

East Lancashire Prostate Cancer Support Group Newsletter



Volume 8

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PSA Testing Day @ Rochdale AFC

ROCHDALE AFC 21ST January 2019

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We're delighted to announce that nearly 200 men took part in the PSA testing day, held at the Crown Oil Arena before Saturday's League One fixture against Fleetwood Town.

We've received the official final figure from the testing team, and 197 people turned out to be tested at the event, organised in conjunction with the Barry Kilby Prostate Cancer Appeal. Dale Manager Keith Hill, the Club's

Chief Executive David Bottomley, as well as representatives from the Dale Supporters Trust and several Club staff were amongst those to get tested.

Associate Director John Smallwood, who was the driving force behind bringing the testing day to the Crown Oil Arena, commented: "I would like to say a warm thank you to the staff from the Barry Kilby Prostate Cancer Appeal, to the medical staff on the day and

to the volunteers from the East Lancs Prostate Cancer Support Group. They were a well organised and good humoured team who looked after us very well. "I would also like to express thanks to the Dale Supporters Trust who supported the event from its announcement, helped with queue control on the day and provided a good deal of background information regarding prostate cancer on their website. "The turn-out was

Happy New Year to Everybody, from the Crew @ ELPCSG Next Meeting 7th Feb 2019 2pm—4pm



above expectation and the Club are pleased that the messages, sent out through several different channels, encouraged men to come and be tested. This is part of the work that an already busy staff at the Club do in order to ensure that the Club is at the heart and hub of the Community. I spoke to some of those attending and there were a good number of Dale fans, but also residents of Rochdale and a few from Preston and Fleetwood. Thank you to the 197 for taking the opportunity to be tested.

"The results of the tests will be available to each individual within a few weeks, and for those who have a follow-up to go through, support will be available from your GP, and from organisations like the East Lancashire Prostate Cancer Support Group www.elpcsg.com.

"If anybody wishes to get in touch with me confidentially for a chat, then please feel free to write to me and mark it as 'personal' for my attention."

You can contact John either by email or post. Email: john.smallwood@rochdaleafc.co.uk

Post: Mr John Smallwood, Rochdale Football Club, The Crown Oil Arena, Sandy Lane, Rochdale, OL11 5DR.





“Question Health”

Date and Time Wed, 6 February 2019 18:00 – 21:00 GMT

Location

University of Central Lancashire (UCLan)

Sports Hall, Victoria Mill

Trafalgar Street

Burnley

BB11 1RA

<https://www.eventbrite.co.uk/e/question-health-the-big-c-registration-54528361798>

Question Health is a televised debate series shining a light on some of the most concerning health issues affecting people in Lancashire. For this, our second event, we turn our attention to Cancer. We have assembled a panel of experts to discuss and debate some of the key issues of the day: prevention, screening, diagnosis, treatment, living with cancer and palliative care. The event format will be similar to BBC's Question Time, with the panel of local health experts taking pre-set questions from the audience. The film crew will consist of students and staff from the University's television, media, continuing drama and film production courses.

Broadcasters Deborah James and Lauren Mahon from the multi-award winning BBC Radio 5 Live podcast 'You, Me and the Big C' will be hosting the debate. Deborah was diagnosed with stage 4 bowel cancer at the age of 35 and Lauren, age 31, is in remission from stage 3 breast cancer. Their fellow presenter, Rachael Bland died from breast cancer in September last year at the age of 40. Rachael completed her postgraduate diploma in broadcast journalism at UCLan in 2001 and this debate has been organised by the University in response to Rachael's passing.

Cancer is a term for a huge variety of conditions in which abnormal cells divide without proper control and cause damage and disruption to the body. Almost all of us know people whose lives have been affected by cancer. Indeed, one in two of the UK population born after 1960 can themselves expect to be diagnosed with some form of cancer in their lifetime. Although cancers account for more than 150,000 deaths per year in the UK, making them the fourth most common cause of death, the good news is that survival rates have been continually improving thanks to better screening and treatments. Now, more than half of all patients diagnosed with cancer go on to live for more than ten years.

