



Cotswolds Prostate Cancer Support Group

Monday 9th October 2017

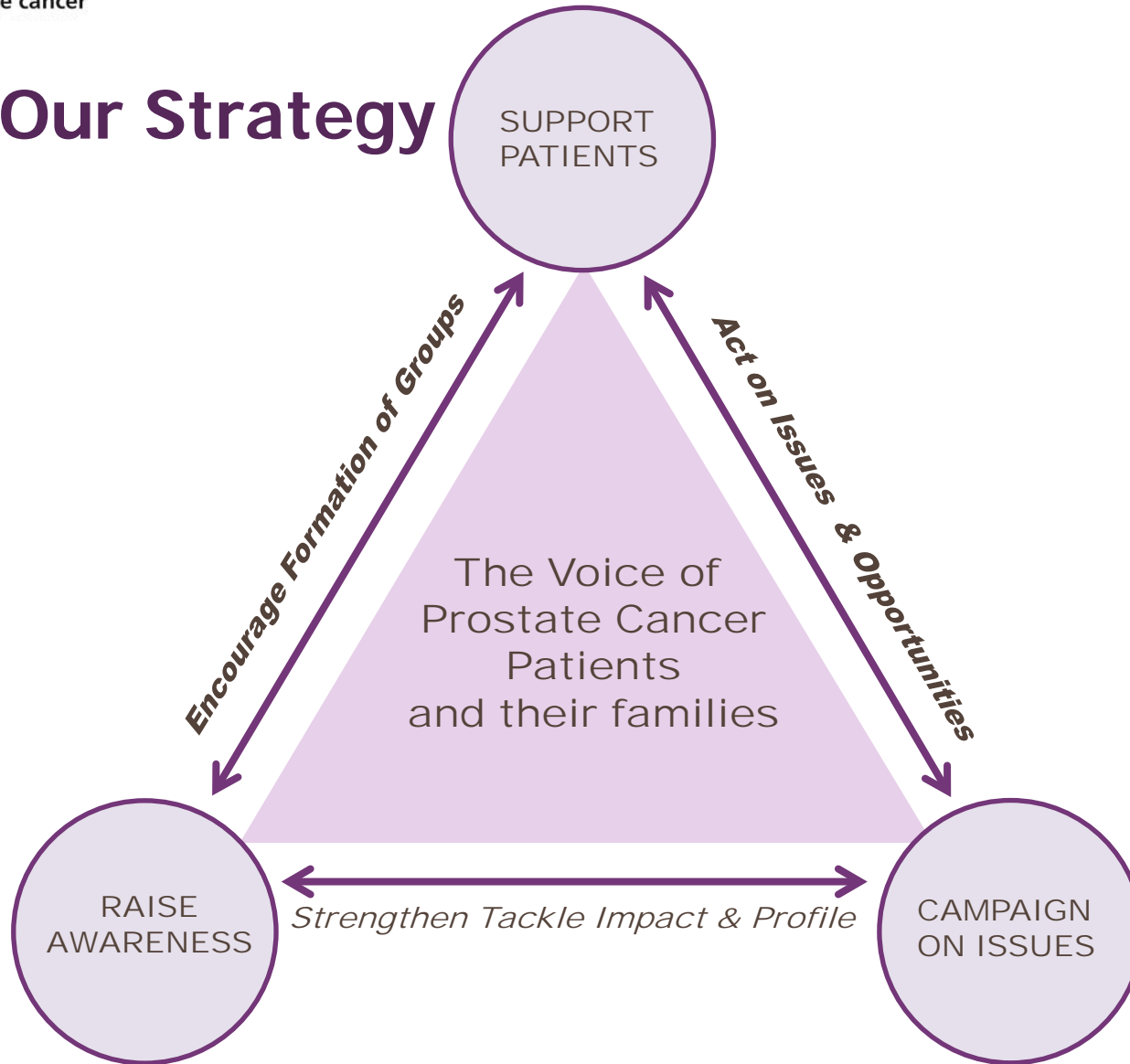
Roger Wotton
Tackle Prostate Cancer

Three topics to discuss.....

- *A word on Tackle*
- *To Screen or not to Screen*
- *The Future*

Followed by Q & A

Our Strategy



Looking at

SUPPORT
PATIENTS



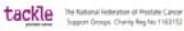
- Encouraging expansion of our support network – now up to 88 groups
- “How to” guide for new groups (setting up, tips and good practice)
- Value-added pack for support groups to include awareness pack, website template, slide presentation, banners, flags and badges
- New national helpline, with local helplines joining and 10% increase in calls
- Patient-focused Regional workshops
- Backing of Clinical Advisory Board
- “Strangers and Friends” video at <https://vimeo.com/152961653>

Examples taken from Tackle's support for groups

www.tackleprostate.org

Worried about Prostate Cancer?

Contact your local support group at



GET A SCORE ON THE BOARD

www.tackleprostate.org

tackle prostate cancer

10,000 men a year die from prostate cancer in the UK, that's one every hour

It doesn't need to be this way...



GET A SCORE ON THE BOARD

Why the walnut?

