

prostate matters

The Newsletter of The National Federation Of Prostate Cancer Support Groups

Free Help Line - 0800 035 5302

tackle

prostate cancer

Action for patients

Registered Charity No. 1163152

August 2018 issue 41



Tackle Prostate Cancer is now a recognised Saga Charitable Trust charity. See page 5.

Tackle 2018 AGM and Conference "Healthy mind, Healthy Body"

Roger Wotton welcomed everyone to the conference reminding us all of the importance of the psychological and emotional impact that prostate cancer has on those diagnosed with the disease.

The National Federation of Prostate Cancer Support Groups is now ninety strong and some twenty six were represented at the conference. Since last year's AGM Roger has personally managed to visit sixteen of these groups with more pencilled in over the next few months.

Chris Booth MBBS FRCS, Emeritus Consultant Urologist Colchester, spoke briefly on the need for more informed testing. The National Prostate Cancer audit showed that over-treatment continues to reduce.

There was a slight increase in the death rate, mainly due to an ageing population. Just over 50% of men diagnosed were over 70 years of age and over half of the men presenting had advanced disease.

Only 10% of men get PSA testing and 8% of those with low risk non-aggressive cancer are still being given radical treatment. It is now more important to have an MRI scan prior to biopsy. Clinical practice has improved and men with non-aggressive disease are being put on Active Surveillance (AS) which means that things are moving in the right direction. Educating people in primary care remains important as we still hear of cases where GPs are reluctant to offer PSA tests.



tackle Has now produced a Lapel Pin Badge. Each group has been sent a complimentary ten. If you need more, we would suggest a donation of 50p each plus P.P. Please contact rob.banner@tackleprostate.org.

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Lifestyle and Prostate Cancer: "A Review of the Evidence"

Prof Robert Thomas – Cons Oncologist – Bedford and Addenbrookes University Hospitals

Robert stated that a 30% detection rate for newly diagnosed men has risen to 80%. Those diagnosed with metastatic disease were once given a survival rate of approx. 18 months which has now increased to 10-15 years, proving that men are now living with the disease for much longer.



Gut health is hugely important. Calories interact with each other causing obesity, arthritis, dementia and heart disease. Moderate exercise which raises the heart rate helps to reduce the risk of prostate cancer. Changes in the body occur when exercising, improving the body's own immunity. The genes you are born with can be altered and the good genes can be enhanced, addressing chronic fatigue. Osteoporosis means that bones are more prone to breaking or fracturing and just walking does not do much to improve this. Squats and weight bearing exercises improve bone density. Exercise can also help to reduce erectile dysfunction (ED) and rectal bleeding and may also help to improve low mood while reducing testosterone levels. Depression is thought to make cancer more likely to return.

Obesity is believed to cause prostate cancer patients to relapse. Sarcopenic obesity, which is fat around the internal organs, raises the risk of cancer. Fasting overnight for 13 hours lowers the risk of cancer recurrence and walking before having breakfast is beneficial. It should be remembered that exercise can still help even before actual weight loss occurs.

Polyphenol foods (plant based) are so important to health, helping to eliminate possible cancerous cells. Processed sugar in foods should be avoided as these give an instant energy hit, leaving you hungry again an hour or so later, inevitably leading you to eat again. Sugar should not be added to tea and coffee. Slow release carbs help you to feel full for longer without giving you that instant hike that sugar does.

Healthy gut bacteria can be found in live yogurt which helps to maintain the correct levels within the gut. A Mediterranean diet has enormous health benefits and improves the immune system. It is very important to eat colourful vegetables, fruits and green foods such as broccoli, Brussel sprouts and asparagus, the last three being especially beneficial. It is a good idea to avoid taking mineral and vitamin supplements. A trial has shown that a polyphenol food supplement, manufactured from vegetable extracts, Pomi-T can slow down the body's PSA.

