

from the charity

# 01

WE CUT
OUT THE HYPE
& FIND THE BEST
BLADDER CANCER
DIET



PROFESSOR
TOM POWLES ON

# PDL1 INHIBITORS

ARE THEY THE FUTURE OF BLADDER CANCER TREATMENT?

MAGAZINE
WE NEED

TO TALK!
PROFESSOR JIM CATTO
TELLS US WHY

WHAT NOW FOR BCG?

OUR FBC FOUNDER INVESTIGATES

**CNS SUPERHERO** 

WHY CANCER NURSE SPECIALISTS ARE SO VITAL

HOOKED ON SUPPORT

ONE WOMAN'S MISSION
TO SHARE THE LOVE

The ONLY magazine for people affected by & working with Bladder Cancer



#### THIS MONTH'S CONTRIBUTORS



#### **Professor Jim Catto**

Professor of Urology at the University of Sheffield and an Honorary Senior Clinical Research fellow at the University of Oxford. He is a member of the Scientific Congress Office for the EAU. Jim has raised over £8.7 million in peer reviewed funding and published more than 50 primary research manuscripts.



#### **Professor Tom Powles**

Academic Leader for Urology Cancer at Barts Hospital. He is also the Lead for solid tumours at the CRUK Experimental Cancer Medicine Centre. He qualified with an MB BS at Barts in 1995 and has been based at Barts Health NHS Trust since 2007, where he is currently the Clinical Lead of the multi-disciplinary group. His research focuses on the mechanisms of resistance to therapy in urology cancer.



#### Dr Simon Crabb

Associate Professor in Medical Oncology within Medicine at the University of Southampton. He joined the University of Southampton in 2002 as a Cancer Research UK Clinical Research Fellow. Following a Clinical Research Fellowship in Vancouver, he returned to the Cancer Sciences Unit in Southampton, where he now works as an Associate Professor and Honorary Consultant in Medical Oncology.



Richard Turner, CNS

Macmillan Uro-oncology Cancer Nurse Specialist at Furness General Hospital, Barrow in Furness.



Hilary Baker, CNS

Lead CNS for Uro-oncology, University College London Hospital.

If you have an idea for an article, or have a topic you think needs discussion, please just drop us an email at <a href="mailto:info@fightbladdercancer.co.uk">info@fightbladdercancer.co.uk</a>

This magazine is not intended as a substitute for the medical advice of doctors. Readers should consult their medical team in relation to their treatment.

#### Fight Magazine

Fight Bladder Cancer 36 Station Road Chinnor Oxon OX39 4QH

+44 (0)1844 351621

info@fightbladdercancer.co.uk www.fightbladdercancer.co.uk

#### **Editor**

Wendy Hobson

#### Deputy editor

Susie Williams

#### Stock photography

Shutterstock.com

#### Drint

Polestar Stones Wheatons Ltd

#### Advertising

Contact

info@fightbladdercancer.co.uk to find out about our advertising rates.

#### Subscriptions

Contact

info@fightbladdercancer.co.uk to order a print copy of this quarterly magazine delivered to your door. Alternatively you can download me for free online at fightbladdercancer.co.uk

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# Contents

#### **FEATURES**

# 3 Let's talk about bladder cancer!

Professor Jim Catto makes the case for talking about bladder cancer

# 6 Light at the end of the tunnel

Professor Tom Powles discusses whether PDL1 inhibitors are the future for bladder cancer treatment



A tasty surprise that's changing the face of charity retail

#### 13 Bringing the Fight to Barrow

We talk to Richard Turner about Fight Clubs

#### 15 CNS superhero

Hilary Baker talks about the role of your Clinical Nurse Specialist

# **16** Bladder Cancer & the 100,000 Genomes Project

Dr Simon Crabb on the part bladder cancer is playing in this ground breaking project

#### **18** What now for BCG?

Andrew Winterbottom investigates the fallout from the recent shortages

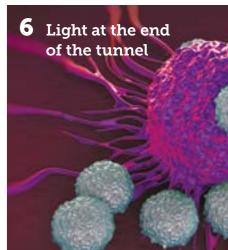
#### 24 Holding it all together

Two-time cancer survivor, carer and self-confessed Ms Memory tells her story

#### 26 Hooked on support

We catch up with FBC forum members Alison Crellin and Mandy Fleckney and discover how yarn is playing a part in helping others







#### **REGULARS**

#### 4 FBC round up

Find out what's happening with the charity Fight Bladder Cancer

# 20 Your questions answeredyou are what you eat

Susie Williams focuses on the best diet for bladder cancer patients

#### **30** Clinical trials

A directory of current open bladder cancer trials across the UK

# Welcome to our first edition

*Fight!* Magazine is a ground-breaking magazine for the whole bladder cancer community – from those directly affected by a bladder cancer diagnosis, including both patients and carers, to those working to help us fight, including medical professionals in both primary and secondary care, the research community and policy makers at every level.

Our aim is to be the place for an informed discussion about the good and not so good things about bladder cancer treatment. Where we can discuss the big topics – prevention, diagnosis, treatment and survivorship – with the goal that together we can make a major change and stop bladder cancer being a killer. We hope you find the magazine fascinating, educational and enlightening.

You can find out more about the charity and get help, information and support on our website:

#### fightbladdercancer.co.uk

Fight Bladder Cancer (FBC) has grown through the support and help of fellow patients and carers across the country, together with a growing band of medical professionals who see the value in a strong patient voice, who support and advise us along the way. Together we can make a difference.

Team FBC

As a charity, Fight Bladder Cancer's aims are simple. We have four key objectives:

#### SUPPORT

Supporting all those affected by bladder

#### **AWARENESS**

Raising awareness of the disease so it can be caught early

#### RESEARCH

Campaign for and support research into this much ignored disease

#### CHANGE

Affect policy at the highest levels to bring about change

fightbladdercancer.co.uk

Fight Bladder Cancer is the only patient- and carer-led charity for bladder cancer in the UK.

We take great care to provide up to date, unbiased and accurate facts about bladder cancer.







# Let's talk about bladder cancer!

#### Talking about your cancer really can make for a better experience.

Bladder cancer is one of the most common human cancers. It is also one of the most expensive for the NHS to manage. Yet this disease is hardly discussed in the media and there are very few role models who admit publicly to having had this cancer.

Given that the main cause of bladder cancer is smoking, that the cure rates are high and that many celebrities smoke cigarettes, I think one can assume that potential role models remain silent about their cancer through fear of adverse publicity. This is disappointing because while the public and the media are mostly ignorant of this disease, those who are diagnosed feel isolated and are reluctant to share their experiences. This leads to fear of the unknown and worsens the healthcare experiences, facts that were borne out in a recent NHS survey, which found that patients with bladder cancer felt that they were some of the most isolated and least supported of all patients with cancer.

While we have many hurdles to jump if we are to improve this, one of the first is to get people talking about this cancer. These might be patients or loved ones talking to each other, to their friends and neighbours, or to the media to raise the importance of this public health problem.

Fight Bladder Cancer has got us talking and must be congratulated for this. I have seen more support, more warmth and more positivity in the last few years than ever before. Talking leads to empowerment through a better understanding of your cancer, so you make better treatment choices and improve your outcomes.

We are at the beginning of a long journey and Fight Bladder Cancer will play a key role in this. Realistic aims should be to engage as many patients as possible within Fight Bladder Cancer (especially those who may have little internet access or lack confidence about speaking out), to lobby their local NHS for better support for this disease, and to lobby major charities to fund more research into new treatments.

Bladder cancer stands out as one in which the last major treatment breakthrough came over 30 years ago. We can improve things, but we must work together.



# FBC round up

Find out what's happening with the charity both here at home and across the globe.



#### **SUPPORT**

#### BLADDER BUDDY SERVICE

For those less confident or for personal help and advice we offer a nationwide one-on-one service, where we connect you with another patient or carer who has been through the same treatment, experience or emotional issues. We have seen an exponential growth in the service over the last six months, since the launch of our new website. Many of these requests come direct from the Cancer Nurse Specialists in support of their patients.



#### FIGHT CLUBS

This month we report on the launch of Barrow Fight Club (p 13), and hot on its heels we also have the launch of the Lancaster, Manchester, Andover and Chilterns clubs. Our network of groups offers a more sustainable service to the bladder cancer community and Fight Clubs are now being launched all over the country. We find that people often find it easier to talk to others in this relaxed environment, whether it's about their worries or more specific advice on treatments and side-effects. It's also a great place to make new friends, be sociable and develop your own support network. If you would like to set up a Fight Club in your area, just drop us a line and we'll help you make it happen.

#### **AWARENESS**

### INFORMATION, INFORMATION, INFORMATION

In addition to the free downloads on our website, we also provide a wide variety of printed awareness and support materials. In the last two years alone we have distributed 20,000 general awareness leaflets, 15,000 patient information leaflets and 10,000 posters free of charge to hospitals and GP surgeries. If you need more supplies for your healthcare facility, please just get in touch! Don't forget they are all free and really help patients and carers by signposting all the services we offer.

#### WORKING WITH GPs

Our team are working closely with GPs in understanding the nuances of diagnosing patients with bladder cancer. We have started running one day workshops with GP surgeries where we share our knowledge of the disease and treatments – helping them provide the best possible support for their patients, no matter where they are on their care pathway.

#### **HEALTH AWARENESS DAYS**

We are working with hospitals and health authorities across the country in raising awareness of bladder cancer at Health Awareness Days. At these events our teams are on hand to explain about the causes and symptoms of the disease, with the aim of preventing new cases and ensuring the earliest possible diagnosis which, as we know, can be life saving. We have more of these days scheduled throughout the year. You can find out more on our website.

#### FIGHTBLADDERCANCER.CO.UK

Our informative new website (launched late 2015) is on track to reach a quarter of a million unique visitors in its first year. Our new online advisory team is responding to several hundred email enquiries a week, for support, information and from people who would like to fundraise for us. The website has made it much easier for people to get good, reliable information about bladder cancer, written in plain English.

