

ABC UK NEWS – APRIL 2016

Our first newsletter for 2016 and we're starting Spring with a new look. We've just launched our new name, logo and website. We feel these better reflect our ambitions and our commitment to being a driving force to improve outcomes for bladder cancer patients.

Please have a look at our website. We'll be working to add even more material and resources over the coming months. Whether you're a bladder cancer patient or a health professional, let us know if there is information or resources you would like to see on our site. Sign up for our newsletter, follow us on twitter, and join us on facebook whilst you're there www.actionbladdercanceruk.org

2015 Review

The past year has been an important and exciting time for ABCUK. We've had a full review of our governance and structure, which has resulted in several very positive changes, helping us to create a much stronger and more effective organisation. We now have an improved charity constitution and a significantly leaner and stronger trustee board. Our trustee board and executive now represents top urologists and cancer research specialists, cancer nursing, primary care and bladder cancer patients (our current Chair is also a patient).

We have a new strategy for 2016 and exciting new programmes planned. We are building our network of volunteers to help us deliver our programmes. Exciting times ahead - and a lot to do.

PATIENT SUPPORT GROUPS

In 2014, we spent time finding out how many support groups there were for bladder cancer patients. Answer? Only 8 - across the whole of the UK. So, from May 2015, we started our programme of helping to get new support groups started. To date, we've been in touch with 21 major UK hospitals that didn't have a group. We offer a support package and guidance notes to help with the admin needed to open up a group, working with them as they prepare to hold their first BCSG meeting, and beyond. We're delighted that so far 9 of these hospitals have already held their first meeting – thank you everyone who has helped set these groups up. We are currently in discussions with a further 12 hospitals. Details on our website.

The new Groups are: Great Western Hospital **Swindon**; Southmead Hospital **Bristol**; University Hospital **Coventry**; Royal Devon and **Exeter** Hospital; Royal **Stoke** University Hospital; County Hospital **Stafford**; Freeman Hospital **Newcastle**; Churchill Hospital **Oxford**; Charing Cross Hospital Hammersmith, **London**.

If your bladder cancer support group isn't on our website list, let us know, we'd be very happy to add it and help in any way we can. If you'd like to link up with other groups, tell us, as we can help with that too.

If you're interested in setting up a local BCSG in your area and would like our help and support, please get in touch. Please email: groups@actionbladdercanceruk.org

www.actionbladdercanceruk.org/patientsupport

We are working to ...

- improve outcomes for bladder cancer patients
- increase research into bladder cancer by encouraging, contributing to and funding research and improvement programmes
- improve patient support by providing high quality information materials and working to increase the number of bladder cancer patient support groups across the UK
- raise awareness amongst the public and health professionals
- give bladder cancer patients a voice

RESEARCH

Bladder cancer is seriously neglected in terms of research funding, which is reflected in poor patient outcomes and a lack of significant improvements in treatments over the past 30 years. Supporting and encouraging new research is one of our priorities – and the ‘Cinderella’ status of bladder cancer has led us to believe strongly in the need for a programme which can support and encourage work into improving outcomes for bladder cancer patients. We also believe that such a Programme can play an important role in the wider context of driving awareness and providing us with evidence to push for further support for bladder cancer. We see our role as acting as a catalyst for change. We’ll be launching our new **ABC UK Improving Patient Outcomes Programme** in 2016 to support small projects aimed specifically at improving patient outcomes or to impact on patient experience. We are intending this programme to also act as a catalyst, creating interest in undertaking new projects. We will be accepting applications not only from lab-based researchers but also from urology specialists, GP’s, cancer nurses and other health professionals.

Details of how to apply will appear on our website in coming months, and on our social media. We will also be pro-actively publicising this Programme to encourage new projects.

2016 Calendar Highlights

- | | |
|----------|--|
| January | We spoke to the BAUN Bladder Cancer Study Day at the University of Surrey, organised by the Royal Surrey County Hospital, Guildford and BAUN. Good to meet over 60 Urology nurses and other speakers. |
| February | We were pleased to work with Public Health England on the recent Be Clear on Cancer: Blood in Pee campaign . It was good to see this public awareness campaign being run again, and we will be campaigning for public awareness programmes to run again in the future. We have a big task ahead to raise awareness of bladder cancer to acceptable levels, and also to improve early diagnosis of bladder cancer. |
| April | We were invited to speak to the Wolverhampton Bladder Cancer Support Group about our work. A terrific group (details on our website), who provided a lively Q&A session. If any other Support Groups would like us to come and speak, contact us on groups@actionbladdercanceruk.org . |
| April | Our Chair, Allen Knight, is presenting to a group of 120 urology consultants, surgeons and nurses at a Bladder Cancer Weekend (sponsored by Prostrakan). |

Why we’re doing what we do...

Bladder cancer isn’t a rare cancer – it’s the 7th most common cancer in the UK – the 4th most common in men.

Over 10,500 people in the UK are diagnosed each year - about half of those diagnosed will die.

It has the highest recurrence rate of any known cancer – up to 80%. Despite being such a common cancer, survival rates have only improved by 1% since the 1980’s.

One of the most expensive cancers for the NHS to treat (£65million annually) yet it only got 0.6% (in 2013-2014) of dedicated research funding.

Support Us

You can support ABC UK by making a donation or by fundraising to help our work.

You can donate online on our website www.actionbladdercanceruk.org

Fundraising News

If you would like to fundraise, there are lots of ideas on our website, or get in touch on fundraise@actionbladdercanceruk.org

We're having a fantastic start to the year – with some marvellous fundraisers doing tremendous things. They're doing it all for very personal reasons – and they've chosen to support our work.

- ✦ Tom Ward has just run the Manchester Marathon.
- ✦ Debra Shaverin has signed up to do the 100km (yes, that's 100km ...) London2Cambridge Challenge in July.

You can read about both Tom and Debra on our **Fundraising Stories** page on our website.

It's not all marathons and trainers – you could walk sedately, play golf or get on your bike. Your talents might be more culinary, musical, or horticultural - or you might just fancy doing something different – there are a lot of things you can do to help us raise funding. Look on our website for some ideas.

If you are **fundraising for ABC UK** – let us know, send pictures, and tell us how you're getting on.

✦ THANK YOU TO ALL OUR SUPPORTERS ✦

Volunteer

We are actively looking to increase our network of volunteers across the UK. If you look at our Volunteer page on our website, you will see details of current opportunities. Get in touch with us on info@actionbladdercanceruk.org.

Contact us

Address Action Bladder Cancer UK
6 Trull Farm Buildings, Tetbury,
Gloucestershire GL8 8SQ
email info@actionbladdercanceruk.org
Phone 01285 841 900

www.actionbladdercanceruk.org



Follow us on twitter



Join us on facebook

Action Bladder Cancer UK Registered as a charity no: 1164374