Questions for the panel are requested when registering online and the University will contact you prior the event if your question has been selected. Question cards will also be provided on the day of the event for you to read from.

This is a free event and light refreshments will be provided on arrival.

There will be filming and photography of the audience and the expert panel throughout this event, therefore your consent is required for footage/images to be used for marketing and broadcast purposes.

FAQs

Car parking: Free parking spaces are available at the Victoria Mill site, but please car share where possible. Disabled bays are available for blue badge holders.

Filming and photography: With this debate being pre-recorded for television, there will be filming and photography throughout. When registering you will be asked to give permission for filming and photography of you to be used by the University for marketing and television broadcast purposes. These images/footage may be used in both on and offline publications, public relations and advertising, such as social media, brochures, information leaflets, adverts, posters and other formats for the promotion of the University and of University courses at its partner institutions.

Floor management: With this debate being re-recorded for television, there will be some stoppages for logistical reasons and direction from the Floor Manager for things such as audience applause.

Broadcast of the debate: The debate will be shown on a Sky Channel. The date and further details are still to be confirmed. Those who attend will be contacted at a later date with information. Due to editing and programme scheduling, it's possible that the broadcast date may be several months later.

Questions for the panel: Please let us know when registering online what question you would like to ask the panel. All questions will be collated and edited by the organisers and you will be notified in advance of the debate if yours has been selected. Questions will be printed by the organisers onto cards and given to you when you arrive at the event. Those asking questions will have designated seats so they can be identified by the film crew.

Accessibility: The building and Sports Hall venue are fully accessible. The entrance to the venue is on the first floor and there is a lift available. The venue has tiered seating and the audience enters from the bottom of the seated area, so please indicate when registering online if you need a space for a wheelchair or if you are unable to use stairs. Also alert us to any specific requirements, such as needing a BSL interpreter or gluten-free refreshments.

On the day enquiries: Contact Tania Callagher 07817 635045

Patient Study Appeal for Participants

21 Jan 2019

Dear Dave

I appreciate it is short notice but we were asked today by Janssen pharmaceutical, one of our industry partners, if we could identify up to six of our members who might wish to participate in an exercise looking at where their PSA is rising even though they are on hormone therapy and have non-metastatic prostate cancer. Alternatively they may have previously not had metastatic prostate cancer while receiving hormone therapy but now have metastatic prostate cancer. Full details are given in the [attached note](#) and the exercise takes place on 31st January in London.

There is also an opportunity to take part in a study to understand better a cancer patient's journey from initial diagnosis to treatment planning and therapy management in Europe. This study is carried out by SIS International via a phone interview of 30 - 45 minutes conducted by a professional moderator with compensation of £118. If you are interested, please complete the following survey to see if you are eligible:

<https://www.surveymonkey.com/r/cancer-patient-study-europe>.

Many thanks for your support.

Best regards
Roger Wotton
Chairman
07818 404 004

Non-metastatic hormone relapsed prostate cancer patient experience and preferences

At Janssen UK Ltd, we are looking to better understand the experiences of men with non-metastatic hormone relapsed prostate cancer and how their treatment is currently managed in the National Health Service (NHS). There is limited information on the perspectives of people with this stage of prostate cancer and what matters to them most when it comes their treatment and care. Non-metastatic hormone relapsed prostate cancer refers to prostate cancer that has not spread to other parts of the body, and patients' PSA rising despite having been treated with either orchiectomy (a surgery to remove the testicles) or with androgen deprivation treatments such as gonadotropin-releasing hormone analogue agonists or anti-androgens. We hope to have 6 men involved in this research which will be carried out as an 'advisory board' – a round table discussion where we will share the current information on patient preferences and also get insights based on the different experiences of everyone involved.

This meeting is planned for the 31st January 2019 and will be held at Janssen's Innovation Centre, in central London.