#### **AWARENESS MONTH**

May saw the launch of Bladder Cancer Awareness Month in the UK, with activities and awareness days across the country, including events in Canterbury, Nottingham and Oxford. The month concluded with the international Bubbles for Bladder Cancer Day where we blew bubbles to remember those who have lost their fight with this awful disease, and to stand together for those currently undergoing treatment and everyone who is affected by bladder cancer.



#### RESEARCH

#### **CLINICAL TRIALS**

We now have an FBC patient representative on the National Cancer Research Institute (NCRI) Bladder Cancer Clinical Studies Group, helping make decisions about which trials are supported and also identifying where there are gaps in bladder cancer research. In addition, we have a role on Trial Management Boards, and we provide assistance in scoping of trials and help to write Patient Information Sheets. Our aim is to dramatically improve the treatments available for patients.

## DEDICATED BLADDER CANCER RESEARCH FUND

This year we have also set up what we believe is the first ever dedicated Bladder Cancer Research Fund with the aim of becoming a major funding source for bladder cancer research in the UK. We are also recruiting for a research advisory panel to help us decide which future research projects to fund.



#### **CHANGE**

#### NHS DECISION AID

Patients faced with a diagnosis of highrisk non-invasive bladder cancer have a potentially life-changing treatment choice to make. NHS England engaged FBC along with another charity to rewrite the existing patient decision aid available via NHS Choices and to advise them on all the decision points experienced by bladder cancer patients across the whole pathway. This project is almost complete and, once published, will help patients and clinicians have the right conversations about treatment choices.

#### TALKING TO THE PROFESSIONALS

The last two years have seen us become regular exhibitors at both the British Association of Urological Surgeons (BAUS) and British Association of Urological Nurses (BAUN) annual conferences. These essential platforms allow us to talk to medical professionals about bladder cancer, what FBC can do to help support patients and how we can work together to make improvements across the bladder cancer pathway.

Pharmacies across the country are also a part of the route to early diagnosis so we have recently written articles for their professional magazines highlighting bladder cancer. We are currently piloting an initiative for a proactive awareness campaign across the whole of the regional pharmacy network.

#### LINKS WITH EUROPE & THE WORLD

Bladder cancer does not recognise boundaries, so we were delighted to be invited to become full members of the European Cancer Patients Coalition. We have played a lead role in the development and presentation of a White Paper on Bladder Cancer that was presented to MEPs in the European Parliament.

The paper has been adopted by many countries across Europe to highlight the lack of awareness and quality of treatment for bladder cancer patients. FBC is now the official lead on bladder cancer at the ECPC, which represents over 400 patient support and advocacy groups across Europe. One of the best things about our involvement in the ECPC is that all our travel costs are met by external funding.

Also on the international stage, we have co-written a paper with BCAN in the USA about patient advocacy in bladder cancer across the world, we've helped set up a bladder cancer group in Australia and are about to start a joint initiative with Bladder Cancer Canada.

#### NICE & SMC

These statutory bodies make key decisions on which treatments are available to patients in the UK. FBC now takes an active role with both bodies in all matters affecting bladder cancer. We were a primary stakeholder in the development of the new NICE guidelines and a specialist member of the NICE bladder cancer quality standards advisory committee.

# Giving you support

#### 24/7 SUPPORT, 365 DAYS A YEAR

Over the last six years we have helped more than 5,000 people on our **Confidential Support Forum**. The forum is a core component of our patient and carer support services with a strong community of people affected by bladder cancer. Patient, carer, family or best friend, the forum is there for you to get and give support.

#### BLADDER BUDDIES

Not everyone is happy to talk and ask questions within our confidential forum, so we provide a nationwide Bladder Buddy Service where we match people up on a one-to-one basis with someone who has been in the same situation or has had the same treatment. Someone to talk to privately, either on the phone or over a coffee about worries or concerns, treatments and side-effects.

#### LOCAL SUPPORT GROUPS

Fight Bladder Cancer started as a small local support group so we know the value of face-to-face interaction with fellow patients. We have launched a linked network of local support groups that offer a more sustainable group support service to the bladder cancer community. Check out our website to find your nearest Fight Club.

Find out more about how we can support you at fightbladdercancer.co.uk/get-help



Immune checkpoint inhibition for patients with metastatic urinary bladder cancer

Bladder cancer is the seventh most common cancer in the UK, with smoking the primary risk factor in 50% of cases. The UK five-year survival rate is about 70%, or 25-50% for muscle-invasive bladder cancer, which is more prevalent among women, and less for cancer that has spread to unrelated organs. Survival rates have remained largely unchanged over the past 30 years, signifying a lack of effective research.

Blood in the urine and painful or frequent urination are the most common warning signs. The standard treatment is surgical removal of as much of the tumour tissue as possible, with tissue examination to determine the subtype and stage of the cancer, followed by an appropriate chemotherapy, radiotherapy or drug treatment.

Currently a number of trials are investigating drugs that support the body's own immune defences. Trials based on Atezolizumab have shown that these drugs are well tolerated with low levels of severe side-effects. However, other aspects need to be taken into consideration in randomised trials, such as quality of life, long-term remission and disease stability. The studies have led to other trials looking at different drugs and combinations at various stages of bladder cancer. There are also trials on using Atezolizumab or Nivolumab in a secondary role in treatment; the significance of the mutation of cancer cells; and the differing responses of anti-cancer cells according to the sub-type of bladder cancer.

Bladder cancer is the 7th most common cancer in men and 19th most common in women globally. Similarly, in the UK, it is the 7th most common cancer overall.

The most common presenting complaint for bladder cancer is painless haematuria, which is present in >80% of patients. Other symptoms may include dysuria, urinary frequency or urgency. The key investigations for the diagnosis of bladder cancer are cystoscopy and transurethral resection of bladder cancer (TURBT). Tissue from the TURBT should be sent for histopathological analysis to determine the type and stage of bladder cancer. The most common histological sub-type is transitional cell cancer. Ideally, complete resection of all tumour tissue should be achieved at TURBT.

Ground-breaking research by the Genome Project is driving forward our understanding of the underlying biology of many cancers & opening up new options for treatment.

> Take a look at the summary and glossary overleaf to get the most out of this fascinating scientific review.



Smoking is the main risk factor for bladder cancer and accounts for approximately 50% of cases. Other risk factors include occupational exposure to certain chemicals and previous treatment with radiotherapy to the pelvic organs.

The overall 5-year survival rate for bladder cancer is approximately 70% in the UK. Muscle-invasive bladder cancer (T2-T4aN0M0) accounts for around 30% of new cases and has a 5-year survival rate of 25-50%. Women are more likely to be diagnosed with muscle-invasive disease (85% vs. 51%) and have a worse cancer-specific survival. Survival rates have remained largely unchanged over the past 30 years, reflecting a lack of effective new treatments.

Recent data shows immune checkpoint inhibitors have significant activity in metastatic urinary bladder cancer. The current data, future trials and a summary of the biomarker research is reviewed in this article.

The current treatment for metastatic urothelial bladder cancer (UBC) is focused around *chemotherapy* <sup>1</sup>. Patients with newly diagnosed advanced or metastatic disease have a median survival of approximately one year with platinum-based chemotherapy. The benefits of chemotherapy at relapse are unclear and survival is short at approximately 7 months<sup>2</sup>. Targeted therapies, which have proven activity in a plethora of other cancers, have not been successfully tested in UBC. There is a need for new drugs in this disease.

PD-1 is a protein biomarker expressed on immune cells and PDL-1 is a protein biomarker expressed in the tumour microenvironment and immune component. When PD-1 binds to PDL-1, this results in an *inhibitory pathway*, which suppresses the immune response against tumour cells. By blocking either of these proteins using checkpoint inhibitors, the inhibitory pathway is deactivated, allowing the immune system to mount a response against tumour cells.

The immune checkpoint inhibitors Atezolizumab, Avelumab and Pembrolizumab have been studied in phase 1b trials in metastatic UBC <sup>3-5</sup>. The studies employed different methods of measuring the PD-L1 biomarker, resulting in different definitions of positivity. Different populations were selected for therapy in these trials, rendering the results incomparable. The Avelumab study included 44 unselected (PD-L1 positive and negative) UBC patients resulting in a response rate of 16%.

#### What did we learn from these trials?

Firstly, the drugs are well tolerated with low levels of severe (grade 3 or 4) adverse events (table 1). Also, they have a significant durable response rate in a biomarker-selected patient population. Atezolizumab also had potentially significant activity in PD-L1 negatives (11%). Overall survival (OS) in the Atezolizumab study was impressive in the PD-L1 positive population. OS with other agents is difficult to interpret due to the small numbers or lack of follow up.

Atezolizumab received fast track FDA designation based on the phase 1 data described above and a phase 2 trial was designed to achieve regulatory approval. This single-arm phase 2 trial was published in the Lancet in March 2015<sup>6</sup>. The trial included UBC patients who had received one or more prior lines of platinumbased chemotherapy, had measurable disease and a component of transitional cell histology. Patients received Atezolizumab until progression of disease, lack of clinical benefit or the development of intolerable toxicity. Cross-sectional imaging was performed on a 9-weekly basis to assess response. Scans were reviewed centrally. The primary endpoint was to achieve response rates above 10%, which was a benchmark for chemotherapy <sup>2</sup>. Subset analysis occurred for PD-L1 positive and negative patients.

The trial recruited 311 patients in a very short period of time, in part due to the excitement around results of the phase 1 trial. At baseline, 78% of patients had visceral metastasis and 32% of patients were PD-L1 positive. The response rates were 27% (95% CI 19–37%) for PD-L1 positive patients and 15% (95% CI 11–20%) in the whole population (n=311). Median duration of response was not reached. 15% of patients had grade 3 or 4 adverse events. Progression-free survival (PFS) was short at 2.1 months and not PD-L1 dependant. This is in line with PFS results seen in other tumour types treated with immune checkpoint inhibitors, and underlines the need for new surrogate markers to monitor treatment effect on therapy 7.

