# Pioneers update

## Investing in saving men's lives

Summer 2017

## WELCOME

I take great pleasure in opening this summer's Pioneers Update as Chairman of Prostate Cancer UK. As a keen cyclist, I first encountered the charity when I took part in the Saxon Classic ride. Seeing the team in action and chatting with people who've been affected by prostate cancer really sparked my interest. Since then, a few people close to me have been diagnosed, and I've seen first-hand how destructive this disease can be.

I truly feel that there is no better time to be part of this exceptional and ambitious charity. We're at a point now where there is real hope that we can beat prostate cancer in the not-too-distant future. As a Pioneer, you play a crucial role in making that vision a reality. Having had the pleasure of meeting many of you at the Panel Debate and Dinner in May, I am humbled by your commitment to taming prostate cancer once and for all.

I share that commitment, and am fully prepared to help in whatever way I can, including bringing more Pioneers on board to join the fight. To that end, I'm excited to extend a very warm welcome to our newest Pioneers: Angela Milne, Hugh Orange, and John Emberson. I look forward to meeting many more of you in the coming months, to thank you in person for your extraordinary support.

Charles Packshaw
**Chairman**
**Prostate Cancer UK**

PROSTATE CANCER UK

## The right treatment for the right patient at the right time

In March, we were delighted to welcome **Dr Joaquin Mateo** to our London Bridge office for our second **Pioneers Series** talk, on his Prostate Cancer UK-funded work at the Institute of Cancer Research.

Joaquin is a clinical research fellow, who brings his expertise as an oncologist to his ground-breaking research into precision medicine for prostate cancer. Joaquin opened with a round-up of the immense strides we've made in advanced prostate cancer treatment over the past decade. Yet for all this progress, we are still forced to use new drugs and treatments like abiraterone, enzaluatamide and docetaxal as blunt instruments, and to treat prostate cancer as one disease with a standard treatment pathway. All too often this means that men will be given a first-line drug treatment, but will have to wait several months to find out if the drug is working, or if their cancer is still growing. This wastes precious time, and means they're enduring the often gruelling side effects of treatment unnecessarily.

This is the challenge that Joaquin is trying to overcome. He argued that we must start addressing how different genetic defects, which vary from individual to individual, will benefit from different treatments. The TOPARP trial, which Joaquin is working on thanks to his fellowship from Prostate Cancer UK and the Medical Research Council, is a crucial first step in this direction. The trial looked at **olaparib**, a drug currently in use for women with ovarian cancer who have a defect in a gene called BRCA (which can be inherited from parents or develop spontaneously). This defect affects how their cells repair damaged DNA, causing mistakes to build up in the DNA, which can ultimately lead to cancer. Olaparib is one of a class of drugs called PARP inhibitors, which block cells from using a back-up DNA repair mechanism that cancer cells rely on far more than normal cells.

Blocking this repair means that cancer cells build up so much DNA damage that they die, which prevents tumour growth while normal cells remain relatively unaffected.

Joaquin explains this as being like a table with a leg missing – with just three legs the table will stay standing, even if it's a bit unstable. If we take out another leg, the table collapses.

Joaquin and his team found that olaparib was incredibly effective in about one third of men with advanced prostate cancer; those men who have a BRCA gene mutation. For these men, Prostate Specific Antigen (PSA) levels dropped by 50 per cent or more, the number of cancer cells circulating in the blood dropped from an average of 37 per cent to less than five per cent per sample, and imaging scans confirmed that tumours had stopped growing or were shrinking.

This has ground-breaking implications. Not only can olaparib effectively prolong life in a third of men with advanced prostate cancer; it might also be possible to preselect those men who will respond to this treatment by looking for BRCA gene mutations in advance. Joaquin has recently published research into a test to do this.

Joaquin left us with a clear vision of the future for precision medicine. We will be able to identify the Achilles' heel of each man's aggressive prostate cancer, and target it from the very first round of treatment. As genetic sequencing becomes cheaper and more efficient, we will better understand how tumours change over time, allowing us to pinpoint when we should change or add treatments, find new treatments, or optimise existing ones to target specific mutations.

Stay tuned for details on the next event in this exciting series.

