

TRUSTEES' ANNUAL REPORT & ACCOUNTS

1 April 2021 – 31 March 2022







Fight Bladder Cancer was registered as an unincorporated charity in England and Wales on 8 July 2014 (1157763).

Fight Bladder Cancer was registered as a Charitable Incorporated Organisation on 28 April 2022 (1198773) and recognised as a cross-border charity in Scotland on 27 July 2022 (SC051881).

Emerging more robust and more determined from the pandemic, a year in which Fight Bladder Cancer's patient information was cited as a national example of best practice in patient communication by the NHS.

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Introducing Fight Bladder Cancer

The Trustees present their annual report and financial statements of the Charity for the year ended 31 March 2022.

The financial statements comply with current statutory requirements, the Charity's governing document, and the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (SORP FRS 102) (edition October 2019, effective January 2019), and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102).

OUR VISION

A future where everyone survives bladder cancer and lives long and well.

OUR MISSION

To lead the fight against bladder cancer, driven by patient and family insights.

OUR **VALUES**

Patient-led
Compassionate
Action-orientated
Ambitious

OBJECTIVES AND ACTIVITIES

The Charity's objectives are set out in its constitution, as summarised below:

- the provision of support to patients diagnosed with bladder cancer, their families, friends and carers
- the provision of information about bladder cancer, its symptoms, range, treatments and aftercare needs
- promoting awareness campaigns regarding the causes, symptoms, treatments and aftercare to the public and within the medical profession
- the provision of funding for research into the nature, causes, diagnosis, prevention, treatment and cure of bladder cancer

Fight Bladder Cancer is the voice of all those affected by bladder cancer in the UK. The Charity was founded by patients and carers and will keep the patient at the heart of all our work. We are making a difference, but there is still much more to do.



Reference & administrative details

Registered Office:

51 High Street Chinnor Oxfordshire OX39 4DJ

Charity Number

Fight Bladder Cancer is a registered charity in England and Wales (1157763). It will change its charitable status in 2022–2023 (see page 42).

Board of Trustees

The Charity is governed by its Board of Trustees. Its management is delegated to the principal staff, who draw on the Board's knowledge and experience from time to time as needed.

During the year 1 April 2021 to 31 March 2022, no Trustees left the board, and no new Trustees joined, maintaining a total of seven Trustees at any one time. The Trustees who served during the year and up to the date of signature of the financial statements were

John Leslie Hester Since 11 May 2017
Alison Jane Birtle Since 19 July 2017
James William Forbes Catto Since 19 July 2017
Valerie Ann Hester Since 11 May 2017
Hilary Mary Baker Since 11 May 2017
Paul John Major Since 11 May 2017
Deborah Jean Major Since 11 October 2015

Principal Staff

Dr Lydia Makaroff, Phd, CEO Sue Williams, Office Manager

Bankers

Lloyds TSB Bank 27–31 White Hart Street High Wycombe Buckinghamshire HP11 2HL

Solicitors

Brian S. Regler
REGLER & COMPANY
98 High Street
Thame
Oxon OX9 3EH

Independent Examiners

Charles Ssempijja FCA
NfP Accountants Ltd
Chartered Accountants
3rd Floor, 86-90 Paul Street
London EC2A 4NE

Structure, governance & management

Status and Governing Document

Fight Bladder Cancer became registered as an unincorporated charity on 8 July 2014. The charity is governed by its present constitution, which was adopted on 14 July 2013 and amended on 29 June 2014.

Public benefit

Our work delivers public benefit by providing information, advice and support to anyone affected by a bladder cancer diagnosis. This information and support help people live better with their bladder cancer by reducing the isolation that can come with a bladder cancer diagnosis, providing clarity on their treatment options and improving their quality of life with strategies to minimise the negative impact of treatment.

Our Bladder Cancer Awareness Month campaign reaches a broader audience, equipping people with awareness of the signs and symptoms of bladder cancer. This empowers them to speak with their GP if they have any concerns and increases the likelihood of earlier diagnosis and effective treatment.

Our website, posters, magazines, handouts and information booklets raise awareness of the signs and symptoms of bladder cancer among patients, carers, GPs, consultant nurse specialists and other healthcare professionals – increasing the likelihood of earlier diagnosis and effective treatment.

Our information booklets provide much-needed, accessible information for patients and health professionals on aspects of the bladder cancer journey, thus enhancing the care of bladder cancer patients. The Trustees confirm that in carrying out their work, they have had regard to the guidance issued by the Charity Commission on public benefit.

Board of Trustees

The Trustees are responsible for the governance and strategy of the Charity. The Charity's constitution requires a minimum of five and a maximum of 10 Trustees at any one time.

During this financial year, all Trustee meetings were held via Zoom.

From 1 April 2021 to 31 March 2022, there were no changes in the Trustees, so there were seven Trustees at any time. They established a balanced mix of governance, business, healthcare and administration skills. Most Trustees are bladder cancer patients or carers.

Fight Bladder Cancer supports the principles of good governance in the Charity.

Governance Code for smaller charities

Trustees have independent control over and legal responsibility for the Charity's management and administration. They must: comply with the Charity's governing document and the law; act in the Charity's best interests; manage the Charity's resources responsibly; act with reasonable care and skill; and ensure the Charity is accountable.

Trustees' recruitment, induction and training

To recruit new Trustees, the Chair (with support from their fellow Trustees and the CEO) identifies the skills and insight required on the Board to deliver the Charity's strategy. A volunteer job specification is drafted and approved before being advertised as widely as possible. This includes Fight Bladder Cancer's social media outlets, online recruitment sites and a direct approach to individuals with the appropriate skill sets. Potential applicants are invited to submit a CV and, if shortlisted, will be interviewed by the Chair and another Trustee.

On appointment, the new Trustees attend an induction via Zoom with the principal staff and identify areas in which they may wish to take a particular interest. New Trustees are provided with an induction pack, including a copy of the constitution, recent Trustee Board minutes, accounts, financial reports and helpful publications, such as the Charity Commission's The Essential Trustee.

RELATED PARTIES

Fight Bladder Cancer Trading Ltd is a related part of the Charity. It is registered with Companies House with Company number 09988853. It is a private limited company incorporated on 4 February 2016.

The other related parties are the Trustees and those individuals connected with them, including family members, business associates and other charities in which they are involved.

Trustees' terms of office are not restricted, and they receive no remuneration for their duties. They may claim reasonable expenses incurred, such as travel to Trustee meetings.

Each Trustee must disclose any potential or actual conflicts of interest to the Chair and at Trustee meetings when relevant. In line with Charity Commission guidance, details of positions held by Trustees outside of the Charity are available to the public upon request from the Office Manager.

REMUNERATION POLICY FOR KEY MANAGEMENT PERSONNEL

Fight Bladder Cancer is committed to paying our staff fairly and in a way to attract and retain the skills needed to deliver our vision and mission effectively. The Board of Trustees is responsible for setting remuneration levels for the principal staff. This is currently identified as the CEO and Office Manager.

OUR HISTORY

Fight Bladder Cancer started from a very personal battle. Our co-founder Andrew was diagnosed with Stage 4 bladder cancer in June 2009. Faced with a poor prognosis and immediate life-changing surgery, Andrew and his wife Tracy contacted a fellow bladder cancer patient and his partner who had recently undergone the same treatment.

Talking to someone else who understood what they were both going through helped them immensely. Although bladder cancer is common, they were amazed that most people knew nothing about it, and there wasn't a dedicated bladder cancer patient charity in the UK. Once Andrew was recovering from his surgery, they started setting up what was to become Fight Bladder Cancer.

Tracy Staskevich acted as the first Chair of the Trustees and led the Charity most impressively through its formative years. She stepped down in 2017, and John Hester was elected as the new Chair.

After ten years of running the charity, upon receiving a terminal bowel cancer diagnosis, Andrew asked his colleague and friend Dr Lydia Makaroff to apply for the role of Chief Executive. Andrew died in 2019.

Lydia continues to lead and grow the organisation. She has worked to implement Andrew and Tracy's vision so that bladder cancer patients and their families across the UK have a better experience and better outcomes.



OUR TRUSTEES

We are so grateful to our Trustees for the financial year 2021–22.

JOHN HESTER

CHAIR

A bladder cancer patient, John became the Chair of Trustees after a period as Treasurer. Now retired, John was the financial controller at a waste management company



in Wales. Throughout all his operations, he maintained a strong focus on sustainability and innovation, sourcing technologies and embracing best practices, which helped the company reduce its environmental impact and benefit local communities. John remains in close partnership with several local county councils, raising awareness of bladder cancer and supporting community projects. He promotes the NHS 'Blood in Pee' campaign in Wales. He leads Fight Bladder Cancer's UK-wide campaign to ensure that as many accessible toilets as possible display a 'Not All Disabilities Are Visible' sign.

'The Charity is a patient-led organisation. I hope to meet many of you — dedicated patients and carers, supporters and friends — as we all work together to improve the outcomes and quality of life for people affected by bladder cancer.'

DEBORAH MAJOR

VICE CHAIR

Deb is a bladder cancer patient and a lecturer at Brockenhurst College – nationally recognised for excellence and innovation in further education based in the New Forest.



She is an active member of the private online Fight Bladder Cancer forum and has created amazing videos to share her reasons for supporting the Charity. She has organised the Bladder Cancer Southern Soirée, the Southampton bladder cancer support group, and the Bournemouth Bladder Cancer Wee Walk

'I was honoured to be asked to be a Trustee because I wanted to give back to the charity that had helped me through frightening times in my life.'

HILARY BAKER

CNS, BSC (Hons), MSC

In 2001, with funding from the NHS Plan, she was employed as uro-oncology CNS and team leader at Buckinghamshire NHS Trust. In September 2014,



Hilary was appointed as lead CNS for uro-oncology. She has a BSc (Hons) in Cancer and Palliative Care and is registered as a specialist practitioner in adult nursing with the Nursing and Midwifery Council. She has completed her MSc in Cancer Studies at Oxford Brookes University.

PROFESSOR ALISON BIRTLE

MB, BS, MRCP, FRCR, MD

Alison is a consultant oncologist, Manchester University Academic Health Science Centre Honorary Clinical Professor, and Honorary Clinical Professor at the



University of Central Lancashire. Alison undertook general medical and specialist registrar oncology training in London Charing Cross and Westminster. She completed her MD thesis at the Institute of Urology, University College London, and the Academic Urology Unit, Royal

Marsden Hospital. She is a past Chair of the National Cancer Research Institute bladder clinical study group. Her research interests include systemic therapy, chemoradiation, radiotherapy and survivorship.

'There is much more to do to raise awareness and funding for this common cancer. The patient voice in bladder cancer must be heard.'

PROFESSOR JAMES CATTO MB, CHB, PHD, FRCS (UROL)

Professor of Urological Surgery at the University of Sheffield and Honorary Senior Clinical Research Fellow at the University of Oxford, Jim qualified from Leeds University in



1994 and trained in York and Sheffield, UK, before a fellowship in Brisbane, Australia. He was appointed an honorary consultant urological surgeon in 2007 and specialised in uro-oncology. In 2014, James took over as editor-in-chief of *European Urology*. Jim has published more than 100 primary research manuscripts.

'Fight Bladder Cancer is a worthy charity. All patients and carers are entitled to be treated with dignity and respect and should be fully involved in decisions affecting their treatment, care, and support.'

VALERIE HESTER

Valerie is the carer of a bladder cancer patient. Before her retirement, she had a long career as a nurse and midwife within the NHS and



attained the position of Senior Midwifery Sister in North Powys. She has experience caring for patients with complex needs and worked to improve the quality of services and outcomes for patients and carers. She is passionate about nursing and believes everyone has the right to the highest possible standard of respectful medical care.

PAUL MAJOR

Paul is a carer of a bladder cancer patient. He is also a Learning Skills Assistant at Brockenhurst College,



a further education establishment in the New Forest, which has been nationally recognised for excellence and innovation.