#### **GLOSSARY**

**adjuvant** after initial treatment to prevent secondary tumours

**basal** relating to the base **baseline** starting point for comparison

**biomarker** something by which the disease can be identified

#### checkpoint inhibitors

drugs that prevent cancer cells from disabling protective T-cells

**chemotherapy** treatment with drugs

**cystoscopy** a procedure to examine the inside of the bladder

**durable response rate** the length of time a response is observed

**dysuria** painful or frequent urination

expressed active
haematuria blood in urine
histology the microscopic
examination of cells

#### histopathological

microscopic examination of tissue to identify disease

**immune component** part of the immune system

inhibitory pathway
a situation in which
defensive cells are

preventing from attacking foreign cells intolerable toxicity the

ntolerable toxicity the point at which the treatment becomes more painful than the disease

lines [of treatment]
treatment regimens
luminal relating to the
hollow

metastatic a cancer that has spread to an unrelated organ

muscle-invasive bladder cancer cancer that has spread from the lining to the muscles of the bladder

neoantigens newly formed cells that are not recognised by the immune system

**neoepitopes** newly formed cells

**primary endpoint** answers to the primary questions posed by the trial

refractory resistant
resection surgical removal
surrogate markers a reliable
substitute for the disease

**T-cell** a cell that can attack a cancer cell

transitional cell cancer cancer of the kidneys and ureter

tumour microenvironment the cellular environment

the cellular environment in which the tumour exists TURBT transurethral

resection of bladder cancer: a surgical removal of a tumour

**urothelial** of the urinary tract

**visceral** of the nervous system

Median survival in the PD-L1 positive (IC 2–3+) population was 11.4 months (95% CI 9.0–NA $\theta$ ), 6.7 months (95% CI 5.1–8.8%) in the PD-L1 (IC1+) population and 6.5 months (95% CI 4.4–8.3%) in patients who did not express PD-L1 (IC0).

The take-home message from this study was that a significant proportion of PD-L1 positive patients responded to therapy (27%), the duration of response was prolonged and the agent is well tolerated. Together these suggest a large subset of patients achieve significant benefit with Atezolizumab. This is especially relevant in the setting of chemotherapyrefractory UBC where existing treatments are largely ineffective and have significant toxicity<sup>2</sup>. Atezolizumab is therefore an attractive treatment option for patients with PD-L1 positive tumours, but what about PD-L1 negatives? This is a grey area. It is evident that a small but significant proportion of PD-L1 negative patients respond to therapy (9–11%). Again these responses appeared durable. It is therefore likely that when patients are faced with largely ineffective chemotherapy options, Atezolizumab may be appealing. Nevertheless this needs to be better defined in randomised trials.

Other considerations beyond response are also important before we can be confident about the precise activity of Atezolizumab. These include the significance of stable disease with immune therapy, the quality of life compared to chemotherapy, the proportion of patients who go into long-term remission with treatment and the prognostic/predictive value of the biomarker. Randomised trials will be needed to define these issues as well as the overall benefit. These studies are ongoing with both Atezolizumab and Pembrolizumab (NCT02450331, NCT02256436).

The phase 1 data has led to a number of other trials looking at different immune agents, different combinations and different stages of UBC. This includes the first line immune combination study testing the PD-L1 inhibitor Durvalumab with or without the CTLA4 inhibitor Tremilimumab against chemotherapy (NCT0251624). Durvalumab was recently given FDA breakthrough status although no

|                              | Pembrolizumab | Avelumab | Atezolizumab | Atezolizumab |
|------------------------------|---------------|----------|--------------|--------------|
| Phase                        | I             | I        | I            | II           |
| Number of patients           | 33            | 44       | 92           | 311          |
| Response rates in all comers | NA            | 16%      | NA           | 15%          |
| RR in PD-L1+ve**             | 28%           | 40%      | 50%          | 27%          |
| OS in all comers             | NA            | NA       | NA           | 7.9 months   |
| OS in PD-L1 +ves**           | 13 months     | NA       | Not reached* | 11.4 months  |
| Grade 3/4 AEs                | 9%            | 2%       | 4%           | 15%          |

Table 1:\* median follow up = 14 months

clinical data is yet in the public domain. The investigational drugs in this study have the potential to replace chemotherapy as first-line therapy. Other first-line studies with different combinations are likely in the future.

Finally, two trials are testing Atezolizumab or Nivolumab in the *adjuvant* setting (NCT02516241, NCT02450331) where checkpoint inhibitors are given post-cystectomy to reduce the risk of developing metastatic disease. These studies have the potential to replace chemotherapy and improve outcomes in the operable setting.

Looking into the future, a new generation of immune therapies will be tested in combination with one another, with targeted therapy or even with chemotherapy. The permutations are potentially limitless. A focused approach based on patients' needs with a strong scientific rationale is required.

The Lancet publication also demonstrated a number of potentially significant biomarker findings <sup>5</sup>. PD-L1 expression correlated with immune activation genes and other immune checkpoint inhibitors. Together these suggest not only immune adaption occurs within the tumour but the potential for immune checkpoint combinations in UBC.

Results also showed that tumours with higher levels of mutations had better response rates. Studies in other tumour types shows immune-specific *neoepitopes* drive this process, suggesting mutational burden itself may not be as crucial as the presence of specific recognisable abnormalities<sup>8</sup>. The generation of *T-cell* specific responses to *neoantigens* underlines the specific nature of immune tumour interaction<sup>9</sup>.

The work revealed that the *luminal* (I–II) and *basal* (III–IV) sub-types of UBC had different immune profiles and differing responses to Atezolizumab. Luminal types II had the highest response rates, while basal types had numerically higher PD-L1 expression in both the immune and tumour component expression. This data adds a new dimension to our understanding of UBC, and specific treatments based on these subdivisions are possible in the future.

#### In summary

Overall this is an exciting time for UBC. It is likely there will be new standard of care for some patients in 2016. As new combinations are tested earlier in the disease setting, long-term remission may become a reality for a significant proportion of patients. There is a need to ensure that our understanding of how the drugs work keeps pace with the speedy drug development to ensure we don't reach a premature plateau. Therefore biomarker studies should run in parallel with the randomised trials. For the first time in a generation there is light at the end of the tunnel for patients with metastatic UBC.

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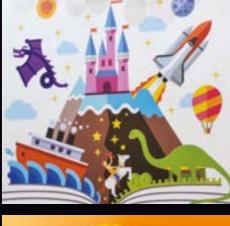
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# FBC's Wee Bookshop & Café

# A TASTY SURPRISE

In April this year we opened the doors of The Wee Bookshop & Café. We wanted to challenge the way that charities usually use the High Street to raise funds and also raise awareness. This very different venture has produced a huge amount of publicity about bladder cancer, including items on BBC TV, national and local radio and in the press.

We sit down with the creative minds behind the shop, Andrew, FBC Founder and Tracy, FBC Chairman. We are sitting down inside the Wee Bookshop and Café. And we can honestly say it feels exactly as we imagined it last year when we dreamed up what we wanted to be a new way for our charity, Fight Bladder Cancer, to fund its activities.

To make an impact, we realised we had to change the way charities think about their space on our high streets. And now we're open for business in our village of Chinnor, which

may not be the first place you'd think of to start a mini revolution – but why not?

Our idea for the Wee Bookshop and Café started with a feeling that our high streets are changing. We wanted to be more than 'another retail space taken over by a charity'. To us, it was important that our space became something the people of Chinnor needed and wanted. The business idea was simple enough: if we provide the food,

drinks and a nice relaxing space for villagers, then we'll earn their loyalty as customers and make money for the charity. It's as simple as that.

Looking at it now, we both believe we have created a real community asset. A place to meet and mingle or, to put it another way, to feed and read. Since we opened we've been working flat out and there have been people queuing out the door. That is so pleasing.

A few years ago we could not have imagined that we would soon be running a charity or opening a cool café. Andrew's own diagnosis of bladder cancer and experience as a patient made him realise there is serious work to be done

## We are hoping the café will make a significant contribution to running our services.

providing support for people with this type of cancer as well as their families and friends. His life changed then and what began with fairly small ambitions has grown into a national charity.

To do the work needs money, so we have applied our own skills to making the Wee Bookshop & Café stand out. We like to think people won't see it as a charity shop before they see a great café.

Inside we have lined the

walls with pre-loved books and it is bright and stylish. Combine that with the aroma of freshly made coffee and we believe we have a place with real character.

It's a passion of ours that charity shops simply shouldn't be boring. We think lots of people in the charity sector realise their retail space needs to provide a great service and add value to our high street. We hope people will come in here, like the café and want to come back because of what we

## We chat to Carrie, The Wee Bookshop & Café's Manager ...

#### Q So what's it like running the bookshop & café?

A It's busy! It's such a rewarding job, I find it fulfilling and enjoy it very much. It can be challenging sometimes as we have a lot of customers, but all in all it's good fun. I enjoy the people ... coffee and cake ... what's not to love?!

#### Q Do you think customers realise it's a charity shop when they first come in?

A I don't think initially they do. Normally after they've ordered coffee and cake they'll ask why it's called the Wee Bookshop & Café, and then I'll tell them that we support people affected by bladder cancer and it really helps raise general awareness of the disease.

#### Q What has the reaction been locally?

A Just brilliant, it's been absolutely fantastic. We have regulars who come in all the time but we still get lots of new visitors, who are just thrilled when they walk in. They love the little train, the atmosphere, the lovely food and drink and the huge array of books.

#### Q To you, what's special about the shop & café?

A Community. To me that's the most important thing. We have a chap who comes in every day on his own at a quarter to three. He's lost his wife recently to cancer. He orders an Americano, has a chat to the staff and then chats to whoever else is here. That's the magic of the shop, that people can sit on their own and other people will talk to them. It's a really welcoming, cosy place.

