

## ABC UK Review – November 2018

ABC UK has been through an exciting change over the past 2 years.

We launched our new name – Action Bladder Cancer UK – in April 2016 and our terrific new website [www.actionbladdercanceruk.org](http://www.actionbladdercanceruk.org). We have lots of new information for patients on our website, visitors to our site have increased dramatically and more and more patients are contacting us directly for support. We have had a tremendous response and will be adding further information and exciting new functions.

We have a great group of trustees - a very strong mix representing patients, clinicians, researchers, nurses and primary care. Our wonderful volunteers (mostly patients) help deliver our projects and plan our work – in particular, working with hospitals and other patients to get new bladder cancer support groups set up, providing one to one support to those with bladder cancer and helping to develop information materials which are of real help to patients.

### Our Work and Achievements



#### Patient Support Programme

##### Bladder Cancer Patient Support Groups

Attending a support group can be of great help, both emotionally and practically, to patients. ABC UK carried out research in 2015 and found only 10 groups offering support for bladder cancer patients across the whole of the UK. Since then, we have worked pro-actively with major hospitals and patients to initiate groups and provide on-going encouragement and guidance.

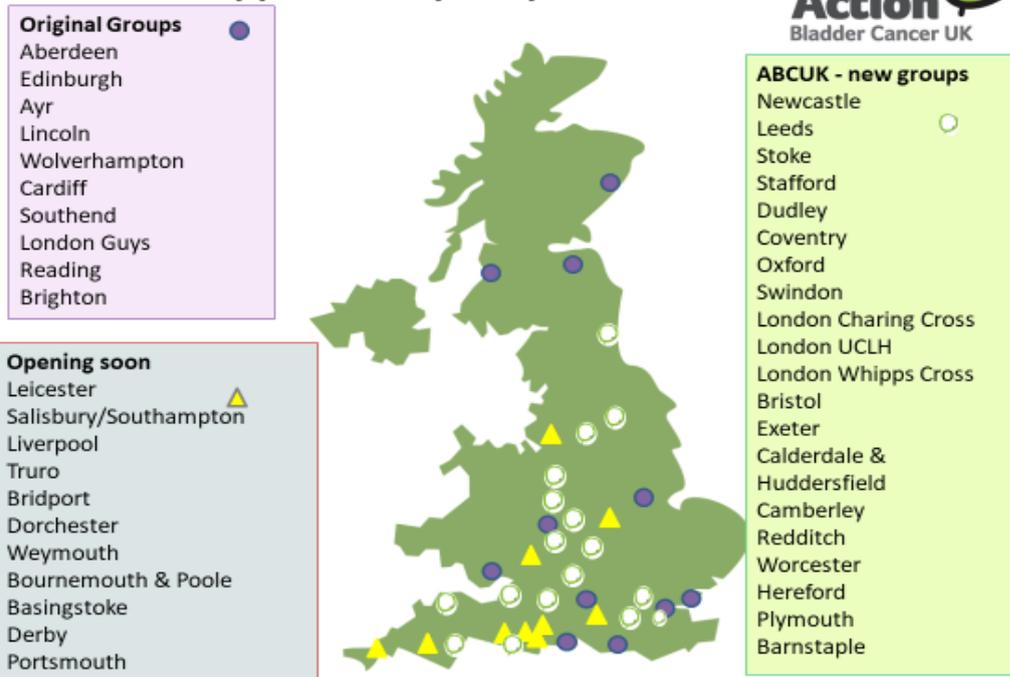
**23 NEW GROUPS** across the UK have now been initiated by ABC UK and are up and running, providing support for bladder cancer patients and carers.

**10 NEW GROUPS** have been agreed and are in process of being set up.

We have many more groups in planning and our volunteer Patient Support Advisors (all bladder cancer patients) continue to target hospitals in regions where no support is available. We are also, increasingly, being approached directly by nurses and patients to help get a group started. All these new groups are listed on our website and we also have a post code search function for patients to find their nearest group. There are however, still large areas of the UK where there aren't any groups, or the nearest one is too far for patients to reach easily so there is much to do. We are also moving our work with patient support groups to the next level, building an effective network for groups and providing a focus for groups to share news, good practice and link with others. We will also be running events bring information to patients, helping groups to make contacts and special workshops for nurses.

We're very proud of our achievements in creating local, direct, support for those with bladder cancer and it continues to be one of our key priorities. We are delighted to have recruited a new ABC UK Patient Support Programme officer who is working on building our programme UK-wide.

## BC Support Groups September 2018



### Information and direct patient support

In addition to extensive information on our website, we also provide materials direct to hospitals, urology departments, support groups and individual patients. We continue to add further information and resources to expand the impact even further and are developing a wide range of new materials both online and in printed form, which we will be distributing widely. ABC UK prides itself on the accessible but authoritative style of our information.

We are getting increasing rates of direct contact from patients asking for advice and support, which they have been unable to find elsewhere. We are increasing our pro-active contact with hospitals and urology cancer health professionals and our one to one support for patients.

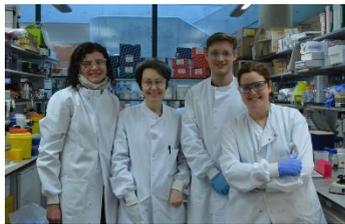


### Mapping and improving bladder cancer data

We have been working on a major new project to map bladder cancer services and statistics across the UK. Bladder cancer patients face many challenges, and access to good quality information about their condition, services and support is one of these issues. Available treatments, standards of care and patient experience vary hugely across the UK. This new interactive resource will be live on our website late 2018 and will help patients to understand this picture and guide them to treatment and sources of support. This will be an important tool for health professionals as well as patients and their families. It will bring together sources of information on bladder cancer and help ABC UK to highlight gaps in knowledge and services. This is a significant new project and will be a live resource as we add new levels of data as it becomes available.

