, to explore the potential needs of gay and bisexual men dealing with prostate cancer. The workshop was the first of its kind in the UK and brought together health professionals, researchers, expert organisations, as well as gay men with prostate cancer. Discussions held on the day recognised the need for more work to develop services to support gay and bisexual men. 'Exploring the Needs of Gay and Bisexual Men Dealing with Prostate Cancer', a report on key findings from the workshop, is now available on the Prostate Cancer UK website. One result of the workshop is that work is currently underway to develop patient information resources for gay and bisexual men dealing with prostate cancer.

Prostate cancer is the most common cancer in men in the UK and its incidence is significantly higher in men over 50. Over 40,000 men are diagnosed every year and around 250,000 men are currently living with the disease. A number of these men will identify as gay or bisexual. There is no evidence to suggest that gay and bisexual men have a higher risk of developing prostate cancer. But if you are in a relationship with another man, be that a long term relationship or one of a purely sexual nature, then you are twice as likely as a heterosexual man or woman to have to deal with prostate cancer in your lifetime; as both partners will have a prostate gland.

The main treatments available for prostate cancer are

surgery (prostatectomy) and radiotherapy, which is often used in combination with hormone therapy. All of these treatments can have gruesome side effects such as incontinence, infertility and erectile dysfunction. These side effects can affect gay and bisexual men differently to heterosexual men.

Prostate Cancer UK, the Lesbian and Gay Foundation and the US based nonprofit organisation Malecare recognise that prostate cancer can affect gay and bisexual men differently to heterosexual men and so are currently working in partnership to set up a prostate cancer support group in Manchester. Existing support groups may lack the resources or knowledge to be able to confidently offer support to gay and bisexual men, who themselves may be unwilling to disclose their sexuality in this setting. If you are a gay or bisexual man dealing with prostate cancer, then this support group will offer you a safe and confidential environment to discuss your concerns and experiences with other men dealing with the same problems.

The support group, 'Out with Prostate Cancer', will meet on the first Saturday of every month, starting from 6th April, between 2-4pm at:

The Lesbian and Gay Foundation's Community Resource Centre, 5 Richmond Street, Manchester M1 3HF.

E-mail outwithprostatecancer@yahoo.co.uk to register your interest.

If you do not live locally and are willing to travel to attend the group, but may not be able to due to financial reasons then Prostate Cancer UK can help pay towards your travel costs. Contact Ann MacEwan, Prostate Cancer UK's support groups manager, for more information.

Email: ann.macewan@prostatecanceruk.org

or telephone: 0141 314 0050

The next meeting will be on Saturday 4th May 2013

(2pm-4pm) in Manchester at The Lesbian & Gay Foundation Community Resource Centre, Number 5 Richmond Street, Manchester M1 3HD for more information e-mail: outwithprostatecancer@yahoo.co.uk

Prostate Cancer Support Federation

the voice of prostate cancer patients and their families

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To View other roles carried out by volunteers, please visit:

<http://tinyurl.com/3psctpv>

Prostate Matters is published four times a year, providing news, information, personal memoir and opinion about prostate cancer. It also reports, quotes and cites published medical views and research findings about prostate problems.

The Federation does not promote any treatments or dietary, drug, exercise or lifestyle change intended to prevent or treat a specific disease or condition. Anyone who wishes to embark on any such treatments should first consult with and seek clearance from a qualified health care professional on any treatment or lifestyle changes

Night Sweats and Hot Flushes and Acupuncture.

Christopher Woodward - Acupuncture from the therapist at Breast Cancer Haven



Christopher Woodward

Night sweats (NS) and Hot flushes (HF) can be distressing symptoms that may be alleviated by a course of acupuncture. Nights of disrupted sleep, days of "too hot, too cold" can lead us to despair, feeling as though our body's thermostat has lost control.

The strength of acupuncture in this situation is that it can help to vent heat from the body and aid the body in recovering its strength to cool itself. The body is both too hot and too tired in this state.

Contrary to much belief, we need enough energy to go into sleep deeply and re-nourish ourselves. Paradoxically, some sleep problems are aggravated by being over tired, insofar as the body and the mind are already agitated by adrenalin when we are trying to unwind. We also need enough strength to hold our core temperature in its correct place, allowing the integrity of our systems to function properly. Lastly, we need energy to adapt and cope with change, physically and emotionally.

NS and HF will obviously be agitated by adding more heat and sedated by coolness. We can say that things can be physically hot (a hot drink, central heating), stimulating (coffee, sugars, chilli, alcohol, some medications), or emotionally heating

(anger, stress, a feeling of confinement). Things can be physically cooling (drinking cool water often, fresh air, loose cotton clothing), energetically cooling (cucumber, celery, green vegetables) or emotionally cooling (relaxation, pacing our day).

Commonly, with weekly acupuncture, the number and intensity of sweats will decline, sleep and energy levels will improve. In the best case scenario NS and HF will stop, within a regime of on going medication they should become insignificant, and in the worst cases ongoing acupuncture can make NS and HF more manageable.

At Breast Cancer Haven we have also introduced a weekly Ear Acupuncture Group. This is a very cost effective way for an organisation to offer ongoing, drop in treatments for a large number of patients. However, it is within a one hour, one to one treatment that the most progress can be made.

As with most things in life, a personal recommendation is the best way to find an acupuncturist that can help you. Otherwise, The British Acupuncture Council will recommend an accredited acupuncturist in your area.

The human body's ability to adapt and survive is remarkable, if we help it, it becomes truly sublime

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