#### Q What are your bestsellers?

- A On our lunch regulars it's definitely the chicken, mozzarella and pesto panini. Cakes varies according to the day. We sell a lot of passion cake as it's quite an unusual but delicious cake, a spiced carrot and banana cake topped with walnuts and an amazing vanilla frosting. On weekends we sell lots of tiffin and flapjacks and our Victoria sponge is becoming quite well known too. As for coffee, we sell Tom Brown lattés more than anything else ... right in the middle flavour wise.
- Q If you wanted people to know one things about the shop above everything else what would it be?
- A That it's friendly. For me it's such a warm and welcoming place.

#### What does the world think?

'A fantastic café for a fantastic cause.' 'Little gem.'



'A unique find.'

'Every town should have a place like this.'

'A totally awesome charity bookshop & café like no other I've seen.'

Have a look at our other amazing reviews on TripAdvisor.

provide to them, not because we are a charity.

We have certainly set out to make this an enterprise which can compete with anything on the high street. We have looked carefully at the food we are offering and we've secured what we believe is one of the best ranges of coffee available anywhere – every taste from the strongest to the mildest and all things in between.

Beside the café tables, we've added a comfortable sofa area and a magical children's space. If we weren't so busy with the charity we like to think we'd spend our time browsing along the bookshelves. And we never stop smiling when our little toy

railway chugs into action along the top of the shelves. It's our tribute to the heritage railway we have in the village.

It is important that we are a success - and not only for us. Fight Bladder Cancer has become a national charity because demand for our support reached far beyond our Oxfordshire and Buckinghamshire roots. There are 10,000 people diagnosed with the cancer each year. Whilst two-thirds are men, it is amongst women that the disease is rising. We are hoping the café will make a significant contribution to running our information and support services.



The Wee Bookshop & Café 39 Station Road, Chinnor, OX39 4QH

01844 351621

Open 8 am until 5 pm Monday - Saturday 10 am until 4 pm Sunday



As a Uro-oncology Cancer Nurse Specialist, I am constantly looking for resources to help my patients deal with their condition. Fight because it is run by people who really know what they are talking about: those who are or have been affected by bladder cancer.

up of our local support group at Barrowin-Furness, earlier this year, to provide a

dedicated point of contact for patients and their families who wanted to talk about any aspect of their bladder cancer. Because it's not always appropriate for patients to discuss things with healthcare professionals; they also want to chat to people who have been through what they are going through and can truly share their experiences. Then the patient can really feel they are understood and gain first-hand knowledge of what to expect.

#### The Fight statistics

WHO? The University Hospitals of Morecambe Bay NHS Foundation Trust (UHMBT) and national charity Fight Bladder Cancer teamed up to create one of the first bladder support groups in the North West of England. It was set up in January 2016.

**WHAT?** Fight Club Barrow is an informal group that organises monthly meetings where people can talk about anything and ask questions. Refreshments are provided and there is free parking.

WHEN? The support group meets on the first Monday of every month from 6–8pm. If the first Monday of the month is a bank holiday, then it takes place on the second Monday of the month.

**WHERE?** In the Conference Room at Furness General Hospital (FGH).

WHY? Fight Club Barrow was fuelled by the current national 'blood in pee' campaign, which urges patients to see their GP if they see blood in their urine, as it can be a sign of bladder or kidney cancer. In these circumstances, visiting your GP as soon as possible can significantly improve early detection and treatment outcomes if a cancer diagnosis is made.



Find out more about starting your own local Fight Club and other national support groups on the downloads section of our website: <a href="https://www.fightbladdercancer.co.uk/downloads">www.fightbladdercancer.co.uk/downloads</a>



Bladder cancer has received little attention from the media in past years and I am happy to see this is now rapidly changing. The Fight Bladder Cancer charity is heavily involved in improving bladder cancer awareness and is actively fighting to improve the treatments and care that patients and their loved ones receive.

As a CNS who attends the local support groups, I can help provide the relevant and specific information requested by the members. But because I am constantly dealing with patients and families, I also understand what doesn't work or what people find frustrating. I can then take this back to my Trust and urology department and use it to make changes that work towards a better and more personalised service. The Trust, CNSs and Fight Bladder Cancer working together cohesively as a team in this way is essential if we are going to make real improvements.

As well as helping those affected by bladder cancer, patient support group feedback is also extremely important to us as it helps us to see what matters most to our patients and their families, and what we can do to support them in the best way possible.

The Fight Bladder cancer support group is very important as it gives local people the opportunity to share their experiences in a place where they can talk openly and honestly about any concerns or fears they may have amongst people who understand how they are feeling through first-hand experience. The group also has access to relevant healthcare professionals, including specialist nurses, consultant urologists and oncologists.

Aimed at anyone affected by bladder cancer, friends and relatives are welcome to come along and learn how they can support their loved ones.

For more information about Fight Club Barrow, please contact Fight Club member, Yvonne Penrice, on **01229 889899**.

# CNS superhero

### The role of your Clinical Nurse Specialist

When you are in treatment for something as serious as bladder cancer, you don't see just one doctor; you are cared for by an entire multidisciplinary team (MDT), a group of specialist doctors and healthcare professionals, all with urology expertise (NICE 2015).

The rock at the centre of that team is the Clinical Nurse Specialist (CNS), registered nurses who have studied to Degree level and who are expected to be working towards Masters level. All are clinical experts within their tumour speciality and nursing practice.

Their role is to provide specialist care, support and information throughout the patient's cancer journey. And they are not only there for the patient, but can also signpost relatives to national information, support services, self-help groups and associated urology-specific support. But equally important is that they are the people who ensure a continuity of patient care by co-ordinating all the various agencies and professionals and providing the vital link between them and their patients. Over and above anything you can put on paper, having one constant reference point provides a huge degree of reassurance and emotional

Being at the centre of the treatment with key access to the urology multidisciplinary team means that the CNS is able to influence effective patient care and experience across the

whole of their pathway and is named in the patient's notes and MDT meeting proforma.

Following the introduction of the Manual for Cancer Services for Urology and the National Institute for Clinical Excellence (NICE 2015), the allocation of a Key Worker (KW) to each cancer patient was introduced in 2004. With the patient's consent and agreement, the KW is responsible for organising and navigating the patient through their care at a practical level. They are the point of contact between the hospital and the patient to provide support, advice and onward referral.

The Key Worker is also a requirement for the National Cancer Peer Review Programme, which is a quality-assurance programme aimed at reviewing clinical teams and services to determine their compliance against national measures. It also carries out an assessment of quality aspects of clinical care and treatment.

The role of the KW was assigned to the CNS so that a single named person is allocated to each individual patient with a new cancer diagnosis.

The CNS may change as the patient passes through various stages of their cancer trajectory or when care is transferred to a different hospital trust. If so, it is the responsibility of the CNS to supply medical notes and all the information necessary to make the handover as seamless as possible for both nurses and patient.

An immensely challenging role, this is an equally rewarding one as the CNS journeys with the patient along their cancer pathway.

#### The key elements of the CNS/KW role:

- providing a pivotal point around which all treatment revolves:
- co-ordinating assessments to meet patient's physical and psychosocial needs, which are identified at key milestones of the patient journey (diagnosis, pre and post treatment, disease recurrence, end-of-life care and at any other time the patient requests);
- being an advocate for the patient and a link between patient and professionals;
- ensuring that holistic care is delivered that responds to individual needs.

Your CNS is at the heart of providing the continuity of care that ensures the best outcome for patients with bladder cancer.



# Bladder Cancer & the 100,000 Genomes Project

Ground-breaking research by the Genome Project is driving forward our understanding of the underlying biology of many cancers and opening up new options for treatment.



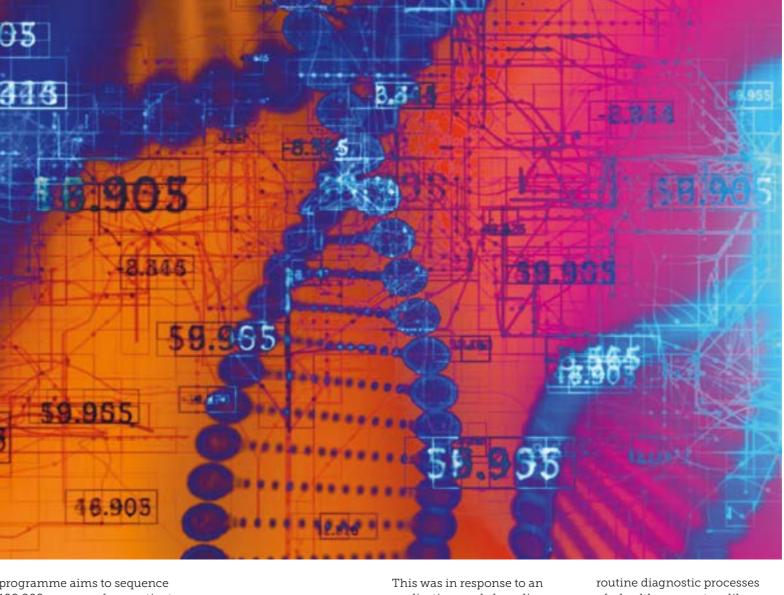
Every one of our cells is tightly controlled by the DNA code within our genes. This complete DNA code – which is called a genome – influences everything about us from our gender to the colour of our eyes, to the way we develop as people.

If specific genes of the DNA code are damaged, this leads to a faulty genome and, at its simplest, this is what causes bladder cancer. As a result, genes can become over or under active as they fail to respond to their normal regulation. This leads to bladder cancer cells

proliferating in an uncontrolled way and eventually being able to spread, or metastasise. Causes of damage to the cancer genome are sometimes well understood (such as smoking, sun exposure or certain chemicals) but often not. In some cases they may be

Genome damage in bladder cancer is phenomenally complex but we are beginning to unlock the detail. In the last decade we have witnessed major advances in our ability to read the genetic code of our cells. That means 'sequencing a genome' – reading the entire 3 billion letter DNA code, including 20,000 genes present in every cell – is now viable in a relatively short space of time and affordable on a large scale. As our understanding of the biology of cancers grows, it opens up exciting new treatment options.