OUR TEAM

DR LYDIA MAKAROFF

CHIEF EXECUTIVE (FULL-TIME)

Dr Lydia Makaroff is the CEO of Fight Bladder Cancer and President of the World Bladder Cancer Patient Coalition. Previously she was the Director of the European Cancer Patient Coalition. She has a PhD in immunology and a Master's degree in Public Health. She has worked in academia, the pharmaceutical industry, and the non-profit sector. She has conducted medical research at the Australian National University, worked as a post-doctoral fellow at the University of Washington, and worked for the International Diabetes Federation. Lydia likes to cycle through green spaces with her loved ones and read a book with a cat on her lap.

SUE WILLIAMS OFFICE MANAGER (PART-TIME)

With over 30 years of experience in bookkeeping, Sue joined Fight Bladder Cancer in 2016. Sue answers telephones, deals with orders, replies to enquiries for leaflets and posters, covers the admin tasks and pulls together the financial paperwork. Together with colleagues, she occasionally loads her car with all things Fight Bladder Cancer and drives to a urology conference or health awareness day to set up our stand. Away from the office, she enjoys needlecrafts, drawing, beadwork, crosswords, Sudoku and reading. She loves hunting for vintage fabrics and beads at car boot sales and markets.

MELANIE COSTIN

SUPPORT SERVICES MANAGER (PART-TIME) AND BLADDER CANCER PATIENT

Melanie discovered the Charity early on after her bladder cancer diagnosis. Her role has many façets, including providing information and support, talking at support groups, raising awareness, running the Bladder Buddy service, and being an administrator on our forum. She gets the patients' voices heard when attending medical meetings. Her current job is far from her pre-bladder cancer life as a technical draughtsperson. Away from work, Melanie runs an art class for dementia patients. She loves cats, music and travel and is a cemetery photographer.

AMY JACOB

SUPPORTER CARE & COMMUNITY ENGAGEMENT OFFICER (PART-TIME)

After years of volunteering with various charities,
Amy joined Fight Bladder
Cancer to help with our fundraising efforts. Her responsibilities involve working closely with our fundraisers, offering them support and guidance. Amy also processes our donations and sends out patient support materials. Outside of work, Amy has a degree in Anthropology and is a keen traveller. She enjoys true crime podcasts and watching the latest Netflix documentary.

VICKY SALES

COMMUNICATIONS ASSISTANT (FULL-TIME) AND BLADDER CANCER CARER

Vicky has joined the charity to help with communications after completing a Journalism degree at the University of Sheffield. She has worked in Prague with their largest English-speaking

media outlet, *Prague Morning*, alongside completing a qualification in Digital Marketing Technologies and Creative Methods for Social Media Marketing with Erasmus plus. Over the years, she has volunteered in many social media roles and written for various national magazines and publications. Vicky discovered the Charity after her dad was diagnosed with bladder cancer and hopes to continue helping with the Charity's excellent patient work. Vicky enjoys travelling, art and the company of her dog, Dolly.

CJ BROWNE

OFFICE ASSISTANT (PART-TIME)

CJ graduated from
Oxfordshire Hospital School
and Icknield Community
College with a Diploma in
Animal Care from the Buckinghamshire
College Group. She has previously worked
at St Tiggywinkles Wildlife Hospital,
Chinnor Hill Kennels, and the Chinnor
Village Hall. CJ plays classical guitar, is an
animal photographer, and has cats, two rats
and a leopard gecko.

MICHAEL SLOANE

BOOKKEEPING ASSISTANT (PART-TIME) AND BLADDER CANCER PATIENT

For over 29 years, Michael worked as an accountant for a fire and security alarm company. He runs the accounting system, data entry and reporting. Michael was diagnosed with bladder cancer in 2013, and whilst he has had a couple of recurrences, he has been clear for the past three years. Michael likes to cycle and has cycled from west London to Brighton several times. He has also enjoyed scuba diving in Australia and Malta.

SANA GILFILLAN

POLICY AND COMMUNICATIONS MANAGER

Sana drives Fight Bladder Cancer's policy work to advocate for improved bladder cancer care in the UK. She builds and helps manage relationships with key stakeholders in Government, the NHS, healthcare institutions and other charities to achieve the Charity's policy goals. She is also responsible for overseeing Fight Bladder Cancer's communications strategy. Sana previously managed the global privacy and cybersecurity portfolios at a trade association in Washington DC, and Brussels. Before relocating to Scotland, Sana lived in Canada, the USA, UAE and Pakistan. She has a degree in International Relations and Political Sciences from the University of Toronto and a Masters in Media and Communications Governance from the London School of Economics. Sana likes to travel, try new foods, and go hillwalking in her free time.

SHANNON BOLDON

POLICY MANAGER (MATERNITY COVER)

Shannon supports the implementation of our policy work to improve bladder cancer care in the UK. She has extensive experience working in health policy – interning at the World Health Organization in Geneva, establishing All. Can International at the Health Policy Partnership and working as an independent Health Policy Consultant with various clients, including the World Bladder Cancer Patient Coalition. She holds a Masters in Global Health and Development from University College London and a BSc in Biochemistry from Acadia University. In her spare time, Shannon enjoys spending time with her puppy, Winston, and exploring the city of Toronto.

OUR VOLUNTEERS

Our work would be impossible without the dedicated volunteers who give up their time to support Fight Bladder Cancer with their skills, expertise, knowledge and enthusiasm. We are hugely grateful to everyone who contributes to our work.

They may be:

- helping with the forum
- writing articles
- doing research
- fundraising
- running support groups
- finding new funding opportunities
- giving medical advice
- supporting other patients
- or any number of other valuable jobs

Every contribution is valued, and every one of our volunteers deserves massive thanks.

THANK YOU!

ANNE MACDOWELL CORPORATE PARTNERSHIPS

Anne has 40 years of experience in the healthcare industry. She has lived and worked in the US, France, the UK and Switzerland. She has an undergraduate degree in music and an MBA from Harvard Business School. Anne stopped paid work in 2017 and is currently working with charities on a volunteer basis. Her role with Fight Bladder Cancer is to build mutually beneficial relationships between the charity and its corporate partners to improve outcomes for cancer patients. Anne has been married to her husband for 30 years, and they have two grown children. She enjoys travelling, learning, singing and sports in her spare time.

SUE MOORE

OFFICE SUPPORT AND BLADDER CANCER CARER

Sue is a radiographer with over 30 years in the NHS.

Her father's diagnosis of bladder cancer led her to leave her role in the NHS, take up other part-time work and free up some time to do some voluntary work with Fight Bladder Cancer. Sue has counted stock, parcelled up magazines, learnt how to use e-Bay, and become an expert at folding T-shirts and packaging them in readiness for the lovely people who buy them online for their fundraising events. Sue has even put together IKEA tables and bookshelves for the charity!

DR ANDREW DEARDENADVISOR

Andrew has been happily married for over 35 years, with three wonderful daughters, three marvellous sons-in-law and five grandchildren. He qualified as a GP in 1994, practising in the Cardiff area. He was active in the British Medical Association, serving in various roles both at Wales and UK levels and, finally, as Treasurer of the British Medical Association until 2018. He has served on several boards, including the British Medical Association and British Medical Journal. He served as Treasurer of the World Medical Association and internal auditor for the CPME (Standing Committee for European Doctors). He returned to full-time GP clinical work early in 2020 at the outbreak of the Covid pandemic.

'I joined Fight Bladder Cancer to utilise my medical and financial skills to help develop and expand the excellent work of Fight Bladder Cancer.'

DOROTHY MARKHAM

CHAIR SCOTTISH STEERING GROUP AND BLADDER CANCER PATIENT

Dorothy was diagnosed with bladder cancer in February 2016. During her journey, she realised that there was very little information for the public on bladder cancer. Scotland has been her home for over 40 years, so setting up a Scottish Steering Group four years ago gave her an excellent opportunity to move forward with Fight Bladder Cancer. The group has been able to get face-to-face meetings with many Scottish MSPs and keep them advised of developments within Scotland. She hopes to share her experiences in Scotland to create a partnership based on a commitment to raising awareness, offering support and, as with all charities, raising more finance for research staffing and other services.

'As an 86-year-old bladder cancer patient, who was 80 at the time of diagnosis, I have been pleased to share my journey. My determination to campaign and make the world a better place remains unwavering.'

DANIELLE MARR

VICE CHAIR SCOTTISH STEERING GROUP AND BLADDER CANCER PATIENT

Danielle is a bladder cancer survivor.

She was diagnosed in 2015 whilst pregnant with her daughter. Danielle and Dorothy were invited to visit parliament and successfully secured a motion within the Scottish Government in 2020 to improve outcomes and raise awareness of bladder cancer. Danielle's background is in healthcare administration, and she works as a treatment advisor at Spire Hospital in Edinburgh, where she has over ten years of experience.

She has also worked as an emergency call handler for the Scottish Ambulance Service.

'I understand how difficult the patient journey can be and feel it is important to try to make a difference to improve this in any way I can.'

PAUL MICHAELS

ADVISOR AND BLADDER CANCER PATIENT



Paul is a bladder cancer patient and a Managing Partner in an IT consulting company. He has many years of experience working for public and private industry clients – helping organisations improve their information technology and save money on their services. His capabilities include benchmarking, evaluation and governance. His recommendations are based on factual data

rather than opinion. Some of his clients include businesses in the healthcare sector.

'Fight Bladder Cancer has made such a difference to me. Through it all, I've had the Wee Family behind me.'

Achievements & performance

This report, on behalf of the Trustees, covers all aspects of Fight Bladder Cancer's activities.

With an excess of 21,181 people annually diagnosed with bladder cancer, and over 100,000 living with the disease across the UK, Fight Bladder Cancer faces a colossal task. The following report summarises ways that the Fight Bladder Cancer team have pulled together following the pandemic and delivered above and beyond expectation during 2021–22.

Fight Bladder Cancer ensures that all our work is impactful and positively influences the lives of people affected by bladder cancer.



We carefully monitor and evaluate our progress to optimise our resources and demonstrate our impact in these four key areas.

- SUPPORT: Giving information, guidance and advice to patients and their families and improving signposting to Fight Bladder Cancer to enhance the quality of life.
- AWARENESS: Raising awareness of this neglected cancer through campaigns to give the patients a voice.
- POLICY: Using patient experiences to bring about change, improve services and eliminate inequalities in patient care.
- RESEARCH: Working with patients to influence research investment and priorities.

Although a challenging year in many ways, we have been able to adapt successfully, and 2021–22 has been highly productive.

JOHN LESLIE HESTER

Bladder Cancer Patient & Chair of Fight Bladder Cancer

DR LYDIA MAKAROFF, PhD CEO, Fight Bladder Cancer

ANN

'It's truly a wonderful charity. As a carer too, it's been such a great support over the years.'

FBC by numbers

The ongoing Covid outbreak has seen Fight Bladder Cancer adapt and maintain a flexible approach to support patients and carers affected by bladder cancer. This statistical round-up demonstrates how successful it has been.

WEBSITE SUPPORT

54,349

sessions on our website



38,127 unique users of our website **29,209 downloads** from our website

FORUM SUPPORT

5,480 members of our private online forum

5,700 annual forum posts
519 new forum members



SUPPORT GROUPS



12 online support meetings

27 people, the average meeting attendance

142 people assigned a Bladder Buddy

SUPPORT

765 carers supported

1,923 patients supported

892 support emails sent

855 phone calls made

949 phone calls received



HEALTHCARE PROFESSIONAL SUPPORT



263 healthcare professionals supported

FIGHT MAGAZINE

2,392 print copies of Fight #11 magazine were distributed, of which 664 were to individuals and 1,728 were in packs of six to healthcare professionals 336 digital copies were also sent out



2,085 print copies of Fight #12 magazine were distributed, of which 615 were to individuals and 1,470 were in packs of six to healthcare professionals 522 digital copies were also sent out

RESEARCH



16 national and international conferences attended and 19 contributions to scientific papers

BLADDER CANCER AWARENESS MONTH

10 news stories about Fight Bladder Cancer during the year

56 locations for Bubbles for Bladder Cancer around the UK

5,700 impressions on **LinkedIn 11,466** people reached on **Facebook**

170,000 impressions on Twitter

PATIENT INFORMATION BOOKS DISTRIBUTED

An additional **140** folders containing reference copies of all booklets sent to health professionals – making a total of **275** folders

7,705 individual booklets were posted to patients this year and **14,703** digital copies of booklets were downloaded or emailed



Our support services

Private online forum

Members include patients, family members, carers and medical professionals. Everyone gets answers to their questions. The support from other welcoming patients and carers can be a boost at a scary and often lonely time. Many people who have lost their loved ones stay with us on the forum for an extended period after their loss to support others.