## **ABC UK Improving Outcomes for Patients Programme 2018**

Lack of research investment for bladder cancer is a serious problem. Despite the levels of incidence, bladder cancer receives a very low level of research funding, having a direct impact on poor patient outcomes and poor patient experience. We launched IOPP in November 2016 to encourage standalone projects which directly improve outcomes for patients. The response to this new programme has exceeded our expectations, with submissions from researchers, urologists and nurses. Three grants were awarded in 2017 and the 2<sup>nd</sup> round has been even better. Summaries of the four successful 2018 grant recipients are below (more information on our website).



### **Professor Anne Kiltie, University of Oxford**

New less toxic treatments to use with radiotherapy in older people are urgently needed, Prof Anne Kiltie Univ of Oxford & team will investigate biomarkers and set up a National Virtual Biobank of FFPE tissue & clinical data.



### **Hilary Baker CNS and Jacqui Duncan CNS, University College London Hospital**

This project will initiate a nurse-led post cystectomy clinic and provide a specialist all-inclusive clinic for patients & family. A great idea improving patient experience.



### **Dr Yee Pei Song, University of Manchester**

Treatment options for Muscle Invasive Bladder Cancer have different long-term side-effects and impact on quality of life. This project addresses the urgent need to find a scientific method to decide which treatment option may be better for each patient.



### **IDENTIFY: Sinan Khadhouri, BURST - British Urological Research in Surgical Training**

This project is looking at creating personalised diagnostics and how to reduce unnecessary tests and will create a dedicated stand-alone IDENTIFY patient and public study group.

IOPP is now an ABC UK annual programme, growing in scope and impact each year - this unique Programme will contribute to knowledge about bladder cancer, improve patient outcomes and also act as a catalyst to encourage further much-needed work.

**IOPP 2019 is now open for applications.** Details on the ABC UK website and social media.



## ABC UK Living with Bladder Cancer Programme

Any cancer patient faces a difficult journey – undergoing treatment or surgery, facing difficult decisions, as well as the emotional impact of a diagnosis on themselves and their loved ones. Living with cancer raises many issues for patients, both emotional and practical. Bladder cancer patients can face particular challenges. Finding the right kind of support and information can help enormously. We are working closely with patients and nurses to provide the kind of information and support which patients need to improve their quality of life and are launching a national programme of well-being events to bring advice and support to local areas. We have a new range of information materials for those living with bladder cancer, which we are continually adding to and are responsive to suggestions from patients and health professionals to what materials they would like to see.



## Awareness

Raising awareness of the symptoms of bladder cancer is one of our core priorities and we are constantly working to get the message home and also to highlight the issues surrounding bladder cancer, such as the fact that bladder cancer is neglected and under-funded despite being one of the ten most common cancers in the UK.

We are pleased to be a founding partner in the Public Health England Be Aware: Blood in Pee campaign, which ran again in July 2018.



## Supporting Nurses

ABC UK works closely with nurses. Often the main point of contact for patients throughout their journey, urology CNS's are a vital source of support and expertise. We work with nurses to set up and sustain support groups for bladder cancer patients; we speak at training days and provide information materials and advice. There is a lot more we are planning to do:

- Work with nurses and patients to develop new materials to set up and sustain bladder cancer patient support groups and provide appropriate information for patients;
- Study days/workshops: for nurses to learn about bladder cancer and feed back experiences;
- E-learning module – we are developing a learning module about bladder cancer for nurses which they can access as part of their professional development and revalidation;
- Our new Improving Outcomes for Patients Programme provides grants for nurses to support projects to improve the patient experience. Grants of this kind for nurses are very rare.



## Primary Care

Bladder cancer can be diagnosed late and working to improve GP awareness of symptoms and when to 'think bladder cancer' is a priority. We are pleased we have been able to fund research projects within our IOP Programme which look at improving diagnosis and anticipate more submissions to this grant programme relating to the area of bladder cancer diagnostics. We are also currently working on producing learning resources for GPs and practice staff to improve early diagnosis. We have already worked with Macmillan to produce a GP bladder cancer symptom resource.



## Putting the Patient Perspective

We regularly attend conferences, seminars and sturdy days for health professionals – such as urologists, cancer nursing specialists and urology nurses – where we work to raise awareness and present the patient perspective.



Caroline Raw, bladder cancer patient and ABC UK Trustee, at the Global Bladder Cancer Congress in Madrid in September 2018 – telling the audience what patients, and ABC UK, want for the future ...

We also provide patient input to clinical trials and consultations and provide patient briefing and viewpoint to many within the bladder cancer sector.



## Policy

We are regular contributors to NICE consultations relating to bladder cancer and lobby on bladder cancer issues. We work to raise the profile of bladder cancer with decision makers and contribute to cancer patient consortiums, conferences and roundtables, both UK and EU. We are a founding partner of the NHS PHE Blood in Pee Campaign (which ran again in July 2018). Whilst short campaigns have been shown to have some impact on numbers of people presenting to GPs with haematuria there is a much more to be done to sustain impact and to raise public awareness.

**If you'd like to find out more about ABC UK or about bladder cancer**  
**E mail: [info@actionbladdercanceruk.org](mailto:info@actionbladdercanceruk.org) Call: 0300 302 0085**