In the UK, the NHS is seeking to integrate routine use of this 'genomic medicine' through the 100,000 Genomes Project. This ground-breaking



programme aims to sequence 100,000 genomes from patients with various cancers or rare genetic diseases over the next few years. For patients with cancer, the aim is to read the complete genome from both their cancer cells and their normal cells. The differences between the two will allow us firstly to understand what makes that patient's cancer 'tick' but also to allow us to search for inherited genetic changes that might pre-dispose someone to getting cancer in the first place.

I am delighted to say that Genomics England, who are overseeing this project for the NHS, have recently agreed that bladder cancer will be included in the 100,000 Genomes project. application made by a diverse group of UK bladder cancer experts that includes urologists, oncologists, cancer biologists, bioinformatics experts (the data crunching is a specialist area in its own right), trainees and patient representatives. We are very excited that within the next few months patients with bladder cancer will be given the opportunity to participate so that both they, and their cancer, will have a complete genetic readout undertaken.

The 100.000 Genomes Project, including our bladder cancer component, has multiple aims. Firstly the simple act of bringing a complete genome readout of a cancer into the

of a health care system like the NHS is unprecedented. It requires the redesign of services involving a broad range of health workers including surgeons, pathologists and dedicated nursing staff. There are also critical issues around provision of informed consent. During the process, we may well discover things of importance not only for the patient but also for members of their family.

These pragmatic issues, however, don't take away from the fact that the research potential is hugely exciting. We will develop a worldleading resource to grow our understanding of bladder cancer biology that we hope

**ARTICLE** 

DR SIMON CRABB Associate Professor of Medical Oncology, University of Southampton

will lead to new and effective treatment options.

Finally one very interesting and novel aspect of this work will be that, alongside the research opportunities, it is intended to use this complex data as a normal NHS test. We will be able, and indeed required, to take the results of each patient's cancer genome and feed it back to the clinician looking after that patient so that, where possible, it will be used to guide their treatment.

We will develop a world-leading resource to grow our understanding of bladder cancer biology that we hope will lead to new and effective treatment options.

The project will evolve through several phases. Phase 1 will sample newly diagnosed and untreated patients. Phase 1 bladder cancer samples will be collected in the next few months. Phase 2 will refine the criteria to allow us to investigate specific questions about bladder cancer biology. Phase 3 aims to link the genetic codes from this project for use as selection criteria for entry into clinical trials to work towards 'personalised medicine'. We are delighted to have the opportunity to shape how bladder cancer will be included in this ambitious and innovative project.



It is about 40 years since Alvaro Morales described the use of intravesical Bacillus Calmette-Guerin therapy (BCG) as a treatment for bladder cancer and now – despite only a limited amount of research – it has become the recommended treatment for the vast majority of cases of high-risk, non-muscle-invasive bladder cancer. The most usual treatment is an induction course followed by a maintenance course of up to two years.

As patients, we accept the treatments that the doctors suggest for us. We know that nothing in life is certain and that it might not work for us. But if we are told that the best treatment is three years of BCG, the odds must be good that it will work and that we will be cancer free within the three years, so we believe that is what we should do. After all, it has been the recommended treatment for so long, it must be the best – mustn't it? And we have been warned about possible side-effects but they're nothing to worry about. We will be well looked after.

There are some lucky people who sail through the treatment with almost no side-effects but not many are that fortunate. Even if it is as good as it gets, life on BCG treatment is certainly not a pleasant life for many. The side-effects aren't usually life-threatening in any way but they are certainly life-changing for many. The treatment is very invasive and comes with warnings of having to keep family away and the use of copious amounts of bleach in your toilet. Pain, time off work and fear can become the norm.

The worst part of BCG treatment is when you go for your check up only to find that the cancer has come back. And this can happen time and time again. The fear is always there. The fear of it not just coming back but the fear of it spreading.

'But it is my only choice. I have to put up with it or they will want to remove my bladder. I'm not going there. I will put up with anything rather than have my bladder removed.'

This fear of recurrence, the fear of progression, the fear of being a 'BCG failure' is real for most BCG

patients. Even if they get do get the all-clear, they know that when the next cystoscopy appointment comes closer, the fears will set in again.

But in 2012 something happened that meant a sudden change of tack for BCG treatment. The supply of BCG was interrupted and patients could not be given their full recommended treatment.

On the 6 July 2012, Professor Sir Mike Richards, from the National Cancer Action Team, issued a letter highlighting the unavailability of BCG for bladder cancer treatment in the UK as a result of the halt in the production of the ImmuCyst strain of BCG. The letter predicted that ImmuCyst would possibly be back in production by late 2013.

The guidance issued by BAUS (the British Association of Urological Surgeons) on what to do during the shortage was:

## Prioritisation for existing (if any) and future stocks should be as follows:

- 1 Patients currently receiving induction therapy.
- 2 Newly diagnosed patients who would normally be offered induction therapy.
- **3** Patients receiving maintenance therapy, where the additional gains are likely to be small.

It was also accepted that in the period until new supplies arrived, the following scenarios would be almost inevitable:

- 1 Patients on maintenance therapy will have to discontinue treatment.
- 2 Patients already on induction therapy may have to stop (at least temporarily).
- 3 New patients who would normally be treated with BCG will either be offered intravesical chemotherapy as a holding measure or, if at the borderline of requiring a cystectomy, may be recommended to undergo major surgery. It is highly likely that the number of cystectomies will increase across the country.

It took a while but the shortage was resolved, with the manufacturer MSD increasing their supply of their BCG strain, OncoTICE, into the UK to match demand. ImmuCyst wasn't available



The worst part of BCG treatment is when you go for your check up only to find that the cancer has come back. And this can happen time and time again.

again by late 2013. It would be another three years until that would happen. So, with just a single supplier in the UK, patients were now able to get their 'recommended' treatment again.

The relief was short-lived, however, as in 2015, MSD announced that, due to a manufacturing problem, they would only have restricted supplies of BCG for the UK market. Our single supplier of BCG for bladder cancer treatment would not be able to supply what was needed. From two suppliers to one and then to limited supply again was another blow for bladder cancer patients. Rationing was introduced for a second time. Treatments were stopped. The worries about recurrence and progression, as you can imagine, became even more acute. Without treatment, we knew that our risks had increased. Without the recommended treatment, our prognosis was in the balance.

But now, in the first half of 2016, it appears that BCG supplies are now able to meet demand once again. ImmuCyst is available again in the UK and everything is back to normal.

#### But is it back to normal?

BCG patients are now finding themselves in a strange situation. They had their treatment stopped but often nobody has talked to them about starting it again. If they start again, do they start again from the beginning or just start again from where they had to stop before. 'I only had my induction course but I've been clear for nine months now. Do I actually need to start again?' 'Do I actually need the maintenance?'

BCG is a hit-or-miss treatment. It is invasive and often causes distressing side-effects. But we will put up with it if it really is the best treatment for us. Three years of pain and discomfort is worth it if it prevents progression and saves our lives. What we need to know is whether it is the best treatment for us personally. We need to know if the extra years of maintenance are worth it.

There is now four years of data covering thousands of patients who have had either the full recommended treatment or different restrictions of no maintenance or limited maintenance. Surely this must be the time to investigate what all this data can tell us about what really is the best for us?

18 <u>fightbladdercancer.co.uk</u>

# You are WHAT YOU EAT

Following a bladder cancer diagnosis, many people want to make positive changes to their lives. Taking steps to live a healthier lifestyle is often a major part of these changes.

This article has been written for people living with or after bladder cancer, who want to know more about a healthy diet. It explains why diet is important, and has tips on how to eat well and maintain a healthy body weight. It aims to help you think about what changes you may want to make, and help you put them into practice.

Before making any changes to your diet, it's best to talk to your dietician, your GP or cancer specialist.

After researching all the options we recommend a Mediterranean diet for people affected by bladder cancer. This diet incorporates the traditional healthy living habits of people from countries bordering the Mediterranean Sea, including Italy, France, Greece and Spain.

FEATURE SUSIE WILLIAMS



Mediterranean cuisine varies by region and has a range of definitions, but is largely based on vegetables, fruits, nuts, beans, cereal grains, olive oil and fish.

# We know what we eat influences our health

Up to 10% of cancers may be linked to diet. Research indicates that being overweight may contribute to 7% of cancers in women. A lack of fruit and vegetables may also be responsible for 6% of cancers in men. Although a lot of research still needs to be done to understand which substances increase our risk of developing cancer, we know what types of food can keep us healthy.

A balanced diet and physical activity have many health benefits. They can help reduce the risk of heart disease, strokes and diabetes. They can also help us maintain a healthy weight which can reduce the risk of developing certain types of cancer.

If you're trying to lose weight, it's important to make sure you still get all the nutrients you need. Your diet should include fruit and vegetables and you should try to limit salt, fat and sugar. Keeping active

will also help you manage your weight. Your GP or dietician can advise you on your ideal weight and offer you support.

Making changes to eat healthier food can seem difficult. Try to improve your diet progressively. You can use the opportunity to discover and try new foods. It can take time to find a diet that works for you, but your GP or dietician can give you advice. It may help to make gradual changes and set small, realistic goals.

Alcohol can increase the risk of developing certain cancers. According to the national guidelines, men should avoid drinking more than 3–4 units of alcohol a day; women should not have more than 2–3 units a day.

A balanced diet contains a variety of foods. Try to eat lots of fruit and vegetables, and include plenty of starchy foods (such as cereals, bread and pasta) in your diet. Your body also needs protein from foods such as fish and meat. Food labels can guide you and help you choose healthier options.

People often ask if what they eat can reduce their risk of the cancer returning. This is the subject of a lot of current research. There is some early evidence from breast and



20 <u>fightbladdercancer.co.uk</u>

bowel cancer studies that diet may make a difference to the chances of the cancer coming back. However, there still isn't enough clear information to make precise recommendations about what someone with a particular type of cancer should eat. In general, cancer experts recommend following a healthy balanced diet.