KAROL

'Welcome to this wonderful group. There will always be someone here to answer your questions.'

CAROLINE

'Everyone is so honest and supportive here; it has made us genuinely humbled and grateful. This group has shaped our whole outlook on his journey so far into a primarily positive one, and we thank everyone who takes the time to post for that.'



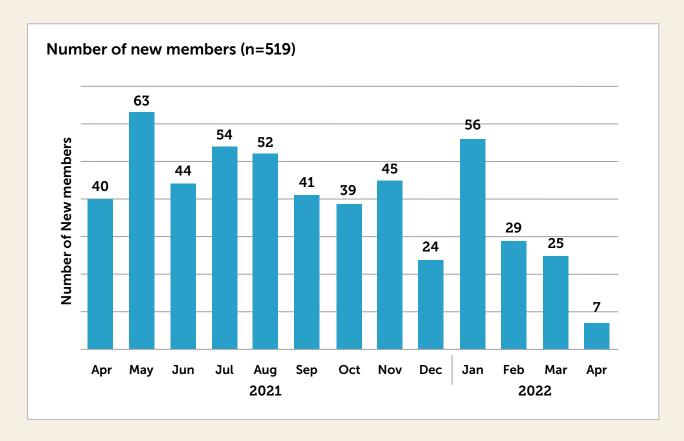
Online forum statistics

During the financial year 2021–22, the private online support forum received 519 genuine new members. When requesting to be admitted, new members are asked

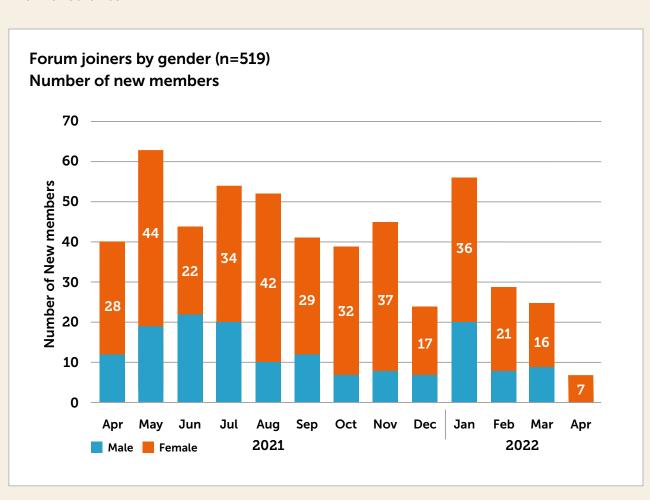


questions about who they are and their reasons for joining. The questions aren't compulsory, although the majority are happy to share these details and help us to gain some valuable insights.

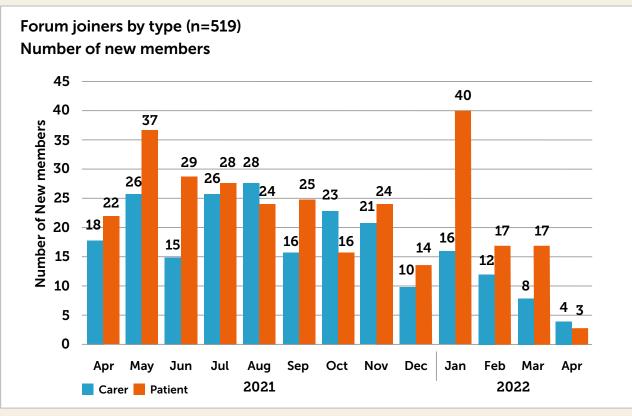
The chart overleaf represents the numbers of new forum joiners by month. The results indicate that more members joined in the warmer months, a contrast to last year when the winter months welcomed more new members. January 2022 had a high number of 56 joiners, as in our previous financial year. However, the higher number of summer joiners in May (63) might indicate appointments getting back on track after the pandemic, as people have renewed confidence in seeking a medical opinion. It may also be affected by the FBC literature becoming more widely available and the growing popularity of our Patient Information Booklets with signposting to support.

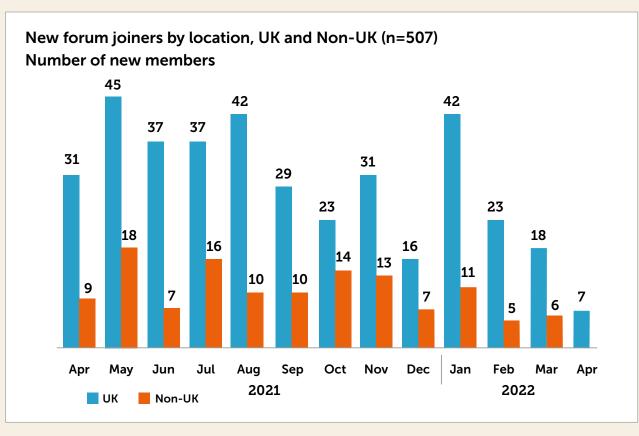


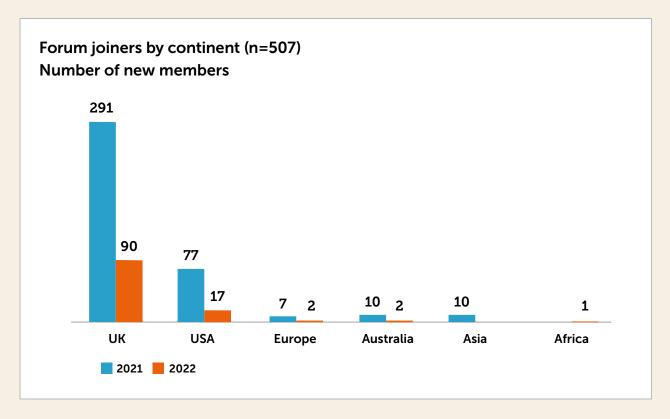
Most new members identified as female patients and carers (365). This could signify that more women are likely to seek out support on a forum than men, either for themselves or their loved ones.



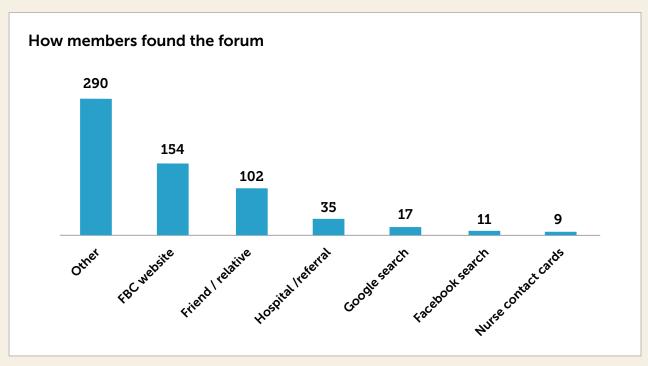
Over half of the 519 respondents reported that they were bladder cancer patients (296) and the rest were carers, family members and loved ones, or friends of someone with bladder cancer (223). In some months, we can see that the number of carers was higher than the number of patients, this represents the central core of patients that we support who are older and being looked after by someone more likely to search for support on an online forum. We also have several family members join together to support their loved one.







New joiners are asked how they found the Fight Bladder Cancer forum. Just under half stated that they found the discussion from an unlisted source, for example as a recommendation from another forum, or did not disclose it. However, a quarter of new forum members indicated that they found the forum from the Fight Bladder Cancer website (n=154). Strikingly only 35 members came from hospital staff, Hospital referrals have grown by 10 people over the previous year, with the number finding us from information on a Fight Bladder Cancer nurse contact card has stayed the same as previously at 9. It could, however, be concluded that patients and carers may have been signposted from the hospital to the Fight Bladder Cancer website and found the forum from there. The pandemic could also reflect the lack of contact cards having been handed to patients.



Zoom support groups

Our monthly Zoom support groups have allowed us to be in touch with people like never before. Our virtual meetings can be attended by people from places such as Portsmouth, Yorkshire and Scotland, therefore, we can offer an enhanced sense of humanity and community.

Melanie Costin is now hosting monthly Zoom support groups, which began this year. These have included:

- Let's raise bladder cancer awareness
- Let's hear about nutrition
- Let's talk about scanxiety
- Let's learn some chair-based exercises



We have established an Instagram profile in the hope of resonating with a different demographic. Instagram will be used to reach predominantly fundraisers, younger family members and younger patients.

KAREN

'Thanks for the Zoom this evening; I found the information very valuable. What a great session!'

Phone, email, web and social media support

In addition to the 24-hour online support, we are also there for our members via telephone, email, web and social media.

Our telephone support line is available from 9.30 am to 4.30 pm Monday to Friday on 01844 351621, with a voicemail for messages outside these hours and numbers redirected while staff were working from home.

LINA

'Thank you for your hard work and brave efforts'

KAREN

'Thank you so much for your informative reply. I've contacted a few places, and nobody has taken the time to reply with all the helpful info you have!'

DAVID

'I learned more by speaking to you than I had by reading about it'

Website

The most popular pages are Downloads, Just Diagnosed and Getting Support. We are conducting a complete refresh of every single webpage and integrating our support pages with the downloadable Patient Information Booklets. The most popular time to visit is Sunday afternoons.

Social media

At the end of March 2022, Fight Bladder Cancer had:

• **Twitter:** 4,780 followers

• Facebook: 4,234 followers

• LinkedIn: 652 followers

Patient Information

Patient Information Booklets

We saw the launch of our series of Patient Information Booklets, born from an idea from our co-founders, Tracy Staskevich and Andrew Winterbottom. Endorsed by the British Association of Urological Surgeons, the British Association of Urological Nurses and the British Uro-Oncology Group, the series of ten booklets have been widely distributed and praised by patients, carers and professionals.



CLARE WAYMONT

BAUN PRESIDENT

'These booklets are fantastically put together and presented beautifully. I find them engaging, informative and easy to read. Happy to give my approval'

Distribution

All Patient Information Booklets are free for download from the Fight Bladder Cancer website at fightbladdercancer.co.uk/downloads

Health professionals request for folder of patient information booklets: fightbladdercancer.co.uk/folder

Health professionals request for booklets for their patients: fightbladdercancer.co.uk/info

Responses to the Patient **Information Booklets**

BLADDER CANCER PATIENT

'Many thanks for your informative booklets. I saw a consultant vesterday, and thanks to the information in your booklets, I could ask the questions I needed answers to'

HEATHER

URO-ONCOLOGY CLINICAL NURSE SPECIALIST, WALES

'We give these booklets to our patients in our clinic. At the time of testing and diagnosis, patients often suffer anxiety and need information'

NHS acknowledgement

On 13 January 2022, the NHS Getting It Right First Time team released a new report called: 'Urology: Towards better care for patients with bladder cancer: A practical guide to improving bladder cancer management' (available at gettingitrightfirsttime.co.uk/wpcontent/ uploads/2021/12/Urology2021-12-10GuidanceBladder-cancer.pdf).

The work of Fight Bladder Cancer is highlighted on page 18 of the report as a best practice example of 'Developing powerful patient information materials'.

Extending the series

At the end of this financial year, we began the process of developing and finding funding for two new titles for the series: Carers' A to Z Guide and New Developments in Treatment for Bladder Cancer. Work is ongoing, and we aim to publish in 2022-23.

Fight magazines

We continued to publish our *Fight* magazine and produced two in 2021–22. Patients, carers and professionals contribute to various articles and features, including information, research and personal stories. Each magazine concentrates on a particular theme and is building into a library of valuable resources.

Fight #11

This edition was dedicated to the tireless work of the carers. Articles included personal stories, results of clinical trials, hints and tips on supporting your loved ones and caring at a distance.

YOUNG CARERS HOW TO HELP LIGHTEN THEIR LOAD CARING FROM A DISTANCE HOW YOU CAN STILL CARE IF YOU DON'T. LIVE NEARBY THE CARERS' A TO Z AUNIOLE AND PERSONAL SURVINGE TO GETTING THROUGH DIFFICULT TIMES THE ONLY magazine for people affected by & working with Bladder Cancer

Fight #12

This edition featured the multi-disciplinary team members who care for cancer patients, from the nurses and CNSs to the anaesthetists, surgeons, secretaries, and counsellors.