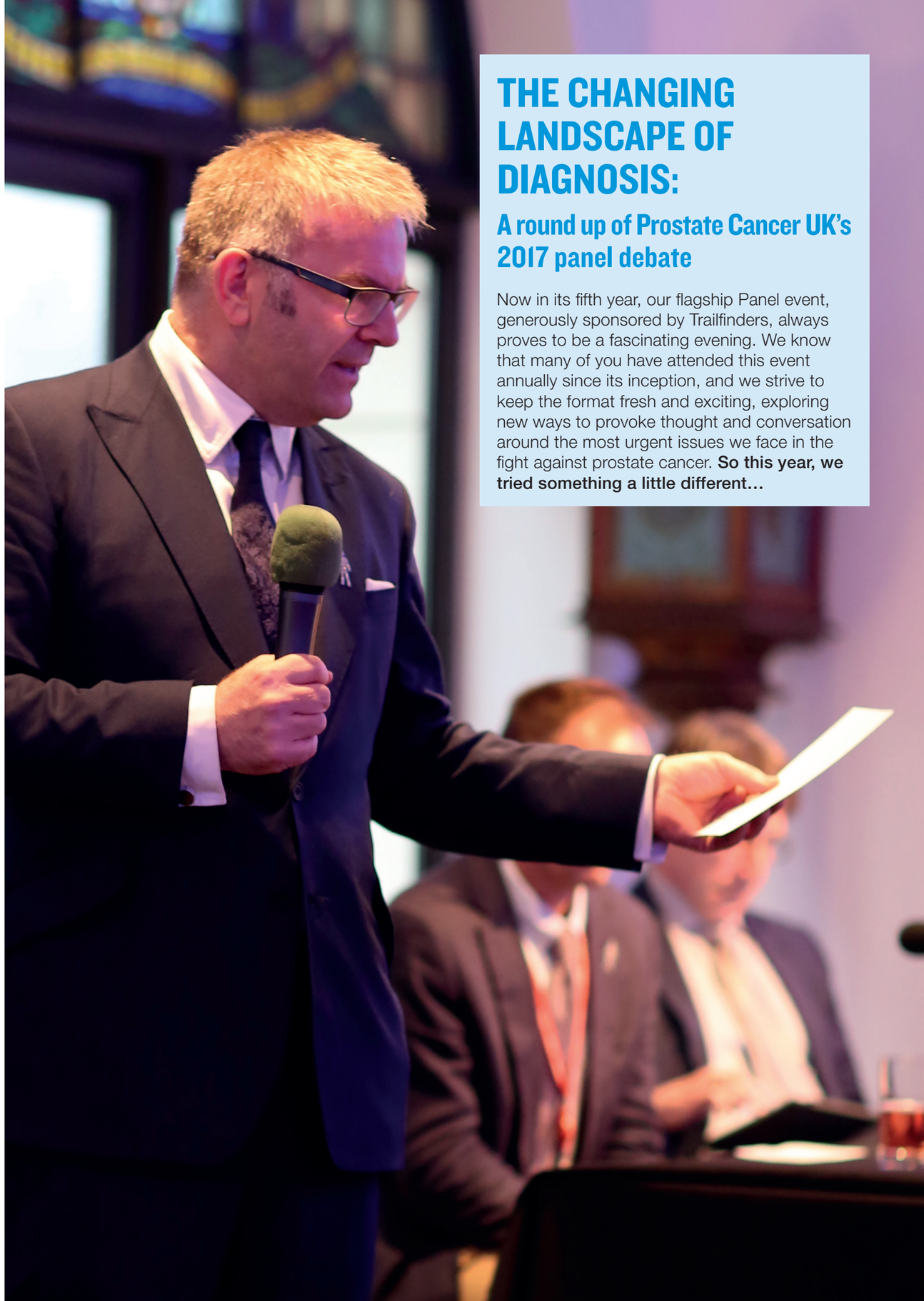

## This trial has turned me around

**Douglas Baker** was guest of honour at the event. He told us first-hand how much he's benefitted from Joaquin's trial.

Twelve years after first being diagnosed with advanced prostate cancer, Douglas was starting to feel desperate. Having been through rounds and rounds of treatment, including three bouts of chemotherapy, Douglas' doctor told him the cancer had spread to his lymph nodes and liver, and become resistant to all available drugs: "There wasn't anything left that he could offer me. I've tried to never worry about my condition and just get on with life, but that was one of my low points – I was in hospital four times in five months."

That was when his doctor suggested taking part in a clinical trial to test a new treatment. "I was told that it was a drug for women with ovarian cancer, so I was a bit surprised that they were giving it to me," Douglas recalls. A year on, the results are clear: scans show that the tumours in his lymph nodes and liver are shrinking, and his energy has returned. He's experienced minimal side effects: "I went on holiday to Spain last year, which I didn't think I'd be able to manage again but I did. I've been very, very lucky – even if that seems like a funny word to use."