For most people, the factors that are most likely to have the greatest impact on your health include not smoking, diet, weight control and regular physical activity. The biggest difference will probably be from a combination of factors, rather than any one particular change.

Your healthcare team are the best people to advise you what, if any, lifestyle changes you can make that may help reduce your risk of cancer coming back.

Instead of looking for a 'superfood', it's better to aim for a 'superdiet' as recommended in healthy eating guidelines.



# What foods should I avoid?

Make sure that eggs are well-cooked, and use shop-bought, not home-made mayonnaise. If your immunity is low, avoid pâté, raw eggs, live bacterial yoghurt and cheeses made from unpasteurised milk, such as Brie and blue-veined cheeses. These foods may contain harmful bacteria.

If you're on high-dose chemotherapy, your health care team may suggest that you avoid additional foods – ask them for advice.

# Should I take dietary supplements?

For most people, a balanced diet provides all the nutrients they need, and taking large doses of vitamins, minerals and other dietary supplements isn't recommended. But people who find it difficult to eat a balanced diet may benefit from taking a multivitamin or mineral supplement containing up to 100% of the recommended daily allowance.

Supplements may be beneficial in some situations, such as for people who aren't able to absorb all the nutrients they need because of surgery for stomach cancer. People at increased risk of bone thinning (osteoporosis) may benefit from taking calcium and vitamin D supplements to help strengthen their bones.

Several studies have looked at whether taking supplements can reduce the risk of developing certain cancers. However, the results have been disappointing. In general the evidence is that taking supplements doesn't reduce the risk of cancer. There is even evidence that taking high doses of some supplements

can increase the risk of cancer developing in some people.

One study found that people who smoke were more likely to develop lung cancer if they took supplements of beta-carotene (a substance the body uses to make vitamin A). The results of other studies suggest that high doses of beta-carotene and vitamin A supplements may increase the risk of getting cancers of the gullet and stomach.



It's possible that some supplements may interfere with how cancer treatments work, and make them less effective. So if you're currently having treatment for cancer, it's important to get advice from your cancer specialist before taking any supplements. They can advise you about which, if any, you should take, and which doses might be suitable for you. They can also tell you about any possible side-effects and interactions with other medicines.

# What about 'superfoods'?

There isn't any scientific evidence for any one particular food being a 'superfood'.

The greatest benefit to your health is likely to come from eating a balanced diet that includes a wide and varied combination of foods. There are many substances in fruit and vegetables that may potentially have anti-cancer properties. However, at the moment we don't know this for certain, and we don't understand which ones are most likely to help or how they work.

So instead of looking for a 'superfood', it's better to aim for a 'superdiet' as recommended in healthy eating guidelines. This will help you make sure you're getting the widest possible variety of these substances. It will also make your diet more enjoyable and interesting, and will probably be cheaper too!

# Should I follow a dairy-free diet?

Many research studies have looked for a link between diets that are high in dairy products and cancer (in particular breast and prostate cancers). However, these studies haven't shown a clear link. For this reason, cancer experts don't recommend following a dairy-free diet to try to reduce the risk of cancer.

Dairy products are an important source of protein, calcium and some vitamins, but can be high in fat. Be careful with the quantities as part of your overall diet. Calcium is needed for strong bones and may help reduce the risk of bowel cancer. So if you decide to follow a dairy-free diet, you'll need to make sure you get enough calcium from other food sources, such as tinned sardines and salmon (with bones); dark green leafy vegetables, such as spinach; or fortified foods, such as some types of soya milk.

## Does sugar feed cancer?

Sugar in your diet doesn't directly increase the risk of cancer, or encourage it to grow. But sugar contains no useful nutrients, apart from energy, and we can get all the energy we need from healthier sources. So it's best to limit the amount of sugar in your diet.

# Should I only eat organic food?

Many people wonder if they should follow an organic diet to prevent their cancer from coming back. Studies that examined the nutritional benefits of organic fruit and vegetables had mixed outcomes. Some claim that organic fruit and vegetables have better flavour and stay fresh for longer. So far, no research has been done to find out if an organic diet is more effective at stopping the recurrence or occurrence of cancer, compared to a nonorganic diet.

Some people may worry that pesticides used in non-organic farming may cause cancer. In the UK, a pesticide can only be used once its safety has been tested. Laws ensure that all agricultural pesticides are used at a safe level. Genetically modified crops have proved to be safe in the 7 years they've been grown. But some people might feel that the long-term effects are unknown. Buying organic or non-organic food is ultimately a personal choice.

The current advice is to wash all fruit and vegetables, non-organic as well as organic, thoroughly before use to remove any form of pesticide.



#### Do anti-cancer diets work?

There has been a lot of publicity about alternative diets for treating cancer over the past few years. Many dramatic claims for cures have been made. It's understandable that people may be attracted to diets that seem to offer the hope of a cure.

However, there isn't good evidence that these diets can make a cancer shrink, increase a person's chance of survival or cure the disease.

Some people get satisfaction from following these special diets, but others find them quite boring and even unpleasant to eat, and time-consuming to prepare. Some diets may lack important nutrients or be unbalanced in other ways, and may even be harmful.

It can be confusing to be faced with conflicting advice about what to eat, but most doctors and specialist nurses recommend a well-balanced and enjoyable diet.

In summary, do your best to keep to a normal, well-balanced diet, keep an eye on your weight (up or down) – and keep away from cigarettes!



'Now I respond to everyone who gets in touch and I try to give the kind of support that I appreciated so much at the time of my diagnosis.'

ARTICLE
MELANIE COSTIN
FBC Trustee

# Two-time cancer survivor, carer and self-confessed Ms Memory, who better to co-ordinate the FBC Confidential Support Forum?

Maybe it was the attention I drew after I was dragged kicking and screaming to a photo shoot for Shout Out About Bladder Cancer. Maybe it was my penchant for plain talking or essay-style responses on the forum. Maybe it was just something that was meant to be. Whatever the reason, I have somehow made the move from Facebook forum member to Fight Bladder Cancer's Support Co-ordinator.

I first joined the forum in a mad panic in December 2013 when my treatment hadn't started particularly well and I thought that the size of a post surgery anti-clotting catheter must surely have been miscalculated and I may possibly go insane! The responses I immediately got from others who knew exactly how I felt made me feel so much less alone, it was an amazing feeling for me as I lay there. (I did also go a bit insane anyway, but that's another story!)

In the past, there really hasn't been that much in the way of helpful and clear information regarding bladder cancer. After the shock of diagnosis, much of what we are told by the urologists will sail right over our heads. We then come home with all sorts of questions invading our minds and need to have them answered without searching frantically online in a complete haze or panic.

This is when I feel that Fight Bladder Cancer is so important. The private and confidential forum that we run through Facebook – called Fight Bladder Cancer Support – is really an amazing place to come for those first diagnosed or even those many years down the line who want to join in and even give advice to others. Although many people like to sit on the sidelines and pick up information this way, there are many others for whom it has really become a lifeline.

It is run by patients and carers so not only does this make it an extremely genuine place to come for information but there is always someone around who has been in the same situation as you. We have a section of our website especially for people who have just been diagnosed because it is a time when you feel so vulnerable and need answers to so many questions without being overwhelmed with too much information. We make sure the text is up to date and easy to understand.

There are many people, however, who prefer to talk to a real person and ask all sorts of questions, and we are there for them, too – no matter how random the questions may seem. Some of them just need a bit of reassurance, the opportunity to chat things through with someone who has been through a similar procedure, to be pointed in the right direction for medical advice or even just to type a couple of words such as 'help needed'.

I have realised that over the years I have gathered quite a bit of personal knowledge on the subject of cancer, which has been from both sides of the page, as a carer and also as a two-time survivor. An ability to recall facts and details about absolutely everything hasn't always been a blessing for me—that is until I began to contribute to the forum!

Now I respond to everyone who gets in touch and I try to give the kind of support that I appreciated so much at the time of my diagnosis when I contacted someone who was basically a complete stranger behind an email address. I initially thought I would need to stay rather aloof when I was speaking to so many vulnerable and frightened people, but that really isn't my way. Consequently, I spend a lot of time thinking about those who contact me via the Bladder Buddy service, wondering how they are getting on both with their treatments and in their lives. Some people never contact me again after I have given them the information they asked for or pointed them in the right direction, others have regular contact and I really enjoy hearing what they have been getting up to.

There was a time when I was also able to make comments on lots of posts and join in more discussions, but now there is so much checking to do as a moderator that often this isn't possible, although I do read everything through and keep up with what is going on.

It still surprises me, though, how many spam requests to join that we get! One false move and we would be inundated with people wanting to sell fake sunglasses, strange plastic shoes or snake oil!

'The private and confidential forum that we run – Fight Bladder Cancer Support – is an amazing place to come for those first diagnosed, or even those many years down the line who want to join in and give advice.'

#### Talk in confidence ...

Our main support service is our online Confidential Forum, which is available 24 hours a day, 7 days a week. You can ask any question and get support from others who have been in the same situation.

This member's only forum for those affected by bladder cancer is where you can discuss any worries or issues, find out about treatment options, and talk openly about your worries and fears with other people on the same cancer journey. Our forum spans every conceivable age, and we count medical professionals, patients and carers amongst our members.

We invite all those affected by bladder cancer, including people who may be writing on behalf of a family member, friend or loved one. All are welcome.

 $\frac{www.fightbladdercancer.co.uk/get-help/}{getting-support}$ 





We catch up with FBC forum member, Alison Crellin

Everyone likes a hug when they are feeling down but what do you do if you are too far away to comfort someone? Alison wasn't going to let distance get in the way of sending her friends on the Fight Bladder Cancer Support Forum a snuggle. She came up with the idea of a Bladder Buddy Blanket – and she hasn't stopped crocheting since. We caught up with her ...