TRISHA

'I was so pleased when I found your magazine in the urology clinic!'

Sign up to receive *Fight* magazine at fightbladdercancer.co.uk/contact-preferences



Other resources

GP pack

The GP pack includes posters about the signs and symptoms of bladder cancer and the support we offer. They can be ordered online at **fightbladdercancer.co.uk/gp** along with a sign-up sheet for GPs to use in their surgeries.



Car stickers

We have designed free car stickers to raise awareness of bladder cancer.



Awareness

Increasing awareness

One of our primary concerns is to increase awareness of bladder cancer among the general population and to take every opportunity to disseminate information.

East Kent Hospitals University

We thank East Kent Hospitals University for signposting to Fight Bladder Cancer on their information on transurethral resection of bladder tumour (TURBT), produced with and for patients.

Karger Health Science Publishers

We worked with Karger Health Science Publishers to share ideas for raising awareness about bladder cancer and highlighting the need for patients to be able to have frank conversations with their medical team about all the aspects of their life that will be affected by bladder cancer, including peeing, sex and body image.

GenesisCare

We were featured on the GenesisCare website as one of the helpful UK organisations offering support and information for people with cancer, highlighting our useful information on bladder cancer and patient stories.

The Sunday Post



We worked with a journalist at The Sunday Post to produce an article highlighting that 'Doctors fear young women are missing early cancer diagnosis'. This article featured quotes from Fight Bladder

Cancer patients and medical advisors, campaigning for a change in the guidelines and greater awareness of the issue.

Healthy Women

One of our forum members was featured on *Healthy Women*, where she wrote: 'never be afraid of asking a healthcare provider for a second opinion. I've been surprised how many people, especially younger people, are reluctant to ask. But I've found that many providers are happy to help patients seeking a second opinion.'



Guardian

Fight Bladder Cancer was featured in the 2021 'Men's Health and Bladder and Bowel campaigns' inside the Guardian. We reminded readers that early cancer detection is likely to give them a far better outcome and encouraged them to visit their GP if they have concerning symptoms.



Hazards Magazine

Fight Bladder Cancer and the GMB Workers' Union published a full-page notice about



the symptoms of bladder cancer and urged anyone experiencing those symptoms to speak to their GP as soon as possible. Hazards is the workers' health and safety magazine, providing information and resources to make the job easier and safer.

Economist Cancer Series

We spoke at the Economist Cancer Series about the potential benefits and risks that machine learning and artificial intelligence can bring to cancer research and treatment.



NHS England

Fight Bladder Cancer worked with NHS England and Public Health England on a new 'Help Us Help You' awareness campaign highlighting abdominal and urological symptoms. The campaign told people to contact their GP practice if they have seen blood in their pee – even just once. Your NHS wants to see them.

Fundamentals of Cancer Care

Hilary Baker (Trustee) wrote the chapter on the cancer pathway for the Fundamentals of Cancer Care book produced by the UK Oncology Nursing Society.



Fight Bladder Cancer Scottish Steering Group

Fight Bladder Cancer took a trip to visit our many supporters, friends, colleagues, and partners in the central belt of Scotland from 25 to 27 October. Our aims for the trip were to:

- Improve awareness of Fight Bladder
 Cancer and our work in patient support,
 awareness, research, and policy
 advocacy in Scotland and across the UK.
- Listen and learn from patients, carers, health professional colleagues and friends about how we can be most effective in the region.
- Build and grow our relationships with patients, carers, health professionals, and supporters in Scotland.

We were thrilled with the success of our trip – we reached many new hospitals, clinicians, and specialists whom we could tell about our Patient Information Booklets, support groups, fundraising opportunities, community champions and patient advocate programs.

The Fight Bladder Cancer Scottish Steering Group finalised its Scottish Development Plan, enabling the Charity to register with the Office of the Scottish Charity Regulator and seek funding for a Scottish Development Officer.



FBC in the news









Podcasts



The Uromigos

Bladder Cancer from a Patient Perspective. Fight Bladder Cancer joined Professor Thomas Powles to discuss critical issues for people with bladder cancer when considering treatment and care.

Clinical Oncology Podcast

Bladder Radiotherapy: is Cinderella Ready for the Ball? An expert panel discussion on current challenges and opportunities in bladder cancer. Chaired by Prof Robert Huddart and co-hosted by Drs Finbar Slevin and Saif Ahmad, Fight Bladder Cancer discussed critical aspects of bladder cancer treatment with Prof Jim Catto, Prof Valerie Fonteyne and Dr Mohini Varughese.



Olympus Healthcare Conversations

Talking The Exemplar Project With Fight Bladder Cancer. Fight Bladder Cancer talked to Dr Hugh Mostafid, Consultant Urologist, about the priorities for the bladder cancer community.



It's Time to Talk

Bladder Cancer Awareness. Fight Bladder Cancer talked to Lindsey Morham about what bladder cancer is, the symptoms to look out for and the resources that can help.

Associations Connect

How can associations become more sustainable? Fight Bladder Cancer joined the Sarawak Children Cancer Society to talk about the issues facing charities during the pandemic and how knowledge sharing can help charity workers learn from their peers.



Bladder Cancer Awareness Month

May is the month we focus on raising awareness of bladder cancer by sharing stories of hope, optimism and love. Fight Bladder Cancer highlights the impact of bladder cancer, promotes awareness of the symptoms and urges policy improvements.

A Challenging Year

Awareness Month in 2021 was a challenge as we continued dealing with the Covid pandemic's effects. In line with the World Bladder Cancer Patient Coalition's global campaign, our chosen theme was 'have you heard about bladder cancer?'. We shared patient stories and launched a new video highlighting the signs and symptoms of bladder cancer.

We developed a Bladder Cancer Awareness Activity Calendar to cover the 31 days of May.

- updating your social media picture with a #BladderCancerAware frame
- wearing a Fight Bladder Cancer wristband
- displaying a car window-sticker
- taking a Wee Walk

We worked hard to maintain our activities, which included:

- wearing orange
- sharing our social media posts
- thanking nurses on International Nurse and Midwife Day

Awareness Month Support Group

We encouraged all the patients and family members attending our virtual support group in May to wear orange and make a noise about bladder cancer. It was beautiful to hear about everyone's awareness-raising activities and share tips on spreading the word about bladder cancer.





Craft and creativity

Throughout May, we encouraged our friends and supporters to get creative during lockdown – with an orange theme! Butterflies featured heavily in our design theme for 2021 – we felt their colour and beauty represented hope, optimism, and warm energy. We shared crafts that included jewellery making, baking, orange bunting, face coverings, and plants with shades of orange.

Bubbles for bladder cancer

31 May is a special day for the Fight Bladder Cancer wee community. We blow bubbles to remember all those affected by bladder cancer and those we have lost. We were bowled over by the number of people who took part in blowing bubbles with us this year, and we created a map to visualise the bubbles that were blown across the region.



Media spotlight during Awareness Month

Despite the ongoing pandemic, we were delighted to see that the 2021 Bladder Cancer Awareness Month received mentions in traditional and social media. During the campaign, followship increased by 10% on LinkedIn, and Fight Bladder Cancer was mentioned 351 times by other stakeholders on Twitter. We reached over 239,000 people via our social media channels. Our top mention on Twitter was Monzo's virtual art gallery that included a hand-drawn version of the Fight Bladder Cancer logo.

Remembering Andrew

It was particularly moving as we shared our memories of our dear co-founder Andrew Winterbottom on the anniversary of his death. We shared a video of our co-founder Tracy's reading of a poem, remembering Andrew with love:



My body's gone but my soul is here, please don't shed another tear,

I am still here. I'm all around, only my body lies in the ground.

I am the snowflake that kisses your nose,

I am the frost, that nips your toes.

I am the sun, bringing you light,

I am the star, shining so bright.

I am the rain, refreshing the Earth,

I am the laughter, I am the mirth.

I am the bird, up in the sky,

I am the cloud, that's drifting by.

I am the thoughts, inside your head,

I am the cuddle, in your bed.

I am the bubbles blowing up in the sky.

Remember me in laughter, and that way, I'll never die.

Research

Fight Bladder Cancer contributed to the following research publications:



Contributions to research

- Agustina Bessa, Cecilia Bosco, Fidelma Cahill, Beth Russell, Louis Fox, Charlotte Moss, Harriet Wylie et al. *Designing a* pragmatic intervention to help improve the bladder cancer patient experience. INQUIRY: The Journal of Health Care Organization, Provision, and Financing 58 (2021): 00469580211030217
- 2. Agustina Bessa, *How to improve the bladder cancer patient experience?* PhD diss., (King's College London, 2021).
- 3. Anita Mansouri, Naomi McGregor, Rachel Dunn, Sam Dobbie, Jane Holmes, Linda Collins, and Shibani Nicum. Randomised phase II trial of olaparib, chemotherapy or olaparib and cediranib in patients with platinum-resistant ovarian cancer (OCTOVA): a study protocol. BMJ open 11, no. 1 (2021): e041463.
- 4. Anke Richters, Lambertus ALM Kiemeney, Niven Mehra, Hans M. Westgeest, Alison Birtle, Richard T. Bryan, and Katja KH Aben. 'Evidence or prejudice? Critical reanalysis of randomized controlled trials comparing overall survival after cisplatin versus carboplatin-based regimens in

- advanced urothelial carcinoma.' Clinical Genitourinary Cancer 20, no. 4 (2022): e346-e352.
- Bladder Cancer Patient Experiences
 Information from the 2019 National Cancer
 Patient Experience Survey. February 2022.
 https://fightbladdercancer.co.uk/survey
- Ibrahim Jubber, Zoe Rogers, James WF Catto, Sarah Bottomley, Adam Glaser, Amy Downing, Kate Absolom, Sexual Activity, Function and Dysfunction After a Diagnosis of Bladder Cancer, The Journal of Sexual Medicine, Volume 19, Issue 9, 2022,
- 7. James W.F. Catto, Amy Downing, Samantha Mason, Penny Wright, Kate Absolom, Sarah Bottomley, Luke Hounsome, Syed Hussain, Mohini Varughese, Caroline Raw, Phil Kelly, Adam W. Glaser, Quality of Life After Bladder Cancer: A Cross-sectional Survey of Patient-reported Outcomes, European Urology, Volume 79, Issue 5, 2021, Pages 621-632,
- 8. Josefine Björkqvist, Rachel H. Giles, Philip Cornford, Lydia E. Makaroff, Mieke Van Hemelrijck, Julie Darraugh, Jane Cowl, Steven MacLennan, Sara J. MacLennan, Providing a Framework for Meaningful Patient Involvement in Clinical Practice Guideline Development and Implementation, European Urology Focus, Volume 7, Issue 5, 2021, Pages 947-950
- Melanie Costin and Lydia E. Makaroff.
 Bladder preservation with radiotherapy:
 the patient perspective. Clinical Oncology
 33, no. 6 (2021): 346-349.
- Mohammed Abozaid, Wei Shen Tan, Pramit Khetrapal, Hilary Baker, Jacqueline Duncan, Ashwin Sridhar, Tim Briggs et al. Recovery of health-related quality of life in patients undergoing robot-assisted radical cystectomy with intracorporeal diversion. BJU international 129, no. 1 (2022): 72-79.