To close the Pioneers Series talk, Douglas spoke movingly of his gratitude to the Pioneers for funding research like this. Indeed, he "can't really put into words" how overwhelmed he is by your generosity, and the life-saving gift you have given to "someone you've never even met. Whatever happens with me, I just hope and pray that this research helps someone else further down the line."



# THE CHANGING LANDSCAPE OF DIAGNOSIS:

## A round up of Prostate Cancer UK's 2017 panel debate

Now in its fifth year, our flagship Panel event, generously sponsored by Trailfinders, always proves to be a fascinating evening. We know that many of you have attended this event annually since its inception, and we strive to keep the format fresh and exciting, exploring new ways to provoke thought and conversation around the most urgent issues we face in the fight against prostate cancer. **So this year, we tried something a little different…**

# ARE SOME PROSTATE CANCERS BEST LEFT UNDIAGNOSED?

**Men affected by prostate cancer tell us that one of the biggest problems we need to fix is diagnosis.**

PSA testing was introduced in the 1980s and is still our current first line diagnostic test, but it's controversial. A high number of false positives mean that too many men are biopsied and treated unnecessarily. For these men, the high risk of infection from biopsy and the side effects of treatment far outweigh the benefits of being tested. Simultaneously, too many men are unaware of their risk of having an aggressive form of the disease, and are diagnosed too late, when their cancer has already spread outside of the prostate and become incurable. We still can't tell at the point of diagnosis if a prostate cancer is harmful – aggressive, prone to spread quickly, and requiring urgent treatment – or harmless, and best left alone.

At this year's event, we set our panellists, all world-class names in prostate cancer research and care, a real challenge. To convey the complexity of prostate cancer diagnosis and the difficult decisions men and their GPs face every day, we asked our panellists to argue 'for' or 'against' the motion **'Some prostate cancers are best left undiagnosed.'** This lively and academically rigorous debate was followed by an audience vote.

## The human face of the grim statistics

The debate was kicked off by our host, **Lord Guy Black**, Conservative Peer, Executive Director of the Telegraph Media Group, and Prostate Cancer UK supporter. As Lord Black explained, this is a cause dear to his heart: eight years ago to that very week, he lost his beloved uncle to prostate cancer.

> My uncle was like too many men diagnosed too late: the disease had metastasised to his bones, and he spent his final days enduring a great deal of pain with stoicism and good humour. For me, he was the human face of the grim statistics about prostate cancer.
>
> Lord Guy Black

Our Co-Chairs – **Dr Iain Frame** (Director of Research at Prostate Cancer UK) and **Professor Mark Emberton** (Director of the Division of Surgery and Interventional Science at University College London, Dean of the UCL Faculty of UCL Medical Sciences, and Co-founder Pioneer) – then led the audience in an initial vote on the motion. Mark reflected that our guests were tackling a "nuanced, challenging and very difficult question – and we have four of the best speakers in the world to help us through."

Our Panellists, from L-R: Professor Martin Roland, Professor Mark Emberton, Dr Iain Frame, Professor Monique Roobol, Dr Mark Ashworth, Professor Malcolm Mason

## For: Professor Monique Roobol

Monique flew in from the Netherlands especially for this event. As Associate Professor and the Head of the scientific research office within the Department of Urology at Erasmus Medical Centre in Rotterdam, her main area of interest is predictive modelling. She is responsible for the Dutch part of the European Randomized study of Screening for Prostate Cancer, and is currently working on the **Prostate Cancer UK-funded development of a risk assessment tool** to improve prostate cancer diagnosis.

Monique opened her argument with autopsy data. Half of men over seventy have prostate cancer, rising to two thirds of men over eighty – a very high incidence of harmless prostate cancers that would not kill them. For Monique, this raises the difficult question: how many men do you want to make a cancer patient to avoid one man dying of prostate cancer? We certainly don't want to subject half of men in their seventies to invasive surgeries or radiotherapy to treat a disease that will never cause them any harm. The difficulty we face is picking out those men who will benefit from early detection and treatment: something the Prostate Cancer UK-funded development of a risk assessment tool, which Monique is working on, will address.