- Q We'd like to get to know you first tell us a bit about yourself.
- A Well, I suppose you'd say first that I am a family person. My husband, Paul, and I have been together for 38 years and married for 34. We were childhood sweethearts I was just 16 when we met. Our daughters Dawn and Claire are 34 and 32 and I am Grandma to four beautiful grandchildren: Lillie is 5½, Maya is 4½, Lucy is 3 and Aaron (AJ) is nearly 2. And I mustn't forget Chester, our trusty Cocker Spaniel, who I rescued 10 years ago.

I work in Children's Services as a Safeguarding Conferencing Officer, but I haven't been able to work for the last year as my job entails a lot of travelling and it was too much. Before that, I was a Medical Secretary for a Consultant in Stroke and Elderly Care.

- Q It sounds like you had plenty to keep you busy. How did you feel when you first got your diagnosis?
- A I actually felt really angry when I found out. I had undergone a knee operation and after that I felt really unwell so I went to see my GP. Then I got pneumonia and a really bad body rash that no one could get to the bottom of. I had my tumour markers done and they were raised, so my GP told me to go back in March to have my bloods retaken. It was the following May, in 2014, that they told me the diagnosis of T1 G3 TCC. I was devastated, scared and worried about what lay ahead.

#### Q What happened next?

A In June 2014 I had my first TURBT (see glossary, p 8) but I couldn't have the planned follow-up TURBT six weeks later as I suffered a perforation. This was a very anxious time - not just feeling so unwell but having to wait until September for my second TURBT, which confirmed the first diagnosis. I was offered a six-week course of BCG or the option of a radical cystectomy, and I decided on the BCG treatment as I want to keep my bladder as long as I can. But I had to wait another month before I could start because of shortages. The treatment wasn't very kind to me, and that was worrying -I didn't know if this was how I was supposed to be feeling.

#### Q Did you ask anyone for help?

A Yes. It was during this course of treatment that my CNS showed me the leaflet for the Fight Bladder Cancer group, and by the time I had been home an hour, I had joined! Finding out that I wasn't alone was such a relief! There were other people undergoing the same treatment as I was and feeling just as anxious.

Finding the group introduced me to a different understanding of bladder cancer and I made some lovely new friends, who really helped me during those difficult times.



#### Q How have you coped?

**FORUM FOCUS** 

INTERVIEW with WENDY HOBSON

A What with the treatment and other operations, it has been very hard, very up and down physically and emotionally. I still don't know how long I will be able to keep my bladder and that is a big worry. Keeping myself busy stops me being miserable. Even though I can't work, I find plenty to do – that helps me cope.

My family has been wonderful – they've inspired me and got me through the down times. And joining FBC has helped me and given me a new perspective. I can stay positive because we all understand each other, we can talk about things and support each other. There are some inspiring stories that I read on FBC from my buddies and how they deal with their diagnosis and treatments.

So my new motto is: 'cancer started this fight, but I will finish it'.

## Q That's wonderful. How did you come up with the idea for your Bladder Buddy Blankets?

A I have been crocheting since I was 11 years old. Abba was hot in the charts and the older girls in the school were making their own hats – like the ones Agnetha and Anni-Frid used to wear. One day I stood behind the older girls and watched them making hats, then I went home and made one for myself. Everyone wanted one, so I was soon making hats for the other girls – and charging 25p! After that, I taught myself to make granny squares, then I made my first tank top. I remember it well! It was blue and orange. I thought I was the bees knees in it.

I did a lot of knitting and sewing and I hadn't picked up a crochet hook for years, but when my daughter went to university, she wanted a 'granny comfort blanket' to take with her, and that got me started again. I enjoyed making it and she loved to snuggle with it when she was fed up so when my father was diagnosed with cancer and had to go into the hospice, I made blankets for his fellow patients.









Then a friend on FBC was going through some of Alison's eally hard time but it was just too far away gorgeous time to visit, so I came up with the idea of blankets.

a really hard time but it was just too far away for me to visit, so I came up with the idea of making something for her to hug and snuggle up to – that was my first real BBB! She loved it and I just thought, 'Well, I had better make some more for other people, too.' So far I have made over 50 for FBC buddies, and I have two ready to make up to send on.

## Q What part of making the blankets do you enjoy the most?

A The best thing is knowing that people enjoy them, but when I am making them, I particularly enjoy putting the finished version all together, playing with the patterns. I'll use any wool, but I mainly use double knitting.

#### Q Are all the blankets the same?

A Oh no. Each one is personal to the individual. When I have decided who I am making a blanket for I try to judge their character and personality and match it to the colours. Some blankets I like to put flowers on, if it suits the recipient's personality. Some people have sent me buttons that I have sewn into their blanket. The buttons belonged to loved ones who are no longer with them, so when they snuggle up to the blanket they are snuggling up to the person they lost.

#### Q How do you choose who you make buddy blankets for?

A I don't really have a method. I just keep an eye out in the group and see who I feel needs one, or I choose someone who does so much for others. I also receive private messages nominating people who they think would like a blanket. I am very keen for this to continue as sometimes I might have missed someone who really needs that little hug.

#### Q Does that leave you time for any other hobbies?

A Plenty! When I'm not crocheting I like to forage. I make a lot of jams, chutney, pickles and preserves. I also enjoy making different gins! I'm currently waiting patiently for my Sloe Gin and Apple and Blackcurrant Gin to mature so that I can bottle it.

I like to go for walks in the Lake District with my husband and the dog, although recently my osteoarthritis and the knee operation have stopped me getting about so much. However, I am hoping in another few weeks time that we can get out there again.



Alison has also made gorgeous hats and tea cosies to send to her Bladder Buddies

I also enjoy knitting and I am currently working on the grandchildren's Christmas jumpers. I also like quilting, although I haven't done any this year.

I absolutely love spending time with my

grandchildren – they keep me busy. When we're together we do lots of fun things and we have arts and crafts afternoons every Saturday. We are currently working on projects for Christmas, when the 'Big Red Man' comes.

#### Q You seem very involved with the Fight Bladder Cancer charity. What has been your experience of the charity and the support forum?

A When I found the FBC website and joined, I felt like I had been given a lifeline. The support from other buddies has been tremendous. When I have felt down or scared, there have always been buddies there to pick me up and put me back on track.

We discuss things that you couldn't discuss openly on other networking sites. I have been inspired by my buddies and touched by their experiences. We have laughed, we have cried. I have even been on a virtual picnic and to the virtual bar - we have some truly crazy buddies! The information on the website has been so helpful to me and has helped give me a greater understanding of bladder cancer.

#### Q What's next for you?

A I have more treatments and investigations lined up for the coming months, but I am hoping to be able to return to work later this year. I love my job and I miss the hectic lifestyle.

Thank you, Alison. It's been really good to meet you!



# Meet Mandy, another Team FBC crocheter!



group like FBC was invaluable to me even after my tumour was removed and I had received an all clear. My love of (and mild addiction to) crochet was also a great distraction at the time.

Other FBC members soon discovered my hobby and there was often friendly banter about it so one day I decided to do something positive with it and raise a bit of money for the

Initially I offered a Minion loo roll cover as a raffle prize as it had a link to wee, but another orange one to reflect the Fight Bladder Cancer colours.

Once completed I posted

Being part of a support the details online to the support group as well as my own friends, customers. Thinking he would raise maybe £20 I was shocked one day to see the donations had leapt to £150!

> Eventually, after reaching £250 the raffle was drawn and one of the original Bladder Buddies had won the cheery little chap. He was delivered complete with a loo roll.



A few months later a Bladder Buddy Ball was being organised, go over the top. To include everyone I came up with the idea to ask people to sponsor a 6" square which would be added to a blanket. The contributors would choose up to four colours and I would crochet a square which would not only showcase the colours but would also be personal and unique.

Everyone got behind it and I got sponsors from Buddies, friends and family from all over, including the USA and Canada. Some people contributed in the memory of lost loved ones who had been such a big part of the group and my personal journey. These were the hardest to do.

Some people requested very specific themes as if I was using

a magic wand rather than a hook but eventually I managed and received very positive feedback. In the end 81 squares were put together, and as they were I would know the story and person behind each one.

sell the raffle tickets, and again I was overwhelmed by the support, people were even arguing over who was going to win it, all in jest of course. On the night of the ball we paraded the blanket in all its glory around the guests, there was a last minute frenzy to buy tickets and we collected a further

£400. The raffle was drawn and the winner immediately insisted that we auction it.

Suddenly it all became so surreal I felt like I was in a dream. All of the love and emotion I'd put in suddenly started surfacing, I looked around the room and all the crazy, loving, kind and very loud Buddies, most of whom I'd only met that night, were cheering on the bidders. Even my best friend got caught up in the bidding. It peaked at £310 and a lovely lady won it in memory of her dad.

Once we had tallied it up the total raised for Fight Bladder Cancer was £1700. However, for me the best thing is that is brought me closer to some amazing people.



31

30

# Clinical trials



#### Developing vital research for bladder cancer

Fight Bladder Cancer supports evidence-based medicine for all those affected by bladder cancer. Consequently, we are passionate about the development of vital research that is needed to increase our knowledge base, to help with prevention and to develop new and better forms of diagnosis, treatment and aftercare.

A clinical trial is something that can be offered at any stage in the bladder cancer journey, from initial suspected diagnosis, through investigations and different treatments and in later follow-ups or at end of life.

A clinical trial is not something to look at when all else fails. Many treatments we use today were developed as part of a clinical trial. For example, the use of chemotherapy at the same time as radiotherapy treatment was developed in the UK as part of a large study (called BC2001) and has changed practice around the world.

There are a number of clinical trials in bladder cancer. These usually compare a new treatment that has the potential to work better or with fewer side-effects, than what is used as the 'gold-standard'. Different trials are available in different hospitals. All studies have particular tick boxes to confirm whether this study is the correct one for you and your cancer. It may be that you and your type of bladder cancer do not match what we call the eligibility criteria for the study.

Knowing about what is on offer is very useful and you can find out information in the UK by going onto the website for the National Cancer Research Network and clicking on the portfolio map for bladder cancer. This gives an up-to-date overview of studies.