An Holistic View of Managing Health

**Dr Stephanie McArdle - Snr researcher in tumour immunology
Nottingham Trent University**

Cancer is a personal, complex disease which each individual can do something about. To be fit and healthy is a lifestyle and it is never too early or too late to have a good lifestyle. We are each unique, born with a set of genes. Our genetic marker is what it is and even in twins they do not get the same disease. The gene is switched on or off and both food and sleep influence this on/off switch. Sleep, stress and diet are influenced by our own DNA or genetic marker.

Having pets can be relaxing and calming and this contact with animals may protect against asthma and eczema. Some dirt and



germs are beneficial as they help to build up our own immunity. Lifestyle directly affects the immune system.

Basically you have to learn what works for you by listening to your body. As we age our lifestyle should change because what is good for you at sixteen may not be at sixty! For example you need more protein as you get older and you need to learn what is good for you at your particular stage of disease. There is a definite link between the brain and gut. Some may eat when stressed while others may be unable to eat. The brain focuses on past emotions which we may suppress, so the need to talk is very important. You have to excise your inner demons to make your own healthy journey. A cancer diagnosis is an alarm bell but each person is not powerless. The power of the mind should never be underestimated.

Re-visit your diet, consider meditation which may work for you, optimise your sleep and look after your oral care. Try your hardest to have a positive mental attitude, a glass half empty and a glass half full, the actual water content is the same. It is a good idea to list both your negative and positive thoughts and to try to be more content. Learn to calm your mind and remember the power of laughter. Physically and emotionally do your own MOT. Ask yourself "How do I feel?" "Am I valued?" Have a purpose in life, help others, get support from family and friends and learn to say "No". Give your brain and body enough time to relax by doing what is good for you. Adopt a craft, read or watch a film. Each patient carries his own doctor inside himself. Nothing is more rewarding than making someone else happy. Attitude matters. Focus on living. The essence of health is the constant renewal of the rejuvenation of life!

Integrating the Art of Living with the Science of Health.

Sue Cooper - Integrative Health and Well-being Advisor to Nottingham Hospice

Sue's aim was to ignite awareness to one's own healing potential. When you merge science with art, such as painting you get clarity and creativity. It is helpful to feel control again and to use support from those around you. The mind and body are interconnected and your thoughts can change your gene expression. Wellbeing is a skill that can be learnt. The Seven Dimensions of Wellbeing are:

- 1 Social wellness: The ability to relate to and connect with others. To establish and maintain positive relationships with family and friends.
- 2 Emotional: To understand ourselves, acknowledge and share feelings of anger, fear, sadness, stress, hope, love, joy and happiness.
- 3 Spiritual: To establish peace and harmony in our lives.
- 4 Environmental: To make a positive impact on the quality of our environment in our homes and on our planet
- 5 Occupational: To get personal fulfilment in maintaining balance in our lives.
- 6 Intellectual: To open our minds to new ideas and experiences, to improve skills and seek challenges.
- 7 Physical: To maintain a healthy quality of life, a healthy diet and exercise, while avoiding destructive habits such as smoking, drugs and alcohol.



A Personal Battle with Terminal Cancer

Connell McNelis

After noticing blood in his urine at age 32 years Connell was diagnosed with a cancerous tumour on his kidney. This was removed, but he had felt a small lump on his head which he mentioned to his surgeon who thought it was probably a sebaceous cyst. His consultant thought that the cancer removed from his kidney seemed to be contained and his lymph nodes were clear.

Connell wondered what he could do to help himself, possibly becoming vegetarian? He booked in to a centre specialising in healthy eating, promoting vegetable and fruit juices, Reiki healing and meditation. He woke up feeling very ill and was told it was just his body detoxing itself. Sure enough the following day he felt great, even going for a six to seven mile run.



He returned home, but the lump on his head was still concerning him so his GP referred him to hospital for it to be removed. The consultant rang him at work with the news that this lump was in fact a metastasis to the kidney cancer. It was thought to be a stage III, but in fact turned out to be a stage IV and that his survival was possibly 12 months. A real bombshell; the new cancer cells were increasing so rapidly that Connell talked about his death and funeral arrangements. He was put into palliative care at his local hospice.