A walnut is about the same size as your prostate gland. We thought it was a good way to make you think about whether you might be at risk of prostate cancer.

Your risk is greater if:

- You are over 50
- You are African Caribbean
- You have a close relative who has had prostate cancer or breast cancer.

If you think you may be at risk talk to your GP about having a PSA Test. It's nuts not to.

www.tackleprostate.org

tackle prostate cancer Action for patients

Free National Helpline
 0800 035 5302
 or email
 helpline@tackleprostate.org

Our Helpline is run by patients for patients and for their families.

SAVE A DAD

Leighton Hospital Prostate Cancer Support Group and Awareness Campaign

10,000 men die of Prostate Cancer each year in the UK.

Home | Support | Awareness | PSA Testing | Contact Us | Gary Steele | Calendar | Links

Welcome to the website of the Leighton Hospital Prostate Cancer Support Group. It is a patient-led group holding bi-monthly meetings, social events, and regular PSA testing sessions in Cheshire, the North-West and beyond.

The group started in 2000 to offer support and advice to men (and their families) who have been diagnosed with Prostate Cancer. It was founded by our Chairman Gary Steele MBE. Click [here](#) to see an interview with Gary just after he won the Scottish Power & Trinity Mirror Cheshire "Your Champions" Award 2013.

Event Calendar

- Group Meeting at Leighton Hospital, Crewe 9 Jul 2016 10:00-12:00
- Group Meeting at Leighton Hospital, Crewe 10 Sep 2016 10:00-12:00
- Group Meeting at Leighton Hospital, Crewe 12 Nov 2016 10:00-12:00

Latest News Items

- Newsletter from Gary on Two Projects 10 Jun 2016
- Boys Canal Bike Ride in Aid of Prostate Cancer 10 Jun 2016
- Retirement With Radium: 223 Found Safe in mCRPC 1 Jun 2016
- Tackle say "Share Your PSA Experience" 30 May 2016

York & Selby Prostate Cancer Support Group

Providing support to prostate cancer patients in York and Selby

Tackle Helpline 0800 035 5302

Home Page | About Us | Contact Us | Meetings in York | Meetings in Selby

York & Selby Prostate Cancer Support Group

At York & Selby Prostate Cancer Support Group, we really do understand just how you now feel after being told you have got prostate cancer. We have already gone through the same traumatic experience ourselves and we have come out the other side. [We are here to support you.](#) Whether you would prefer to talk privately to one of our members, or alternatively to come along to one of our meetings, you choose and we will be with you, to help you manage your stress and any side effects from your treatment.

Come Along to our Support Group Meetings

Our formal support group meetings are held at York Hospital four times a year and from 2016, we will be holding two additional meetings at York Sports Club. If you decide to come to one or all of our meetings you will be made very welcome and your partner will be made welcome as well. It is unfortunate that our partners also have to share the consequences of our prostate cancer. As well as being able to talk to group members and their partners, you will listen to talks by specialists and among other things, they will tell you what progress is being made towards earlier diagnosis, better more effective treatments and hopefully in the not too distant future, a cure for prostate cancer.

Get in Touch with Us

If you think it would be helpful to talk to fellow sufferers – and it almost certainly will be – do [get in touch](#) with us. Our four York hospital meetings are held on Monday evenings, starting at 6.00pm and this year to make it easier for those who have had difficulty in getting to York hospital by 6.00pm, there will be two additional meetings at York Sports Club. These will be on Tuesday evenings and will start at 7.30pm. For details of all of our meetings during 2016, click on the Meetings tab.

If you live on the south side of York, you may also be interested in our monthly (first Wednesday in the month) meetings, which we hold at Selby Bowling Club, Buffam Lane, Selby, starting at 7.30pm. These [Selby meetings](#) are usually quite informal, and they provide an opportunity to meet, have a drink together and to share our experiences.

Important Information

York & Selby Prostate Cancer Support Group provides up to date information about prostate cancer. We offer support and help to members and their families.

Medical advice about an individual member's illness should always be obtained from a qualified medical practitioner.

Support Group Meetings

Support Group Meetings are held regularly in York and Selby. Refer to meeting pages for details.

Useful Links

- Tackle Prostate Cancer
- Prostate Cancer UK
- NHS Choices – Prostate Cancer
- Cancer Research UK
- Macmillan Cancer Support
- York Hospital
- York Sports Club

GET A SCORE ON THE BOARD

Tackle prostate cancer promotes early detection

Tackle prostate cancer is encouraging men to know their PSA or "Get a score on the board". Men who are at greater risk of prostate cancer are the most likely to benefit, for example if you are an African-Caribbean man you are three times more likely to develop prostate cancer than white men in the UK. If you have a family history of the disease, that is if your father or brother have had prostate cancer, you should also think about being tested. You can talk to your GP about having regular PSA tests as it may be useful to "Get a score on the board" so that any changes can be tracked. There is no screening programme in the UK but men over 50 are entitled to a PSA Test on request.

Can you help?

Tackle prostate cancer does not receive any statutory funding and is entirely reliant on raising its own funds. If you would like to support our work, there are many ways to do so: make a donation, fund raise for us, get your company involved, volunteer your time and skills.