Remember that you should ask your doctor if you are suitable for a clinical trial, and it is always helpful to take information to show your doctor in case the trial is not familiar. If it looks as though you may be eligible for a study that is not available locally but is open elsewhere in the UK (and you are prepared to travel), you could ask your doctor to refer you.

#### How clinical trials work

Clinical trials are carried out in phases, usually phases 1 to 3 although occasionally there is an earlier phase 0 or a later phase 4. These phases cover issues from what side-effects a drug might cause to testing whether a new drug is better than an existing treatment.

#### PHASE 1

After a treatment has been tested in the laboratory, a phase 1 trial would be set up to look at things like: the safe dose of a drug, the side-effects and how the body copes with the drug, and whether the drug will affect the cancer. This testing has to be done first before moving to the next phase of the trial, which tests the effectiveness of the drug in treating the cancer.

Phase 1 trials can take a long time to complete even though a small number of patients are involved. The trial will work with small groups of patients, increasing the dose of the drug slightly with each group, as long as the results go well; this is called a dose escalation study. The results of these studies will indicate the best dose for this particular drug. Patients in a phase 1 trial may or may not benefit from the new treatment.

#### PHASE 2

A phase 2 trial would compare an existing treatment with the new treatment or with a placebo. It will move into a phase 3 trial if the treatment proves to be as good as or better than an existing treatment. Some phase 2 trials might be randomised trials, where participants are put into groups at random. One group receives the new treatment, while another receives the current, standard treatment (that is, the best treatment which is currently available). If there is no standard treatment, the control group may be given a placebo. Phase 2 trials will look at whether the treatment works well enough to go to a larger, phase 3, trial.

#### PHASE 3

These trials will compare the new treatment with the existing standard treatment or compare a standard treatment in a new way or in different doses. These trials are usually much larger than phases 1 or 2 and might involve thousands of patients in hospitals across the UK and even abroad. Success rates or percentage changes may be small, so a much larger trial group is needed to show these differences accurately. Most phase 3 trials are randomised trials.

# Current open trials

Current UK trials for bladder cancer are outlined here. For more details or eligibility criteria, please contact the appropriate trials team whose details can be found via the UK Clinical Trials Gateway at <a href="https://www.ukctg.nihr.ac.uk/home/">https://www.ukctg.nihr.ac.uk/home/</a>

# Non-invasive bladder cancer

#### **BRAVO**

The BRAVO trial will study the choice between BCG treatment or bladder removal for high-risk, non-invasive bladder cancer. The initial part of the study will look at the feasibility of undertaking a randomised trial of BCG and radical cystectomy as treatment options for highrisk. non-muscle-invasive bladder cancer and what information from a patient, nurse and clinician point of view is necessary to enable patient randomisation for this comparison.

#### CALIBER

The CALIBER study is for people with low-risk, non-invasive bladder cancer, which has returned after initial treatment. People who take part will either have surgery or a course of Mitomycin C. Mitomycin C is a chemotherapy drug, has been used in bladder-cancer treatment for many years and is normally put into the bladder following surgery for bladder tumours. CALIBER aims to find out whether a course of Mitomycin C treatment might be an alternative to surgery for people whose low-risk bladder cancer has returned.

#### HIVEC II

HIVEC II is a study in nonmuscle-invasive bladder cancer looking at hyperthermia treatment. This trial is for people with newly diagnosed early bladder cancer or bladder cancer that has come back after initial treatment. Hyperthermia is a new treatment where the bladder is heated to between 42°C and 44°C and Mitomycin C is washed through the bladder.

The trial is comparing hyperthermia and Mitomycin C with Mitomycin C alone. The aim of this trial is to find out which treatment is better at controlling cancer growth, as well as more about the sideeffects and quality of life.

#### PHOTO

The PHOTO study is for people with a new diagnosis of non-invasive bladder cancer which has a medium or high risk of returning following treatment. Everyone taking part will have surgery to remove their tumours. The surgery will be done either using a white light to see inside the bladder, or a blue light. PHOTO aims to find out whether using blue light in surgery reduces the likelihood of the cancer returning.

# Muscle invasive bladder cancer

#### HYBRID

The HYBRID study is a radiotherapy study for people who have muscle-invasive bladder cancer who are not able or well enough to have a cystectomy or to attend a hospital five time a week for radiotherapy, which would be the usual schedule. Everyone

taking part will visit the hospital once a week for six weeks for radiotherapy. HYBRID aims to find out if using recent advances in radiotherapy delivery techniques can help reduce the side-effects of this treatment.

#### **IDEAL**

The IDEAL trial is looking at combining three different ways to plan radiotherapy treatment for bladder cancer. This is so that doctors can target the cancer more accurately and give a higher dose of radiotherapy than they are normally able to.

#### MARBLE

The MARBLE study is looking at some new scans to see if they can show how well treatment has worked in people having chemotherapy before surgery or radiotherapy for bladder cancer.

## MRI SCANS and PET-CT SCANS

MRI scans are important scans for doctors wanting to look at cancer. Researchers in this study have developed some new ways of looking at tumours using a type of MRI scan called a functional MRI scan (fMRI). They believe that fMRI may be better at showing how well cancer treatment is working early on. They now want to see how reliable these scans are when looking at bladder cancer.

The study is also looking at how well a new type of PET-CT scan can show up bladder cancer and give them more information about it.

#### **NEOBLADE**

Neoblade is a study of neoadjuvant chemotherapy for patients with bladder cancer which has grown into the muscle but not to elsewhere in the body. These patients will ultimately go on to have either a cystectomy or chemoradiation treatment, and the neoadjuvant chemotherapy is given prior to either of these. The usual treatment is to start with two drugs as upfront chemotherapy and NEOBLADE is looking at adding another drug called Nintedanib to see if this makes the treatment work better.

#### SPIRE

SPIRE is another study of neoadjuvant chemotherapy for patients with bladder cancer who are due to have neoadjuvant chemotherapy. This study is in set up and involves an experimental drug called SGI-110 in addition to the two standard chemotherapy drugs Gemcitabine and Cisplatin. This is a very early study looking at how well the combination is tolerated and what its ideal dose is.

#### **ABACUS**

ABACUS is a study for patients who are not able to receive neoadjuvant chemotherapy prior to cystectomy, usually because their kidney blood tests are not good enough to have Cisplatin chemotherapy. In ABACUS, another drug is given for 6 weeks or so before cystectomy to see if this improves the results of the surgery and to see if there are any side-effects that might make the surgery more difficult. The drug in ABACUS is MPDL3280A, a PDL-1 inhibitor.

#### RAIDER

The RAIDER study is for people with muscle-invasive bladder cancer who choose to have daily radiotherapy as treatment. Everyone taking part will have daily radiotherapy five times a week. People who take part will be in one of three treatment groups: standard radiotherapy, radiotherapy with the highest radiation dose focused on the tumour, or radiotherapy with a higher dose than normal focused on the tumour. RAIDER aims to confirm that this higher dose radiotherapy is safe and can be delivered at multiple hospitals within the NHS.

#### **TUXEDO**

TUXEDO is a trial in patients who are advised to have chemoradiation for muscle-invasive bladder cancer. This study is in an early stage and is looking at adding another drug to the standard radiotherapy and chemotherapy, given at the same time as radiotherapy.

#### Advanced muscleinvasive bladder cancer

#### **FIESTA**

This is a study in advanced/ metastatic bladder cancer. Patients receive standard chemotherapy with Gemcitabine and Cisplatin and with the possible addition of a drug called AZD4547. This is a very early study (phase 1) where the combination treatment is being evaluated for safety and side-effects.

#### MPDL 3280A

(The IMvigor Trial)

MPDL 3280A (IMvigor) is a study for patients who have undergone a radical cystectomy for muscle-invasive bladder cancer and who have highrisk features on their surgical specimen, meaning that microscopic examination of the bladder, after removal. suggested that the cancer had a higher rate of coming back in the future. This study is looking at whether giving a new drug called Atezolizumab, an Anti-PDL-1 antibody, reduces the chance of the cancer coming back.

#### TOTEM

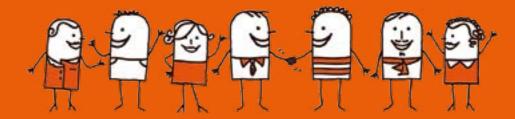
This is a study in advanced/metastatic bladder cancer.
Patients receive standard chemotherapy with
Gemcitabine and Cisplatin and with the possible addition of a drug called Tensirolimus. This is a very early study looking at the safety of the drug and what is the ideal dose.

# Invasive upper tract urothelial carcinoma

#### POUT

The POUT study is for people with invasive cancer of the upper urinary tract (ureter and kidney). Everyone taking part needs to have recently had surgery to remove their ureter and kidney. People who take part will either be given chemotherapy immediately or will be closely monitored and only given further treatment if their cancer comes back. POUT aims to find out if giving chemotherapy soon after surgery reduces the likelihood of the cancer returning.

# Help us Fight Bladder Cancer!



- Make a donation
- Fundraise
- Become a bladder buddy
- Volunteer
- Run awareness events
- Distribute support materials
- Start a support group
- Fund research
- Join a clinical trial

Every time you work with us, from giving a simple donation to helping distribute our posters and patient information booklets, you are helping make a big difference to all those living with and affected by bladder cancer.

Whether you are a medical professional or someone directly affected by a bladder cancer diagnosis, your help is invaluable. Working together we can make big changes and stop people dying of this disease.

Email <u>info@fightbladdercancer.co.uk</u> to find out more.





## Congratulations on the inaugural issue of Fight Magazine.

# Each year, **10,000** are diagnosed with bladder cancer in the UK

Bladder cancer is the **5th** most common cancer in the Western world

Increasingly, those under **60** are affected by the disease

**Intuitive Surgical** salutes the vital work of **Fight Bladder Cancer** on behalf of patients and their families, and those who will be diagnosed this year and beyond.

And, we thank the skilled UK robotic-assisted keyhole surgeons who offer patients a minimally invasive option.

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