- 11. Orphé Matthys, Aline De Vleminck,
 Sigrid Dierickx, Luc Deliens, Vincent Van
 Goethem, Lore Lapeire, Mogens Groenvold
 et al. Effectiveness of a nurse-delivered
 (FOCUS+) and a web-based (iFOCUS)
 psychoeducational intervention for people
 with advanced cancer and their family
 caregivers (DIAdIC): study protocol for an
 international randomized controlled trial.
 BMC palliative care 20, no. 1 (2021): 1-18.
- 12. Paramananthan Mariappan. Imran Ahmad, Tarik Amer, Lars Dyrskjøt Andersen, Simon Baker, Jaimin Bhatt, Mary Brown et al. The Scottish Bladder Cancer Quality Performance Indicators Influencing Outcomes, Prognosis, and Surveillance (Scot BC Quality OPS) Clinical Project. European Urology Focus 7, no. 5 (2021): 905-908.
- 13. Pramit Khetrapal, Ronnie Stafford, Pádraig Ó. Scanaill, Huriye Kocadag, Constantinos Timinis, Angela HL Chang, Adamos Hadjivasiliou et al. Measuring Patient Compliance With Remote Monitoring Following Discharge From Hospital After Major Surgery (DREAMPath): Protocol for a Prospective Observational Study. JMIR Research Protocols 11, no. 4 (2022): e30638.
- 14. Sara MacLennan, Lydia Makaroff, Eamonn Rogers, Esther Robjin. Key Messages from the European Association of Urology virtual Patient Poster Session, European Urology Today, Volume 33, 12 January 2022
- 15. Simon Crabb, Syed A. Hussain, Eileen Soulis, Samantha Hinsley, Laura Dempsey, Avril Trevethan, Yee Pei Song et al. 'A randomized, double blind, biomarker selected, phase II clinical trial of maintenance PARP inhibition following chemotherapy for metastatic urothelial carcinoma (mUC): Final analysis of the ATLANTIS rucaparib arm.' (2022): 436-436.
- 16. Simon Crabb, Syed Hussain, Eileen Soulis, Samantha Hinsley, Laura Dempsey, Avril Trevethan, YeePe Song et al. A randomized, double-blind, biomarker-selected, phase II clinical trial of maintenance poly ADP-ribose polymerase inhibition with rucaparib following chemotherapy for metastatic urothelial carcinoma. Journal of Clinical Oncology (2022).

- 17. Syed Hussain, Jason F. Lester, Richard Jackson, Matthew Gornall, Muneeb Qureshi, Anthony Elliott, Simon J. Crabb et al. Addition of nintedanib or placebo to neoadjuvant gemcitabine and cisplatin in locally advanced muscle-invasive bladder cancer (NEOBLADE): a double-blind, randomised, phase 2 trial. The Lancet Oncology 23, no. 5 (2022): 650-658.
- 18. Tom Powles, J. E. Gschwend, S. Bracarda, D. Castellano, M. Gross-Goupil, J. Bjerggaard Jensen, A. Kann et al. 716TiP IMvigor011: A global, double-blind, randomised phase III study of atezolizumab (atezo; anti-PD-L1) vs placebo (pbo) as adjuvant therapy in patients (pts) with high-risk muscle-invasive bladder cancer (MIBC) who are circulating tumour (ct) DNA+ post cystectomy. Annals of Oncology 32 (2021): S721
- 19. Ulrik Lassen, Lydia E. Makaroff, Albrecht Stenzinger, Antoine Italiano, Gilles Vassal, Jesus Garcia-Foncillas, and Bernard Avouac. *Precision oncology: a clinical and patient perspective*. Future Oncology 17, no. 30 (2021): 3995-4009.



Supporting research projects

Anyone affected by bladder cancer who wants to participate in research can contact us. You can see a list of all studies recruiting bladder cancer patients in the UK at fightbladdercancer.co.uk/research



DR ALISON BIRTLE,

TRUSTEE OF FIGHT BLADDER CANCER AND SECRETARY OF THE BRITISH URO-ONCOLOGY GROUP

'There isn't a urothelial cancer trial in the UK that Fight Bladder Cancer hasn't been asked to provide a patient representative to advise on.'

Experiences before and after bladder removal

A patient representative from Fight Bladder Cancer was invited to speak at the BLADDR World Bladder Cancer Congress about the experiences before and after bladder removal and how health professionals can improve their communications with patients.



The patient and family experience of bladder cancer

Fight Bladder Cancer spoke at the Bladder Cancer Translational Research Meeting on 'The Patient and Family Experience of Non-Muscle Invasive Bladder Cancer'. We shared that it is common for people with bladder cancer to experience a dip in mental health, with feelings of depression or anxiety, but this often reverses as treatment progresses.

Patient engagement within guideline development

Fight Bladder Cancer is an active member of EVOLVE: A study to develop a model of meaningful patient engagement within guideline development. This study determined the priority topics for patient and public involvement within clinical practice guideline development and implementation for prostate cancer, testicular cancer, bladder cancer and kidney cancer. The Academic Urology Unit runs the study at the University of Aberdeen. The results were presented at this year's European Association of Urology congress.

Scottish Bladder Cancer Training Day

Fight Bladder Cancer medical advisor Param Mariappan convened and chaired an online training day on muscleinvasive bladder cancer, featuring an overview of Scottish standards,



Quality Performance Indicators, interactive case studies, surgical approaches, immunotherapy, clinical trials and Fight Bladder Cancer resources.

Understanding cancer's DNA

Fight Bladder Cancer spoke at the HTAi Health Technology Assessment International Conference and the Genomic Drivers and Advanced Cancer Virtual Summit about incorporating patient preferences into decision-making and how genomic testing can improve prognosis and treatment. A better understanding of cancer's DNA could make a difference in the lives of patients and their families undergoing their cancer journey.

National Cancer Data

We spoke at the National Disease Registration Service's 'Get Data Out' event on how routine publication of detailed data on small, anonymous groups of cancer patients can help us better understand and improve cancer outcomes.

Participation in clinical research



Fight Bladder Cancer chaired a session at the European Association of Urology that allowed healthcare professionals to engage directly with patients and patient organisations. Patients are more likely to participate in clinical research if

they see its relevance and if the benefits of participation outweigh the risks.

Improving efficiency in cancer care

Fight Bladder Cancer offered its perspective on the 'Building Efficiency in Cancer Care' blueprint at the All. Can Global Summit, offering broadly applicable measures to support collaborative policy action for efficient cancer care through multi-stakeholder collaboration.

The Institute of Cancer Research

We collaborated with the Institute of Cancer Research to find a patient to speak about the benefits of a shorter course of radiotherapy.



Targeted therapy without immunotherapy

Fight Bladder Cancer has a patient representative on the ATLANTIS clinical trial. This clinical trial found that targeted therapy (cabozantinib) without immunotherapy didn't show significant benefit compared to placebo as maintenance therapy in people with advanced bladder cancer who had responded to platinum-based chemotherapy. These results were presented at the American Society for Clinical Oncology GU meeting.

Quality of life after bladder cancer

The Quality of Life After Bladder Cancer (Q-ABC) study compares patient-related outcomes following radical surgery and radiotherapy. It has now completed its recruitment, and analysis is ongoing. The Quality of Life After Bladder Cancer (LABC) study is a cross-sectional survey of patient-reported outcomes.

The double-blind study was designed

to evaluate the efficacy and safety of adjuvant treatment with immunotherapy compared with placebo in people with muscle-invasive bladder cancer, who are at high risk for recurrence following cystectomy.



Policy

Our policy work focuses on improving the experience and outcomes for bladder cancer patients in the UK.

We partner with different organisations across the UK to achieve these goals. We also established a group of dedicated patient advocates representing Fight Bladder Cancer externally. They provide feedback on our advocacy strategy and activities; they lead parliamentarian outreach across the UK, support awareness-raising activities, especially in May (during awareness month) and share their personal experiences of bladder cancer to help drive change.

Exemplar report

The Exemplar research project was conducted to better understand gaps in bladder cancer care across the UK. We launched the Exemplar report with a policy roundtable discussion, which highlighted that the lack of specialist staff leads to problems with the quality of life and sexual wellbeing of bladder cancer patients. We called for more investment in the bladder cancer workforce so patients can receive the care they need and deserve, no matter where in the UK they live.

The recommendations fall into three areas:

- putting in place an Exemplar pathway
- developing and growing the bladder cancer workforce
- improving patient support and involvement in care

The report was launched at a virtual meeting in May.



Symposia & consultations

British Association of Urological Nurses Symposium

Fight Bladder cancer spoke with Julia Taylor, Param Mariappan and Pauline Bagnall about how health professionals and patients can work together to improve the bladder cancer pathway.

Urinary tract infection in adult women

Fight Bladder Cancer submitted feedback on the Scottish Intercollegiate Guidelines Network's consultation on 'Management of Suspected Bacterial Lower Urinary Tract Infection in Adult Women'. We are pleased to see that it includes the following statement: 'If symptoms do not go away within a few days, or you are distressed by more severe symptoms or have repeated episodes within a short time, then get help from your healthcare professional.'

Innovative Licensing and Access Pathway Patient Reference Group

We were selected to join the Innovative Licensing and Access Pathway Patient Reference Group, which was established to ensure that patient views are an integral part of the delivery of the Innovative Licensing and Access Pathway ambition.

JIM CATTO,

FBC TRUSTEE AND CONSULTANT UROLOGIST

'A national bladder cancer audit must be a priority. The national prostate audit drives standards of care. Fight Bladder Cancer will be key in speaking to HQIP – Healthcare Quality Improvement Partnership – part of NHS – for this.'

The Patient Reference Group will provide their expertise from the broader patient perspective, particularly about the Innovation Passport designation stage, Target Development Profile stage and the specific patient engagement tool of the toolkit. The Patient Reference Group will work with the Medicines and Healthcare Products Regulatory Agency, the Scottish Medicines Consortium and the National Institute for Health and Care Excellence.

European Association of Urology

We participated in a strategy meeting with the European Association of Urology patient advocacy group to improve the urology patient journey. We also spoke at the European Association of Urology and European Association of Urology Nurses congress about how they can better understand the patient experience and highlighted how to address the needs of the patients before and during their treatment.

Medicines and Healthcare Products Regulatory Agency

Fight Bladder Cancer responded to the Medicines and Healthcare Products Regulatory Agency consultation on the role that patients could play in the UK's new regulation of medical devices. We reminded them that patients are the ultimate beneficiaries of many medical devices, with unique experiences and insights, and must be involved in the consultation process.

Access to immunotherapy

When NHS did not recommend bladder cancer maintenance immunotherapy

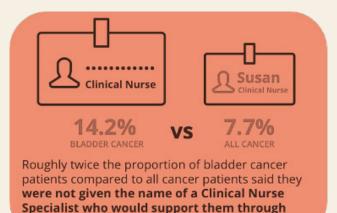
treatment in England, we expressed our disappointment, called for discussions to resolve uncertainties around costeffectiveness, and submitted an official appeal. Fight Bladder Cancer shared stories of the experiences of people living with bladder cancer at recent NHS meetings reviewing immunotherapies for bladder cancer. The appeal was upheld.

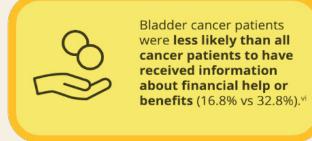
All-party parliamentary groups

Fight Bladder Cancer spoke at the Cancer and Immunodeficiency event for the All-Party Parliamentary Group for Vulnerable Groups to Pandemics and said, 'patient groups demonstrated clear communicative value through the pandemic'.

National Bladder Cancer Audit

Fight Bladder Cancer presented with Jo Cresswell (BAUS Vice President) on 'The Value of a National Bladder Cancer Audit' at the British Association of Urological Surgeons Section on Oncology meeting.





their treatment (14.2% vs 7.7%)."

Waiting times

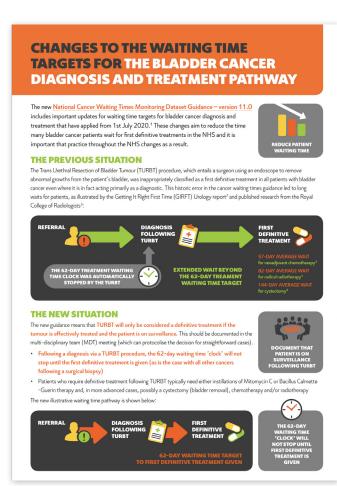
Fight Bladder Cancer won the Communiqué Award for Excellence in Communications for our Cancer Waiting Times Guidance campaign, which means bladder cancer patients will have faster access to treatment after an urgent referral from their GP.

We have successfully campaigned for changes in the English National Cancer Waiting Times Monitoring Dataset Guidance to ensure that TURBT is no longer automatically classified as a definitive treatment. We produced an infographic to be distributed to hospitals.

ALISON BIRTLE,

TRUSTEE OF FIGHT
BLADDER CANCER AND
SECRETARY OF THE
BRITISH URO-ONCOLOGY
GROUP

'Fight Bladder Cancer has successfully changed the classification of TURBT as a diagnostic procedure rather than a definitive treatment.'