We need your help. Please get in touch.

0800 035 5302
or email
helpline@tackleprostate.org

www.tackleprostate.org
 Twitter : [tackle@TackleProstate](#)
 Facebook: [www.facebook.com/tackleprostate](#)

The National Federation of Prostate Cancer Support Groups. Charity Reg No 1163152

tackle prostate cancer Action for patients

Looking at

RAISE
AWARENESS



- **“Tackle Man Van” is being developed with QEH Birmingham and UNITE Trade Union**
- **“Get a Score on the Board” continues with Rugby clubs**
- **Support for local PSA testing through Graham Fulford**
- **Black community awareness through “It’s a Man Thing” Jazz concerts, and partnering with Tackle**
- **“Manversation” initiative with Orchid and Bayer**
- **PSA testing : TUC Black Workers Conference April 2017 with agreed motion; ASLEF Conference May 2017; Letter to TUC; Prison officers’ Association in 2018**
- **Participated in PSA Consensus work; Promoting “To Screen or Not to Screen” debate**
- **“Tackle the Tiger” video at**
https://www.youtube.com/watch?v=HxZP_ZXf5j8&feature=youtu.be

Looking at

CAMPAIGN
ON ISSUES



- **Access to Cancer Medicine Coalition (working with 19 other cancer charities); CDF submission; Letter to The Times and MPs; Question in House of Lords; 30,000 signature petition to NHS England**
- **Submission to National Screening Council**
- **UK 5-year cancer task force strategy**
- **Drug campaigns (Enzalutamide, Abiraterone, Cabazitaxel, Degarilix, Radium 223)**
- **Increasing media coverage**
- **Europa Uomo**
- **NICE consultation partner (note recent agreement on Docetaxel , mpMRI and imaging)**

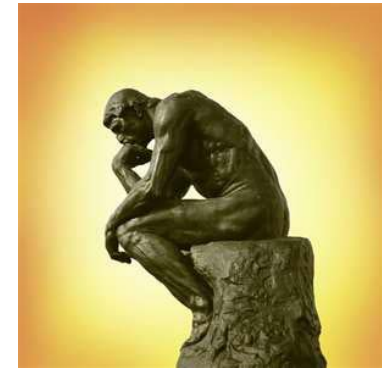
Looking at press and radio.....



Success in lobbying for drugs

Drug	Manufacturer	Tackle involvement	NICE Outcome
Denosumab For Bone Health)	Amgen	None	Passed for use in all cancers apart from prostate
Enzalutamide	Astellas	Patient Rep. on NICE Appraisal	Passed for use
Enzalutamide (Prior to Chemo)	Astellas	Patient Rep. on NICE Appraisal	Passed for use
Radium 223	Bayer	Patient Rep. on NICE Appraisal and appealed the preliminary decision	Now passed for use for all patients from September
Firmagon (Degarelix)	Ferring	Patient Rep. on NICE Appraisal and on appealing the final decision. Tackle became an appellant and had to give evidence twice at appeal hearings	Passed for use in patients presenting with spinal metastases.
Abiraterone	Janssen	Patient Rep. on NICE Appraisal and on appealing the preliminary decision	Passed for use
Abiraterone (Prior to Chemo)	Janssen	Patient Rep. on NICE Appraisal and on appealing the preliminary decision. Made the front page of the Times.	Passed for use
Cabazitaxel	Sanofi	Appealed against removal from Cancer Drugs Fund	Put back on CDF and then passed by NICE for NHS use

To Screen or not to Screen : That is the Question



- Ongoing debate amongst clinicians, patient groups, charities, the Establishment
- National Screening Council say PSA test too unreliable and can lead to over-diagnosis and over-treatment
- Guidance for GPs not perfect – 25% are not familiar with guidelines
- Only 8% of men aged 50-69 have the PSA test – lower in some socio-economic groups
- UK study in 6 cities found 42% of those tested were age 70+
- **BETTER INFORMED PSA testing is the way forward. We need to:**
 - Raise awareness of prostate cancer
 - Improve the response of primary care
 - Promote baseline testing
 - Introduce risk based profiling
 - Standardise best practices

Looking to the Future



- **Remain a patient-led charity as the voice of prostate cancer patients and their families**
- **Continue to press for a more informed approach to testing**
- **Implement a sustainable approach to fundraising**
- **Continue to provide leverage for support groups**
- **Grow the network so that every Uro/Onco centre has a support group**
- **Work more closely with other charities in our field**
- **Cycle to the Moon, Save a Dad! (see next slide)**



- Major project for Spring 2018
- We would like to raise £250,000 by cycling to the moon – all ages, anywhere, anyhow
- The Save a Dad campaign will take us into every secondary school
- We are recruiting an event manager
- All support groups will be asked to take part
- We will link with the cycling community and sports clubs



PCUK and Tackle Prostate Cancer

There's room for both : play to our strengths and work together where we can add value



PCUK :
Taming Prostate Cancer

TACKLE Prostate Cancer :
The Voice of Prostate
Cancer Patients