Connell's quality of life plummeted, he lost his sense of taste, his appetite, the feeling in his fingertips and had crops of mouth ulcers. He felt his treatment was making him so ill that after discussion with his consultant he stopped his treatment. He listened to his own body. He tried fasting, detoxed his body and started coffee enemas.

Sadly, he was then diagnosed with a brain tumour which was found to be aggressive after its removal. Connell continues with the coffee enemas which he finds very useful and now takes cannabis oil. He is fighting his disease his way with courage and realistic hope. This was a moving story told with humour and positivity.

**Reporting of our AGM by Terry Garrigan - Purley Prostate Cancer Support Group (SEHC)
All the speakers presentations are available on our website.**

Videos of the presentations will shortly be available on our website and contain much more information than can be included here. www.tackleprostate.org

Captain Julian Burgess Appointed as an Ambassador for Tackle Prostate Cancer



We are pleased to announce that Captain Julian Burgess Master of the MV Saga Sapphire has agreed to become an Ambassador for Tackle Prostate Cancer. We are very honoured that he has joined our team and feel sure he will continue to increase awareness of Prostate Cancer and raise funds for us to continue our work. The Captain's interest in our charity was sparked by John Coleman, one of our trustees, who was on a Saga Sapphire cruise; at a 'meet the Captain party', the Captain noticed the lapel badges he was wearing and enquired about them. After a few more discussions about our charity he decided to support us. Thanks to him we are now a recognised Saga Charitable Trust charity.

Captain Julian started his nautical career in 1980 and was appointed as a Third Officer in 1984 with Princess Cruises, sailing mainly on the Island Princess and Pacific Princess, affectionately known as 'The Love Boats' from the US television series.

He was promoted to Captain in 2004 at the age of 40, at the time he was the youngest Captain in the P & O/ Princess Cruises Fleet. During his 14 years as Master on P & O Cruise Ships he had the honour of taking command of Cunard's newest liner, Queen Elizabeth, for two years including her maiden world voyage.

Julian is 'now done' with big ships, and is thoroughly enjoying his new career with Saga Cruises where he feels he has found his niche and fully understands the high level of personal service and attention that make Saga so special.

'Beat the Ship' and 'Cycle to the Moon' Events

On the 18th June, Captain Julian Burgess and his staff started the 'Beat the Ship' charity cycle ride he had planned along the Kiel Canal and a Cycle to the Moon event on board .



Beat the Ship Team

The 'Beat the Ship' team disembarked at the Haltenau Lock with the aim of beating the ship to the Brunsbuttel lock, a distance of some 110km or 68 miles. After some eleven hours, the cyclists finally arrived at the agent's office in the dark and only just beat the ship. They looked "rather tired"- there were a few stories to tell, especially from Stuart Anderson, resident house musician, who seemed to take an "alternative" route to everyone else. Falling into a ditch, walking down a railway track

and asking some fire-fighters for directions were just a few tales he shared!!

Whilst this was going on 30 crew and seven passengers took part in a 'Cycle to the Moon' event on the Veranda Deck of the ship which started at 9.00am going on to 6.30pm

The events raised over £6,000 for Tackle Prostate Cancer when the gift aid is included. We very much appreciate what Captain Julian has done for us and he has informed us that he intends to stage similar events in the future to raise more funds for us.



Captain Julian starting the event

Captain Julian also supports the charity Silver Line, a charity for older people. They have a 24 hour, 365 day per year, free helpline, 0800 4 70 80 90, giving advice etc. to older people. Their website can be found here:

<https://www.thesilverline.org.uk>

Hugh Gunn 1943 - 2018 In working to improve the lives of others, he transformed his own.



On Monday 18th June my friend Hugh Gunn, Trustee, long time editor of Prostate Matters and the Federation's Patient Representative to NICE, passed away after a 12 year battle with prostate cancer. When he was diagnosed, the disease had already metastasised throughout 75% of his skeleton and his PSA count was over 700. He was given approximately two and a half years to live. This devastating diagnosis forced his retirement from running the family business and utterly changed the course of his life.