Health & Select Committee inquiry into cancer care

Fight Bladder Cancer endorsed Cancer52's Response to the Health & Select Committee inquiry into cancer care.

Our key recommendations:

- NHS England should establish a Rare & Less Common Cancer Taskforce
- published cancer data must be disaggregated for all cancer types
- recommendations from the Task & Finish Group on Psychosocial Support should be implemented
- the Government should invest in a £500m community fund to support charities

The COVID-19 Pandemic

We co-created surveys with Cancer52 about cancer patient experiences during the Covid-19 crisis and found that:

- 35% of bladder cancer patients had their outpatient appointments delayed, moved or cancelled
- 26% of patients perceived themselves to be at high risk of Covid
- 66% were anxious about their cancer
- 56% were anxious about Covid

The information was used in discussions with the government, NHS and industry to push for the best possible care and treatment.

Fight Bladder Cancer was determined to ensure that we continued to fulfil our promises to offer support, raise awareness, pursue policy change, and further research. On top of that, we pledged to respond to the additional needs created by the pandemic. We had little thought at the pandemic outbreak that it would still be with us, but Covid remained a prominent factor during 2021–22 and will remain so for the foreseeable future.

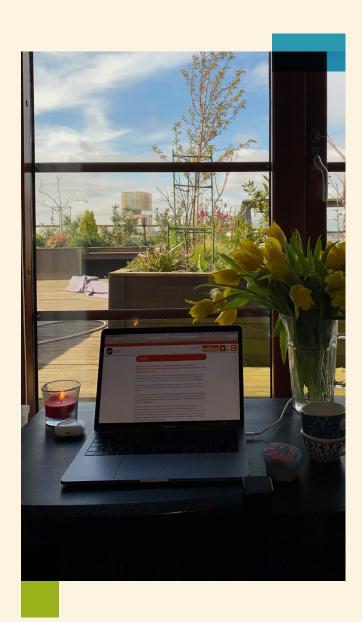
Our Covid-specific support

We continued to follow the new routines established since the outbreak began by:

- maintaining existing services and projects
- keeping our website updated with Covid-19 news
- continuing online support groups
- extending our contact base of professional healthcare personnel
- conducting surveys of the patient experience
- continuing to attend regular meetings of NHS England and Cancer52

Staff working arrangements

We managed to work out a schedule of taking turns working in the office, then later – as the pandemic eased – we began carefully working together in the office again while maintaining social distancing and Covid safety.

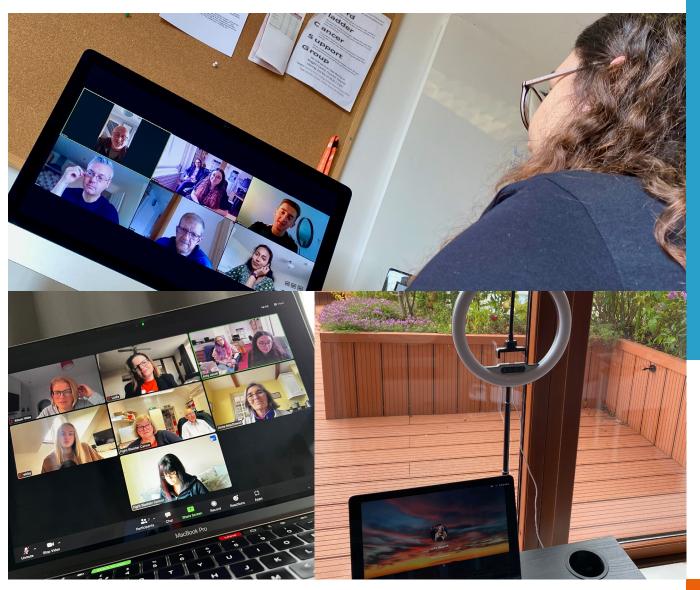


Training

We invested in training to ensure that the Fight Bladder Cancer team has the skills and knowledge they need to drive the charity forward. Training included:

- Acceptable internet use
- Business ethics
- Constituent relationship management
- Coping with change in the workplace
- Discrimination and equal opportunity
- Emotional intelligence in leadership
- General Data Protection Regulation (GDPR)
- How to communicate effectively
- Hygiene for the workplace
- Information security management
- Integrated care systems

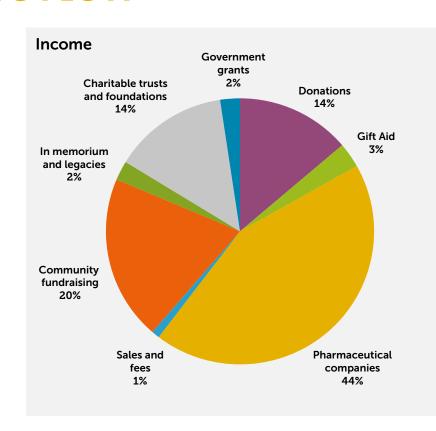
- Leading virtual teams
- Mediation
- Mental health first aid skills for patient organisations
- People management
- Running effective virtual meetings
- Sexual harassment training
- Supporter care
- Time and priority management
- Translational research
- Workplace bullying and harassment
- Workplace mental health



Financial review

Where our money comes from

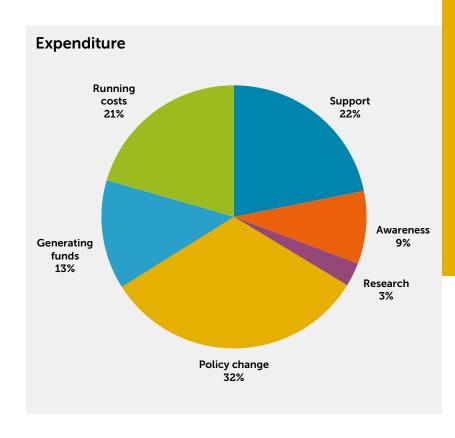
In 2021–22, the charity raised £376,362 from diverse income sources; in 2020-21, it was £303,976. We couldn't have done this without our amazing supporters, volunteers and campaigners. Our life-changing work would not be possible without such generous people. We appreciate every single gift we receive and work hard to ensure that no penny is wasted in our fight against bladder cancer. Our money comes from lots of different places. We aren't reliant on one funding source, so we can be entirely independent.



How we spend the money

The total expenditure was £359,379; in 2020-21 it was £324,283. We forecast to come on target at the end of the current financial year. We understand that when anyone makes a charitable donation, they want to know exactly where that money is going, and we pledge to be clear and transparent when it comes to spending every contribution.

For every £1 of income, 87p is available to fight bladder cancer. Every pound is important, so we carefully consider where we spend our income and what we commit our money to. We make every penny count.



Where our money comes from – Partnerships

We have good working relationships with pharmaceutical and device companies involved in bladder cancer. Specifically, Astellas, AstraZeneca, Bristol-Myers Squibb, Janssen, Merck Group, MSD, Olympus, Pfizer, Roche and Sanofi have provided funding during 2021–22. In addition, we offered patient organisation input to activities conducted by Astellas, Janssen, Merck Group, Pfizer and Roche.

Where our money comes from – Supporters

We are hugely grateful to our incredible supporters, who make a massive contribution to our finances and to whom we are eternally grateful for supporting our work for bladder cancer patients across the country. They all want to give something back to FBC in recognition of the help they have received during their treatment or that of a loved one.

Our fundraising team support and encourage, and can give advice, design posters and flyers, supply sponsorship forms or anything that helps supporters raise money. They also advise on Gift Aid, so every penny raised is worth more and working hard to fight bladder cancer. Amy Jacob now co-ordinates the team (see page 9).

Running into funds

All these supporters ran, cycled or walked, burst bubbles, searched down the back of their sofas for lost coins, or did other imaginative things to raise money for FBC.

Helen Tabor took on the Virtual London Marathon in memory of her dad.

Piers Govier and partner **Becci** completed the Virtual London Marathon.

Karen Lillystone, and her dog Scamp, challenged themselves to complete the distance of the River Thames 'from Sea to Source' – which was an eyewatering 375km!



Lizzy and **Emma**, accompanied by their dogs, Stevie and Honey, took on the challenge to walk 15km, resplendent in their FBC t-shirts.

Paula Ryan and **Naomh Gallagher** signed up for the Virtual Halloween 5km event.

Sue and **Sean Denny** created their virtual event – the 'Not the Great South Run' when the actual Great South Run was cancelled through Covid.

Wayne Birch walked more than 15,000 steps a day and went alcohol free for a month in support of his dad.

Nicola Kelly completed the Virtual London Marathon in memory of her colleague and mentor, Tony, and has plans for more fundraising in future.

Sharon and **Jenny Guy** have created a range of FBC products as part of their Wensleydale Wicks collection, donating a percentage of the proceeds.

Clare Graham, supported by friends Rhys, John, Jacqui, Molly, Lyndsey, Angie and Emma all took part in the Virtual New Year marathon following Clare's daughter Rebecca's cancer diagnosis.

Brenda and **Paul Clarke**, along with their children and grandchildren, walked, ran and cycled the distance from Cardiff to Benidorm (1,377 miles).

We are so grateful to each of them for putting on their trainers and going out in all weathers to complete their challenges.



Janire and **Sarah** climbed Pen-y-Ghent, Whernside and Ingleborough in just 10 hours!

Sid Parkin completed his Virtual Three Peaks Challenge.

Andy and **Kerim** each climbed the equivalent of the Three Peaks on treadmills and Stairmasters.

Sam and **Matthew Jonas**, with friends **Sam**, **Matt**, **Jack**, **Hannah**, **Jon** and **Laura** climbed the Three Peaks in relentless weather in memory of their stepdad Kev.

Tia Caswell collected the loose change her friends could find in strange and funny places.

Vicky Atkinson ran 51 miles over 12 hours.

The Bay Medical Group in Morecambe hosted an Easter egg decorating competition.

Poppy Bermingham-Byrne of Holy Family High School raised £170 at her Krispy Kreme fundraiser!

Don and **Dorothy Markham** organised a Wee Walk in Fife, followed by a picnic under a vast canopy.

Jen Marr hosted a book sale.

John and **Rachel Parker** joined the BCAM Big Step Challenge and walked 12,000 steps a day for 12 days, following John's diagnosis.

Steve and **Eve** hosted a 'Cuppa and a cake' event featuring everything orange.

Robyn, Nicky, Lesley, Juliet, Michelle, Carla, Louise, Nicky, Beth, Andrea, Colette, Linda and Laura turned their whole Urology dept at Broadgreen Hospital, Liverpool orange! We are incredibly grateful for their efforts.

Anthony Tapsell organised a dress-down day at work.

Tom Gamble started the 12,000 steps for 12 days challenge but kept going, walking 12k steps for 19 days straight.

Danielle Marr hosted an online Wee Couples Quiz.

Sharlene Taylor walked 12,000 steps for 12 days in May in support of her friend Gemma.

Iain McGregor walked a total of 248,165 steps over 12 days.

Francesca Cosway took the challenge of walking 10,000 steps a day for the whole of May in support of her friend Emma.

Param Mariappan and his wife **Kokila** encouraged colleagues to wear orange and held a Wee Walk in Edinburgh.

Tanya Lord ran a mile or more every day in May.

Gordon Morrison climbed Ben Nevis Following his wife's diagnosis.

Sarah and **Gemma** ran the Leeds 10k in support of their dad.





Facebook fundraisers

Over the last year, we have had people celebrate a birthday by asking for donations to Fight Bladder Cancer, fundraise for events or show their support through a gift via Facebook – for a special occasion or none. 100% of the money donated comes straight to the Charity as a twice-monthly payment.

In memoriam

We are so touched and grateful to those who choose to donate and fundraise undertaken in memory of a loved one – whether this is people choosing to ask for a donation instead of flowers at the funeral or honouring special dates such as an anniversary with a gift to Fight

Bladder Cancer – it all means so much. Graham McKenna and Abdul both raised money in memory of their fathers, while Patricia O'Sullivan's family felt it was a fitting tribute to her.

The Mini Hero Challenge

We have many young supporters who are generous owiththeir time and energy in support of family members.

Maisie Hoggins, Rebecca Lilley, Kearney, Kerensa, Kallen and Arnav Bhatt all donated money earned by doing chores around the house and garden. At 22 months, Murray McArthur was our youngest fundraiser this year.