We are interested in hearing from men who meet either of the following criteria:

1. Men with non-metastatic prostate cancer who: have undergone orchiectomy (a surgery to remove the testicles) or are currently receiving long-term androgen deprivation therapy (ADT). Examples of ADT include bicalutamide, flutamide (Eulexin) , Leuprolide (Lupton), Goserelin (Zoladex)and Triptorelin (Decapeptyl) and who have been informed that their PSA levels are rising
2. Men who previously had non-metastatic cancer and were on ADT, but have now been diagnosed with metastatic prostate cancer

If you meet the above criteria, are available on the 31st January 2019 and would like to be involved we would love to hear from you. Please contact Jordan Rankin at patient-team@its.jnj.com

We will be able to pay a small honorarium for your time and also to arrange and pay for your travel to and from the meeting.

December 2018 Meeting Minutes

Minutes of meeting No.94 Dec. 2018/Jacobs Join - Thurs. 6th Dec. 2018 Mackenzie Centre B.G.H. 2 – 4pm

Present: 25 people with more arriving all the time, including 3 new members, 2 ladies from Barry Kilby's Charity, bearing a Magnum of Prosecco and 3 visiting members from the Walnut Group at Preston, bearing Wine! Apologies from David & Carmen

Dave, Chairman, reported on the 2 days and an evening when the group's Awareness Stand was manned in shifts by several volunteers from our group, at Saffron Nacelles, Burnley. This was a very successful morning, afternoon and evening shift and £296 will be donated to the Group's funds.

A TV costing £250 has been presented to Blackburn Royal Hospital's refurbished Oncology waiting room - recognised by a small plaque denoting the donation by the East Lancs Prostate Cancer Support Group.

There's to be a PSA Testing day on 19th January 2019 at 11.00 am on match day at Rochdale Football Club with volunteers from the ELPCSG organising the event with the Barry Kilby Charity, who will be subsidising it. The volunteers will get tickets for the Rochdale Match that day. There is also a bucket collection for Barry Kilby's Charity on Boxing Day at Rochdale Football Club where volunteers are required to help. Free tickets for the match will also be given to volunteers on that day.

The Group has been contacted by the Freemasons Hall at Farnworth, Bolton to hold a PSA Testing event in the New Year – perhaps March. The Masons will pay for everything on the chosen day and give a donation to our Group. Other Freemason Lodges could also be interested in blood testing events.

A testing event was held for 40 drivers at Greggs Bakery, Manchester. 6 volunteers and a phlebotomist worked hard on the day and 40 men were tested with an outcome of 2 red, 1 amber and 37 green.

Stuart and Dave attended the Celebration of 100,000 blood testing events by Graham Fulford's Charitable Trust and Stuart had the opportunity to speak to David Baxter Smith, a retired Urologist, who is 100% behind PSA blood testings until we get anything better! David analyses the results for the Graham Fulford Trust. Stuart asked him if he could give a talk in the New Year - with our group perhaps funding his expenses – It appears that he would be willing to do so. More information later!

Colin S. told us about the **I Chroma** machines that are coming onto the market for blood testing. He told us that the Federation has purchased two, so they must think that they are a worthwhile investment. Colin told us that further details can be found on the **I Chroma Website** www.bodytech.co.kr The company is **I Chroma – Boditech Med Inc.** Stuart said that he would download the information and anyone interested could read this at the next support group meeting.

The Raffle made £78 (two raffles) – one of the prizes was a Christmas Cake donated by John Laycock and his wife. This showed the Logo of the “Man of Men” and was made by Mrs Laycock's friend. A picture of this can be seen on our Website. It was won; very appropriately, by Barry Kilby's fund raising Manager, Janine. There was an auction for the Magnum of Prosecco – which made £15.

The Jacobs Join was opened with loads of scrumptious food & drink donated by our members with a delicious Christmas Cake hand-made by Pat – and greedily devoured by all with not a crumb left. After eating our fill we were royally entertained once more by Dusty Young, comedian. He was procured for us by Glenn Southworth and we thank Glenn for this light hearted entertainment.

The next meeting is in the New Year on Thursday, 3rd January 2019 at 2.00 pm in the McKenzie Medical Centre.



Contact Information

Tel: 07548 033930

E Mail elpcsginfo@virginmedia.com

From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an embarrassing subject. We have lively, informative, interactive, sharing and above all supportive meetings.