> Unscrupulously detecting every prostate cancer that can be detected is not the way to go.
>
> Professor Monique Roobol

## Against: Dr Mark Ashworth

Mark brought a fascinating dual perspective to our debate. He has worked as a General Practitioner for thirty years, combining this work with a medical director position and his current role as Reader in Primary Care at King's College London, publishing academic studies on health inequalities. Until recently, Mark's professional opinion was against administering PSA tests to men at low risk to avoid causing unnecessary worry and over diagnosis. However, as a man in his fifties with no other risk factors, symptoms, or noticeably raised PSA, four years ago Mark was diagnosed with aggressive prostate cancer, with two "bony hotspots" requiring radiotherapy. For Mark, if his prostate cancer had not been detected, the alternative is "unthinkable." He identifies the real issue as not whether we diagnose all prostate cancers, but how we diagnose only the harmful ones:

> Clearly the science needs to move beyond just PSA screening which is a very blunt tool that leaves us all wallowing in false positives... We need something that is better, that shows who has a cancer that matters. And we need science to guide that progress.
>
> Dr Mark Ashworth

## For: Professor Martin Roland

Martin is a Trustee of Prostate Cancer UK and Emeritus Professor of Health Services Research at the University of Cambridge. Martin's research focuses on developing methods of measuring quality of care, and evaluating interventions to improve care in the NHS. He worked as a practicing GP for thirty years, alongside holding the Directorship of the National Primary Care Research and Development Centre. In 2003 he was awarded a CBE for Services to Medicine.

Martin echoed his "teammate" Monique's point regarding the high incidence of prostate cancer in men over 70 "if you look hard enough," and asked our audience to imagine what would happen if all of those people were diagnosed. First of all, he argued, within the bounds of our current diagnostic pathway, "you would have to biopsy everybody… and this is not a benign process." One in a hundred men develop septicaemia as a result of biopsy, and that's before serious side effects like impotence and incontinence from the actual treatments for prostate cancer kick in. All of this for a condition that, in most cases, men would not have died from. Martin is proud that Prostate Cancer UK "puts in an enormous research effort to tell which prostate cancers need to be treated, and which should be left well alone."

> **If we diagnose all prostate cancers we would end up doing huge harm.**
>
> Professor Martin Roland

## Against: Professor Malcolm Mason

Finally, we heard from Professor Malcolm Mason, Cancer Research Wales Professor of Clinical Oncology at Cardiff University. Malcolm is a clinician who specialises in the management of urological cancers, an experienced clinical researcher, Chief Investigator for a number of Medical Research Council trials, and he has over 250 publications in his field.

Malcolm asked our audience to focus on two facts. Firstly, Monique's European trial of screening using PSA "undeniably" did save lives. "Yes, you have the concept of over-diagnosis, but if you don't diagnose, you don't save lives, plain and simple." Secondly, from the recent ProtecT trial – Malcolm ran the radiotherapy arm – double the number of men on active surveillance rather than treatment ended up with their cancer advancing or becoming metastatic: "treatment prevents disease progression." He also touched on our Co-Chair, Professor Mark Emberton's, revolutionary PROMIS trial, which strongly suggests that it may be possible to identify prostate cancers without biopsy using an expertly administered and interpreted mpMRI scan.

> **We have to look to the future and change the diagnostic model.**
>
> Professor Malcolm Mason

## What can we actually do to move the needle?

Our Co-Chairs then opened to the floor, and as always, our guests brought their own personal experiences of prostate cancer to bear in putting some probing questions to our panellists. Our final questioner, Pioneer Jemima Jowett-Ive, spoke movingly of losing her father to prostate cancer, and said: "I believe hugely in this charity… but I think ultimately we have really limited resources: money, time, minds on the panel…. What can we actually do to move the needle?"

This question really gets to the heart of the issue. Of course, we must treat men with aggressive prostate cancers, stop the disease before it spreads, and save their lives. But to do that, we need to know who those men are as early as possible in their diagnosis. That's why Prostate Cancer UK have just committed £2 million of funding to improve diagnosis, primarily through the second stage of developing a risk assessment tool. Further, more than half of this year's budgeted Research Innovation Awards – five projects worth £2.8 million between them – are focussed on how to prevent and diagnose prostate cancer.

In the meantime, while the PSA test is far from perfect, it is the only diagnostic tool we have in action for now – so to ensure it continues to save men's lives, last year we worked with three hundred health professionals to produce PSA Consensus Guidelines, a set of clear recommendations for GPs on how to best support men, weighing the value of the test based on a man's individual risk.

