



Action on Bladder Cancer 2015 Review

Since our founding in 2009, we have established ourselves as an active charity, focusing on improving awareness of bladder cancer, providing patient information and working to raise the profile of bladder cancer as a cancer which is seriously neglected in terms of research funding and patient support.

2015 has been an important year for ABC – one of consolidation, improvement and planning new programmes. We have developed a new strategy for our activity and have also undertaken a full review of the management of our charity, our governance and structure. This has resulted in several very positive changes which have helped us to create a much stronger and more effective organisation.

Governance

One conclusion of our review of governance was that the charity required a more appropriate structure and constitution. Following advice from the Charity Commission, we have established a new Charitable Incorporated Organisation registered with the Charity Commission under our new name Action Bladder Cancer UK. The old charity, Action on Bladder Cancer, will be dissolved. All assets from the existing charity, and all officers, will be transferred to the new CIO (Charity Number 1164374) in early 2016. The Charity Commission launched this new structure for small/medium sized charities in 2013 and many charities are transferring to this new constitution for the benefits in governance and operations.

Over the past 18 months we have also strengthened our trustee board. Our trustees and executive now represent top urologists and cancer research specialists, cancer nursing, primary care and bladder cancer patients. Our new administration support based in Gloucestershire provides improved office and finance operations. We have recruited a Head of Fundraising.

Hugh Mostafid stood down as Chair of Action on Bladder Cancer in July 2015 – Hugh's commitment and vision has driven the many positive changes for our charity, and we are delighted that he is continuing to be involved with us. We are equally delighted that an existing trustee, Allen Knight, was appointed as Chair to succeed Hugh. Allen's business background, as well as his personal experience as a bladder cancer patient, is already proving a great asset to our organisation.

A new name, charity brand and online presence

We have a new name – Action Bladder Cancer UK - and a new brand, which better reflect our role as a UK-wide, pro-active, modern charity.

We will be launching our new brand and a new website in early 2016 – a more accessible, modern website which will reflect our new projects and stronger engagement with patients and the public.

Strategy

We have developed a new strategic plan for our activity which puts the focus, with more drive, on improving outcomes for patients, increasing the research into the causes and treatment of bladder cancer, improving support available for bladder cancer patients, and improving awareness amongst health professionals, the public, the scientific community and government. This planning has helped us to define several key areas of new work where we are focussing our activity – all these new areas focus on directly improving outcomes for bladder cancer patients.



Some of our current projects

Patient Support

There is a significant lack of support groups for bladder cancer patients across the UK - this is one of our key areas of activity. We have been working on identifying the main cancer hospitals across the UK who do not have a support group for bladder cancer patients in the area. Using our contacts and experience we then encourage hospital staff to commit to setting up a new group, providing advice and support to help them do so. With the new groups due to become active in early 2016, we will have an additional 10 groups set up by June 2016 – doubling the number of existing groups in the UK. There are more planned for 2016.

We are producing new information materials for patients and their families and guidance packs for groups, and hope to run a patient support phone line in the near future.

Research

Bladder cancer is seriously neglected in terms of research funding – we have plans to set up a new Small Grants Programme in 2016 which will support one off research projects and provide seed funding to encourage research into directly improving outcomes for bladder cancer patients. The programme would be open not only to researchers and urologists, but also to cancer nurses and GPs. We intend this to become an annual programme.

We also plan to be able to support pieces of research which may arise from our work or in response to a particular need, such as recommendations in the recent NICE Guidelines for bladder cancer.

Patient Decision Aid

We were commissioned by the Department of Health to produce a revised decision aid to help bladder cancer patients understand the options available to them during their treatment journey and to make informed decisions.

Improving Diagnosis

Late diagnosis is an issue for bladder cancer patients – and another of our priorities is improving knowledge of bladder cancer within primary care, particularly that of GPs, and having an impact on raising the rate of early diagnosis of bladder cancer and improving the outcomes for those diagnosed. We are working on ways of educating GPs about bladder cancer – including e-learning resources and other methods of engagement.

Raising Awareness

We are committed to improving awareness of bladder cancer as a serious condition affecting thousands of people in the UK every year and the issues of lack of funding, the need for improvement in diagnosis and treatments, and the lack of support and information for patients and their families.

2016 and onwards ...

We are entering 2016 a stronger organisation, with a highly committed, significantly strengthened, trustee board, and exciting projects. We have a great deal of work to do...

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