Instead of accepting this prognosis, he and his wife Kate researched all options and he was fortunate enough to be accepted on the STAMPEDE trial; he became active in PROSTaid, his local support group and quickly joined the management committee. He subsequently became a trustee and the Honorary Treasurer and worked tirelessly in both outreach and fundraising events.

In 2008, Hugh joined the Prostate Cancer Support Federation, which now operates as Tackle Prostate Cancer, and was soon a Trustee and Honorary Treasurer. Three years later, he became the Federation's Patient Representative to NICE and made representations with regard to the evaluation of treatments for advanced patients. He travelled the country attending and speaking at conferences to help broaden the knowledge of patients and also addressed groups of health professionals and lobbied politicians. He was frequently interviewed for radio and television, giving the patient's perspective of living with the disease and discussing new treatments as they became available. For ten years Hugh and Kate were also part of the team who manned the Federation's helpline, giving advice and comfort to countless worried patients.

In all the many tributes to Hugh there have been constant references to his warm and generous spirit, his inability to say no to any request and his utter determination to fight for other men to have access to the treatments he had benefitted from. Typically, when Hugh's health worsened, he was concerned about the Federation and set about succession planning. He asked me if I would take on the editorship of Prostate Matters and Steve Allen if he would become the Tackle Patient Representative to NICE.

At the Tackle AGM in May, although it was apparent that he was failing and was too ill to attend, Hugh was re-elected as a Trustee, a mark of respect and appreciation for all he had achieved. He will be greatly missed.

David Marsh

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Two months before he sadly died, Hugh Gunn had asked me to take over his responsibility as the Tackle Patient Representative to the National Institute for Health and Care Excellence (NICE). I know that originally he found this task a little challenging but he came to view the work of the committee with great respect and to view the people concerned as a very committed group often required to make extremely difficult decisions.

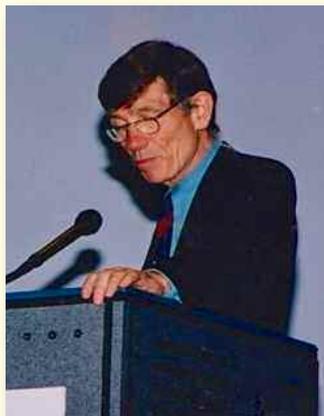
I recently had my first experience of observing a NICE meeting and can echo Hugh's views. The meeting was to discuss an application for Abiraterone to be used in a new clinical setting – the treatment of newly diagnosed patients with hormone naïve metastatic prostate cancer. This would mirror an indication already approved for the chemotherapy drug Docetaxel.

Sadly a definitive decision could not be made at that time as NICE were still awaiting the details of the complex pricing structure being discussed by the drug manufacturer and NHS England. However, approval has not been categorically denied and a continuation of the appraisal will be made at a later date.

I will keep everyone informed of future progress and any other important developments in prostate cancer treatment that require NICE approval.

Steve Allen

John Dwyer 1928 – 2018 A Gentleman and a Scholar



In 1996 Roy Nixon and Ray Dalton met to discuss their condition at a pub in Cheadle Hulme near Manchester and a local patients' group grew from there. John had been diagnosed with moderately advanced prostate cancer in 1998 and he joined 80 patients and carers at a meeting in Christie's hospital in Manchester that year.

Another group, set up in London by Angus Earnshaw in 1995, developed into the Prostate Cancer Support Association (PCSA aka PSA) in 1999. A number of regional groups affiliated with this group, including the North West group led by Roy Nixon. When John first joined the national committee of the PCA the one thing everyone agreed on was that the atmosphere was divisive and not conducive to collaboration. The aim, going forward, was to both encourage as much local initiative as possible, and combine as one voice for patients nationally.