**As a Pioneer, your annual donation to our research programme is already funding this work. Please do get in touch with Caroline or Naomi (contact details on the back page) if you would like to hear about any of these exciting projects in more detail.**

**Thank you** to our event sponsor, Trailfinders. Mike Gooley began supporting Prostate Cancer UK through the Mike Gooley Trailfinders Charity in 1997, and has since contributed £2.4 million, which includes their annual sponsorship of this event.

**Thank you** to Victoria Dawe Photography for volunteering to photograph the evening.

Our host, Lord Guy Black

## Let's make Prostate Cancer UK a bigger part of our lives, so we can make this disease a smaller part

**Our after-dinner speaker, Jane Elphick, told us about her father, Hugh, who she lost to prostate cancer in 2015.**

Hugh "loved literature, all sports, food and wine, the sea, to travel and above all his family, friends and even his colleagues… One friend commented on his ability to make impromptu speeches that were extremely well crafted and funny. No pressure on me!" He was diagnosed with prostate cancer in 2007 and battled countless surgeries, radiation therapy, and the loss of bladder control "with great grit and humour" for eight years. For example, Jane recalled Hugh returning home from hospital with a catheter singing "Papa's got a brand new bag!"

Since losing her dad, Jane has done whatever she can to raise funds for Prostate Cancer UK: selling Man of Men badges from her desk at work, running the London Marathon in 2016, and coercing ten friends to take on the Tough Mudder with her this spring. Jane has raised over £9,000 to date, but knows that our funding "whilst ever-growing, does not yet match the need. We need science and we need money – because as strong as we all are (and this disease certainly pushes you to your limits) humour and grit only gets you so far."

## Roll up, roll up!

It's still not too late to take a table at this year's Gala Dinner, returning to Rosewood, London on Thursday 14 September 2017. This fantastic night of music, entertainment and comedy is Prostate Cancer UK's longest running event to date, where we celebrate the men in our lives as well as raise vital funds to stop prostate cancer being a killer.

The Gala Dinner has raised over £2.8 million to date, and we're aiming to hit the £3 million mark for Prostate Cancer UK's life-saving work this year. And this time, there'll even be some surprises along the way as we bring all the fun of the fair to life!

Please contact Caroline Gellatly (details on the back page) to book your table, or to support the event by taking advertising space in the Gala Dinner brochure.


Barbara Windsor, really selling her auction lot at the 2015 Gala Dinner!

## We have updated our privacy statement

Prostate Cancer UK is committed to protecting your privacy while providing a personalised and valuable service. We have made improvements to our Privacy Statement with a clear explanation about how we collect and use the personal information either you provide us, that we collect via our website, from any other correspondence with you or from third parties. Developing a better understanding of our supporters is vital; it enables us to raise funds more efficiently and cost-effectively and ultimately will help us tame prostate cancer sooner. We may sometimes use techniques to analyse geographic, demographic and other information so that you receive information that is appropriate, relevant and timely. Personal details collected this way will only be used to provide you with information you would reasonably expect or have agreed to.

Please take the time to read our Privacy Statement which you can find in full at:
**prostatecanceruk.org/about-us/terms-and-conditions/privacy-statement**
If you have any questions about this, please do speak to Caroline or Naomi.

# THANK YOU TO OUR PIONEERS

- Jonathan Abrahams
- Ralph Aldwinckle
- Thomas Allen
- The Anthony and Pat Charitable Foundation
- John Bloor CBE
- Lady Joy Bourne
- Brian and Jill Moss Charitable Trust
- Sir Martin and Lady Jocelyn Broughton
- Joseph Burns
- John Caudwell
- Hadyn Cunningham
- Tom Curtin
- Tony Elliott
- Professor Mark Emberton
- John Emberson
- Lord Evans of Watford
- Chris Field
- Douglas Flint CBE
- Nigel Gee
- Alistair Gibbons
- Timothy Hailstone
- Michael Harris
- Sir Maurice Hatter
- Duncan Heath
- Julian Howard
- Ken Hydon
- Caroline Jowett-Ive
- Jemima Jowett-Ive
- Nathan Kirsh
- The Stanley and Zea Lewis Foundation
- Sir Stuart Lipton
- Stewart Matthewson
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- Jill Moss
- Jim and Caroline O'Neill
- Hugh Orange
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- Bill Smail
- Ivor Spiro
- David Sullivan
- Michael Tabor
- Sharon Thorne
- Ron Wahid

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PROSTATE CANCER UK

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