Income from Charitable Trusts and Foundations

As part of our commitment to raising income from diverse sources, we continue to apply to charitable trusts and foundations for a combination of unrestricted grants towards our core services and restricted grants specifically for particular projects and outcomes. The total income raised through trust and grant fundraising during the year was £50,544, with most funds directed towards patient information and support. The unrestricted grants we saw during the start of the pandemic have been reduced. In the coming year, we are working to draw in grant funding for local support around the UK and new initiatives in Scotland.

Financial notes

Reserves Policy

The Trustees have forecast the level of free reserves (those funds not tied up in tangible fixed assets or categorised as restricted funds) that the Charity will require to sustain its operations in a period when it is anticipated that there may be some reduced income performance. Such reduction in income may lead to the curtailment or cancellation (temporarily or otherwise, depending on the specific nature of the income reduction) of projects detailed in the strategic plan (whether in progress or not yet commenced). The overriding concern of the Trustees at such a time will be the maintenance of the services that provide the most benefit to people affected by bladder cancer.

The Trustees consider that the most appropriate level of free reserves to be held by the Charity should be sufficient to cover six months of budgeted forecast expenditure.

Whilst the current level of income generated may prove sufficient to meet identified requirements, it is the Trustees' view that there should be sufficient free reserves available to provide financial flexibility, having regard to known and anticipated future expenditure and to provide contingency funding to meet any shortfall in income generation and any unplanned emergency expenditure which may be required.

Therefore, the Trustees' policy is to closely monitor the Charity's financial and operational activities and maintain free reserves within the parameters identified above

Exemptions from disclosure

The Charity did not undertake any grant-making activity in the year ended 31 March 2022. The Charity has disclosed all relevant key personnel details.

Funds held as custodian trustees on behalf of others

The Charity did not act as a custodian Trustee for the assets of any other charity in the year ended 31 March 2022...

Income and Expenditure

The results for the year are set out in the financial statements below. The financial statements show a total income for the year ended 31 March 2022 of £376,362 (year ended 31 March 2021: £303,976). The total expenditure was £359,379 (year ended 31 March 2021: £324,283). Combined with a loss from Fight Bladder Cancer Trading Ltd of £500 (year ended 31 March 2021: gain of £4,978), the Charity recorded a surplus of £16,483 (year ended 31 March 2021: deficit of £15,329). The Trustees consider the results for the year to be satisfactory.

Assets

For the year ended 31 March 2022, the Charity had tangible assets of £5,576 (year ended 31 March 2021: £2,263), stocks of £3,174 (year ended 31 March 2021: £3,174), debtors of £13,661 (year ended 31 March 2021: £69,286), cash of £213,462 (year ended 31 March 2021: £127,400). The Charity had amounts falling due within one year of £36,647 (year ended 31 March 2021: £19,380), leaving it with net assets of £199,226 (year ended 31 March 2021: £182,743). For the year ended 31 March 2022, the Charity had restricted funds of £54,260 (year ended 31 March 2021: £38,637), and funds remaining for general use were £144,966 (year ended 31 March 2021: £144,106). On 31 March 2022, the bank balance was £212,315.

Reserves

The reserves policy states that the Charity should have unrestricted funds equivalent to six months of budgeted forecast expenditure – £180,000. The unrestricted funds as of 31 March 2022 were £144,966 – equivalent of 4.8 months of budgeted forecast expenditure. As the current level of reserves was below the level in the reserve policy, the Trustees curtailed some future projects, raised additional funds, and diversified the Charity's funding base.

Going concern

When approving the financial statements, the Trustees expect that the Charity has adequate resources to continue operational existence for the foreseeable future. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.



The Trustees' Annual Report

Future Plans

New charity status

Fight Bladder Cancer was registered as a Charitable Incorporated Organisation on 28 April 2022 (1198773) and recognised as a cross-border charity in Scotland on 27 July 2022 (SC051881).

The objectives of the new Charitable Incorporated Organisation are the relief of sickness and the preservation of health amongst people affected by bladder cancer, in particular, but not exclusively, by:

- the provision of support and assistance to patients diagnosed with bladder cancer, their families, friends and carers
- the provision of information on the subject of bladder cancer, its symptoms, range, treatments and aftercare needs promoting awareness campaigns regarding the causes, symptoms, treatments and aftercare to the public and within the medical profession
- supporting research into the nature, causes, diagnosis, prevention, treatment and cure of bladder cancer

 promoting and advocating for effective policies for the prevention, care, treatment and support for people affected by bladder cancer

Projects

Fight Magazine

The theme for the next *Fight* magazine is 'living well after bladder cancer surgery'. We will print 3,000 copies of this magazine and post it for free to health professionals and other stakeholders around the UK. We aim to have the magazine sitting in every urology centre around the nation and available for free digital download on our website.





Support – Patient Information Booklets

Over the following years, we will launch two additional booklets – one on innovative treatments for bladder cancers and the other a booklet for carers. We will update and print our 'questions to ask your healthcare team' leaflet and create a leaflet on sex and intimacy.

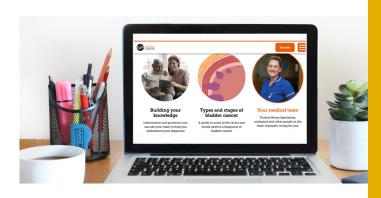
The impact of these booklets will be measured by recording the number of patient information booklets distributed to patients and carers, along with the preference for digital or print copies. In line with GDPR, the gender, diagnosis and geographical location of the cancer patients will be recorded. A survey will be distributed to assess their needs, asking for the recipients' opinions on the value of the information and if they would recommend these resources to other cancer patients.

The information booklets produced by Fight Bladder Cancer are unique because they are large-print, full colour, contain photos and stories of real-life survivors, are endorsed by medical professionals, and are filled with handy tips from others who have gone through a similar journey. There are no similar booklets available.

Support - website

The platform that fightbladdercancer.co.uk is built upon – Drupal 7 – will no longer be supported as of November 2023, so we now need to rebuild the architecture of our website from the ground up in WordPress. The new rebuild will allow us to include maps and a search bar, help people with disabilities use our website, expand our online shop, deter spam bots, improve user navigation, make the website easier to use

and edit on mobile phones, integrate our social media, and produce backups quickly. It will also provide information about innovative treatment options, clinical trials, support groups and patient information.



Support – Support groups, helpline and online forum

Our plans for the coming years include annually moderating 6,000 forum conversations, answering 1,000 support calls and emails, welcoming 500 new members to our private forum, pairing up 50 Bladder Buddies, hosting monthly virtual support groups, and helping inperson support groups to restart



Policy change – Exemplar policy work

Fight Bladder Cancer is ambitious to do more to improve the policy environment across the UK for patients with bladder cancer. Recent Fight Bladder Cancer activities, most notably the Exemplar Report, have identified numerous areas needing policy activity.

Fight Bladder Cancer has developed a strategy that allows Fight Bladder Cancer to deliver policy change with the finite resources available to the charity. Fight Bladder Cancer will prioritise areas where change will significantly impact patients and are achievable for our small team to deliver. A focus will be placed on:

- Issues that directly impact bladder cancer patients
- Activities where a consensus already exists on what needs to happen and change
- Activities that we can work on in partnership with organisations that have similar ambitions

Policy change – Supporting best practice in Scotland



We will continue our work to support Scottish urologists in using Quality Performance Indicators to ensure that bladder cancer patients are receiving timely and high-quality treatment and share these best practices with health professionals in England, Wales and Northern Ireland.

Policy change – Advocating for guidelines improvement

The 2015 NICE Guideline, 'Bladder cancer: diagnosis and management' [NICE Guideline], the 2017 Scottish Clinical Management Guideline for Bladder Cancer, the 2020 Wales National Optimal Pathway for Bladder Cancer, and the 2018 Northern Ireland NICaN Urology Cancer Clinical Guidelines should be reviewed and updated.

The NICE guideline, published in February 2015, is the clinical practice guideline on bladder cancer for use in the NHS in England, Wales and Northern Ireland.

NICE checked this guideline in April 2019 and stated that they found no new evidence that affects the recommendations in this guideline, despite submissions from stakeholders stating that new evidence that meant that these guidelines required updating was available.



The update to the 2017 Scottish Clinical Management Guideline for Bladder Cancer should highlight the Bladder Cancer Quality Performance Indicators, and the importance of a high-quality TURBT biopsy.

The update to the 2018 Northern Ireland NICaN Urology Cancer Clinical Guidelines should highlight that women with visible haematuria and repeated UTIs that do not respond to antibiotics should be referred through the "red flag" pathway. For muscle-invasive bladder cancer, clinicians should be encouraged to strive to offer radiotherapy or surgery instead of palliation to as many suitable patients as possible. There should also be an emphasis on signposting to patient support groups.

The update to the 2020 Wales National Optimal Pathway for Bladder Cancer should update the definition of intermediate risk non-muscle-invasive bladder cancer to that used in Scotland. For muscle-invasive bladder cancer, clinicians should be encouraged to strive to offer radiotherapy or surgery instead of palliation to as many suitable patients as possible. There should also be an emphasis on signposting to patient support groups.

We will create an updated evidence review and needs assessment and submit this to the relevant stakeholders, accompanied by a letter requesting a new public consultation.

Policy change – launch Steering Group for England and Wales, with Patient Advocates

We will launch a Steering Group for England and Wales with the support of our committed Patient Advocates. This group will continue to foster relationships with their parliamentary representatives and work to forward our policy goals in England and Wales.

We will set priorities for action with our patient advocates and host a Steering Group launch event in Autumn 2023.



Awareness – Bladder Cancer Awareness Month

During Bladder Cancer Awareness Month, we will work in partnership with the Global Bladder Cancer Patient Coalition and join our friends worldwide to raise bladder cancer awareness. We hope to organise 'wee walks'; we will wear orange clothes, take orange photographs, design orange-themed activities and finish the month by blowing Bubbles for Bladder Cancer on 31 May.

Fight Bladder Cancer will lead the UK activities associated with Bladder Cancer Awareness Month in the month of May. It will achieve a dynamic social media campaign, targeted traditional media



coverage, and a UK-wide celebration of Bubbles for Bladder Cancer on 31 May. The international theme of Bladder Cancer Awareness Month from 2022 to 2024 will be 'don't go red – go to your doctor'.



Awareness – Webinars for nurses and patients

We will partner with the British Association of Urological Nurses to produce training webinars for nurses on cystectomies and neobladders. We will also create a webinar on robotic surgery and a webinar on living with a stoma. These resources will be available as a live webinar and later as an on-demand video on our website and YouTube channel.

Research - Bladder cancer clinical trials

Fight Bladder Cancer will continue to maintain a current list of all the current clinical trials in the UK to make patients aware of the opportunities available. The list will continue to be available on the website and in each edition of *Fight* magazine. We will also publish lay summaries of bladder cancer research in our magazine and on our website. Increasing the quantity and quality of bladder cancer trials is another crucial way Fight Bladder Cancer can demonstrate its impact.

JOHN HESTER

CHAIR OF TRUSTEES, 23 JANUARY 2023

This Trustees' Annual Report was authorised by the Board of Trustees on 23 January 2023 and was signed on their behalf by John Hester.

INDEPENDENT EXAMINER'S REPORT TO THE BOARD OF TRUSTEES

For the year ended 31 March 2022

I report on the accounts of the charity for the year ended 31 March 2022.

Respective responsibilities of the Trustees and examiner

As the charity trustees of the charity, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under s. 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under s. 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
- 2. the accounts do not accord with such records; or
- the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view which is not a matter considered as part of an independent examination or
- the accounts have not been prepared in accordance with the Charities SORP (FRS102).