John was in many ways the inspiration and moving force behind this vision. He proposed and chaired a working party, to look into the PSA's constitution, which considered a variety of organisational structures, before recommending that the regional groups become independent, self-managing charities, with which smaller local branches (themselves self-managing) could associate. The charities themselves would come together in a federation. In November 2001, the group's proposals were unanimously adopted.

John showed amazing calm and leadership throughout this period, smoothing ruffled feathers and focussing minds, with the result that in 2009 we were finally able to launch the charity and get commitment from nearly 50 local support groups. It is fair to say that without John's wise leadership this would not have happened. We miss him, and we should be grateful for all he gave to Tackle.

The PCS Federation was launched at Imperial College in April 2008, John was the chairman. The federation's purpose, he said, was to provide a focus or forum for views, to generate a single voice of patient led prostate cancer groups, in relation to awareness, health care, advocacy and research priorities.

John also represented the federation on the British Prostate Group and the Patient User Group and as a patient, in a number of groups developing protocols for clinical trials. He was a member of the STAMPEDE trial management group, the Prostate Clinical Studies Group at the NCRI, the Greater Manchester and Cheshire NHS Cancer network, the Patch trial and the Low Risk trial.

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www.tackleprostate.org

The National Federation Of Prostate Cancer
Support Groups

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Supporter

Jason Leonard OBE

Honorary President

Sandy Tyndale-Biscoe

Our volunteers:

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Ken Mastris, Secretary
Professor Frank Chingwundoh MBE,
Clinical Advisor
Erik Friis-Scheel, Finance
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John Coleman Help Line Co-ordinator
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This edition compiled by David Marsh
who would like to thank everybody who
has contributed to Prostate Matters.
Without you, we would not exist. Please
keep the contributions coming to:
editor@tackleprostate.org
Please send any photos separately at
high resolution.

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Your individual copy of Prostate
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Contact details can be found here
<http://tinyurl.com/omp6y5e>



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TACK13 £

Please Check Your Details

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

We are asking all affiliated groups to check their
details on the Tackle website. The information has
been updated to include meeting times and places.

See the map at: <http://tinyurl.com/omp6y5e>

If there are any corrections required please

contact Simon Lanyon by email:

simon.lanyon@tackleprostate.org.

PSA Testing Events

If your group is holding a PSA testing event,
we'll add it to the list on the Tackle website.
Email info@tackleprostate.org with the date,
time, town, post code, contact name and phone
number.

Don't forget, the National Help Line
is now Free of charge:

0800 035 5302

Half of Wales still denied access to 'biggest breakthrough in prostate cancer diagnosis for decades'

Prostate Cancer UK calls for action to tackle this injustice.

A Freedom of Information request from Prostate Cancer UK has
found that large parts of Wales still don't have access to the
latest diagnostic scans for prostate cancer. Eighteen months
after the PROMIS trial first proved multiparametric MRI (mpMRI)
before a biopsy could radically boost detection of prostate
cancer, Wales is lagging behind other parts of the UK in terms of
making this breakthrough diagnostic available, putting Welsh
men at a disadvantage.

Only three out of seven Welsh Health Boards are providing
mpMRI before biopsy. Out of those three, only two, Aneurin
Bevan and Cwm Taf, are providing mpMRI to a high enough
standard to safely rule men out of biopsy. This represents no
improvement since the Boards last responded to an FOI on this
in Autumn 2016. The level of provision compares poorly to Eng-
land where the majority (92%) of areas are providing mpMRI
before biopsy and 60% are providing to a high standard.

Prostate Cancer UK is calling on the Welsh Government and
Health Boards to take urgent action to end this variation in
access by prioritising the service transformation and additional
resources needed for all men with suspected prostate cancer to
access an mpMRI scan before a biopsy.

Dr Thomas Stuttaford OBE, born May 1931, died June 2018

It is with great sadness that we announce the death of our
patron, Dr Thomas Stuttaford, GP, MP and medical journalist.
"Dr Tom", as he was known, first joined us in 2009 when he
spoke at the Annual Conference and became our media and
political advisor. He accepted the role of Patron in 2011. A full
obituary will appear in the next edition of Prostate Matters.