I understand that the financial statements have been prepared to give a 'true and fair' view, and have departed from the Charities (Accounts and Reports) Regulations 2008, only to the extent required to provide a 'true and fair view'. This departure has involved following SORP 2015 FRS102, rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 (SORP 2005), which is referred to in the extant regulations, but has since been withdrawn.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Date: 24 Jan 2023

Charles Ssempijja, FCA

NfP Accountants Ltd **Chartered Accountants** 3rd Floor, 86-90 Paul Street London EC2A 4NE

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STATEMENT OF FINANCIAL ACTIVITIES For the year ended 31 March 2022

	U	Inrestricted	Restricted		Total	Unrestricted	Restricted	Total
		Funds	Funds		Funds	Funds	Funds	Funds
Note	es	2022	2022		2022	2021	2021	2021
		3	3		£	£	£	£
INCOME FROM	_	040.070	405.000		040 470	100 170	0.4.500	070 700
Donations and legacies	2	213,970	135,203 1,320		349,173 16,129	192,170 13,321	84,538	276,708 13,571
Other trading activities Other income	3	14,809 11,046	1,320		11,046	13,321 13,697	250	13,571 13,697
Investment income		11,040	<u>-</u>		11,046	13,097	-	13,697
investment income			_			_	_	_
TOTAL INCOME	_	239,839	136,523		376,362	219,188	84,788	303,976
EXPENDITURE ON:								
Awareness		26,240	15,367		41,607	61,817	11.886	73,703
Support		54,369	45,324		99,693	40,762	54,837	95,599
Policy Change		50,358	103,253		153,611	31,022	2,324	33,346
Research		7,502	7,916		15,418	32,403	37,227	69,630
		,	,		-, -	- ,	- ,	,
	_	138,469	171,860		310,329	166,004	106,274	272,278
Raising funds	4	49,050	-		49,050	52,005	-	52,005
TOTAL EXPENDITURE	_	187,519	171,860		359,379	218,009	106,274	324,283
Net			(0= 00=)				(0.4.400)	(00.007)
income/(expenditure)		52,320	(35,337)		16,983	1,179	(21,486)	(20,307)
before transfers Gains/(losses) on								
investments: FBC		(500)			(500)	4.978		4.978
Trading Ltd		(500)	-		(300)	4,970	-	4,970
Net income /	-						-	
(expenditure) for the year		51,820	(35,337)		16,483	6.157	(21,486)	(15,329)
· · · · · · · · · · · · · · · · · · ·	14	(50,960)	50,960		-	-	-	-
NET MOVEMENT IN	_							
NET MOVEMENT IN FUNDS		860	15,623		16,483	6,157	(21,486)	(15,329)
. 61126			10,020		10, 100	0,.07	(=1,100)	(10,020)
RECONCILIATION OF FUN	DS							
TOTAL FUNDS AT								
BROUGHT FORWARD		144,106	38,637		182,743	137,949	60,123	198,072
2								
TOTAL FUNDS	_			_				0 105 715
CARRIED FORWARD	5	E 144,966	£ 54,260	£	199,226	£ 144,106	£ 38,637	£ 182,743
	-			_				

The annexed notes form part of these financial statements

(Registered charity number 1157763)

BALANCE SHEET As at 31 March 2022

	Notes			2022			2021
		£		£	£		£
FIXED ASSETS							
Tangible assets	11			5,576			2,263
CURRENT ASSETS							
Stocks		3,174			3,174		
Debtors	12	13,661			69,286		
Cash at bank and in hand		213,462			127,400		
	_	230,297	-		199,860	-	
		,			,		
CREDITORS: amounts falling due							
within one year	13	(36,647)			(19,380)		
NET CURRENT ASSETS	-		-	193,650		-	180,480
NET ASSETS			£	199,226		£	182,743
FUNDS							
Restricted funds	14			54,260			38,637
General fund	14			144,966			144,106
			£	199,226		£	182,743

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

The financial statements were approved, and authorised for issue, by the Trustees on ... 23 Jan 2023 and signed on their behalf by:-

Mr J L Hester, Trustee

STATEMENT OF CASH FLOWS For the year ended 31 March 2022

	2022		2021	<u> </u>
	£	£	£	£
Cash flows from operating activities Net income for the period Add back depreciation Change in stock		16,483 2,636		(15,329) 1,555 (3,174)
Net cash provided by / (used in) operating activ (Increase)/decrease in debtors Increase/(decrease) in creditors	ities 55,625 17,267	72,892	(47,661) 9,325	(38,336)
Cash flows from investing activities Purchase of fixed assets Sale of fixed assets		(6,447) 498		(418) -
Cash flows from financing activities		-		-
Change in cash and cash equivalents in the year	ar -	86,062		(55,702)
Cash and cash equivalents at the beginning of	the year	127,400		183,102
Cash and cash equivalents at the year end	_ _	213,462	_	127,400

1. ACCOUNTING POLICIES

Basis of preparation of financial statements

The financial statements have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (Charities SORP FRS 102), the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following SORP 2015 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 (SORP 2005) which has since been withdrawn.

Public benefit entity

The charity meets the definition of a public benefit entity under FRS 102.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

Income

Income is recognised when the charity has entitlement to the funds: this is when any performance conditions attached to the income have been met, it is probable that the income will be received, and that the amount can be measured reliably.

Income is only deferred when: the donor specifies that the grant or donation must only be used in future accounting periods; or for performance related grants, where these are received in advance of the performances or specific event to which they relate.

Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

Fund accounting

Restricted funds are to be used for specific purposes as laid down by the donor. Expenditure which meets these criteria is charged to the fund.

Unrestricted funds are donations and other incoming resources received or generated for the charitable purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular purposes.

Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is considered all to relate to Charitable activities and includes the costs of delivering services undertaken to further the purposes of the charity and their associated support costs.

Charitable activities costs

Direct costs of charitable activities are those costs incurred by the charity and are directly attributable to the delivery of its activities. The total costs of each charitable activity also includes allocated staff and support costs.

Allocation of staff costs

Staff costs are allocated to charitable activities on the basis of staff effort, for example by reference to staff time, for each activity.

Allocation of support and governance costs

Support and governance costs are allocated between charitable in proportion to staff costs.

Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar

Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

Judgements and key sources of estimation uncertainty

No judgements have been made in the process of applying the above accounting policies and there are no key sources of estimation uncertainty.

Foreign currencies

The reporting currency is GBP. The Foundation operates a no loss no gains policy with regard to currency fluctuations between GBP and Kenyan Shillings. Currency fluctuation is contained within

Intangible assets

Intangible assets are stated in the Balance Sheet at cost less accumulated amortisation and impairment. They are amortised on a straight line basis over their estimated useful lives as follows:

Website - 20% straight line

Tangible fixed assets

Individual fixed assets cost £300 or more are initially recorded at cost, less any subsequent accumulated depreciation and subsequent accumulated impairment losses, calculated as follows:

Office equipment - 25% straight line

2. DONATIONS AND LEGACIES

	Unrestricted	Restricted	Total	Total
	Funds	Funds	Funds	Funds
	2022	2022	2022	2021
	£	£	£	£
Donations received	50,145	10	50,155	76,086
Donations in Memorium	8,054	-	8,054	3,511
Grants - Pharmaceutical donors	29,280	129,150	158,430	157,338
Grants Received - Other	53,168	6,043	59,211	4,026
Bequests and legacies	500	-	500	2,044
Fundraising activities	72,455	_	72,455	32,621
Other fundraising income	368	-	368	1,082
•				•
	£ 213,970	£ 135,203	£ 349,173	£ 276,708
2021				
Donations received	76,086	-	76,086	
Donations in Memorium	3,511	-	3,511	
Grants - Pharmaceutical donors	72,800	84,538	157,338	
Grants Received - Other	4,026	-	4,026	
Bequests and legacies	2,044	-	2,044	
Fundraising activities	32,621	-	32,621	
Other fundraising income	1,082	-	1,082	
	£ 192,170	£ 84,538	£ 276,708	

Grants received - other: this includes £4,585 in government grants through the job retention scheme (2021 - £726), and Kickstart scheme grants amounting to £4,082 (2021 - Nil).

NOTES TO THE FINANCIAL STATEMENTS For the year ended 31 March 2022

3.	INCOME FROM OTHER TRAD	ING ACTIVIT	TIFS					
J.	THOOMET HOM OTHER THAE		Unrestricted Funds 2022 £	Restricted Funds 2022 £		Total Funds 2022 £		Total Funds 2021 £
	Sales		1,509	-		1,509		1,408
	Magazine Sales Fees received		- 13,001	- 1,000		- 14,001		12 9,660
	Advertising Sales Sundry income		- 299	- 320		- 619		1,900 591
			£ 14,809	£ 1,320	£	16,129	£	13,571
4.	ANALYSIS OF EXPENDITURE	: Staff /						
		consultant		Support				
	Current year	costs £	costs	costs £		Total 2022	,	Total 2021 £
	Charitable activities	£	£	£		£		£
	- Awareness	17,644	14,446	9,517		41,607		73,703
	- Support	39,744	38,513	21,436		99,693		95,599
	- Policy Change	69,859	46,073	37,679		153,611		33,346
	- Research	9,258	1,167	4,993		15,418		69,630
		136,505	100,199	73,625		310,329		272,278
	Fundraising costs	25,482	23,568	-		49,050		52,005
	Governance & support costs	36,253	37,372	(73,625)		-		-
		£ 198,240	£ 161,139	£ Nil	£	359,379	£	324,283
				-	· ·			
		Staff /						
		consultant		Support				
			Direct costs	costs		Total 2021		
	Charitable activities	£	£	£		£		
	- Awareness	33,815	23,907	15,981		73,703		
	- Support	<i>29,475</i>	<i>52,194</i>	13,930		95,599		
	- Policy	21,788	1,261	10,297		33,346		
	- Research	35,162	17,850	16,618		69,630		
		120,240	95,212	56,826	_	272,278		
	Fundraising costs	43,568	8,437	_		52,005		
	Governance & support costs	21,952	34,874	(56,826)		-		
		£ 185,760	£ 138,523	£ Nil	£	324,283		

Of total expenditure of £359,379, £171,860 (2021 - £106,274) was out of restricted income funds, and £187,519 (2021 - £218,009) was unrestricted.

5. TRUSTEES' REMUNERATION AND EXPENSES

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year (2021 - none).

No trustees have received any reimbursed expenses or any other benefits from the charity during the year (2021 - none).

6. OTHER RELATED PARTY TRANSACTIONS

There were no other disclosable related party transactions (2021 - the same).

7. STAFF COSTS AND NUMBERS

Colomy acesta	Unre	estricted Funds 2022 £	Re	estricted Funds 2022 £		Total Funds 2022 £		Total Funds 2021 £
Salary costs Wages and salaries Social security costs Employer's pension		72,291 4,536 511		89,387 6,455 1,516		161,678 10,991 2,027		171,294 11,435 3,031
	£	77,338	£	97,358	£	174,696	£	185,760

The monthly average number of persons (including senior management team) employed by the charity during the year was 6 (2021 - 5).

One employee received emoluments of more than £60,000 (£60,000 - £70,000), including benefits, during the year (2021 - the same).

Total remuneration for key management personnel amounted £89,956 during the year (2021 - £90,320).

8. PENSIONS

The charity operates a defined contribution pension scheme. The pension cost charge for the year represents contributions payable by the charity to the scheme and amounted to £2,027 (2021 - £3,031).

NOTES TO THE FINANCIAL STATEMENTS For the year ended 31 March 2022

9. SUPPORT AND GOVERNANCE COSTS				
		2022		2021
		£		£
Governance costs:		_		~
Independent Examiner's fee		2,025		2,100
•		2,023		-
Other governance costs		-		784
	'	2,025		2,884
Support staff costs: wages and salaries		36,253		21,952
Other staff costs		6,516		3,908
Premises costs		6,237		15,618
		•		-
IT and equipment		7,127		4,999
Postage, printing, and communications		1,610		3,490
Graphic Design		2,860		-
Professional fees		5,460		2,296
Marketing and publicity		-		58
Depreciation and amortisation costs		2,636		1,555
Sundry		2,901		66
33,		_,		
	£	73,625	£	56,826

Support costs all relate to the charitable activities on the basis of staff time.

10. INTANGIBLE FIXED ASSETS

Website		£
Cost At 1 April 2021 and at 31 March 2022		21,631
Amortisation At 1 April 2021 and at 31 March 2022		21,631
Net book value At 31 March 2022	£	Nil
At 31 March 2021	£	Nil

NOTES TO THE FINANCIAL STATEMENTS For the year ended 31 March 2022

11. TANGIBLE FIXED ASSETS				
				Office
			eq	uipment
				£
Cost				
At 1 April 2021				9,955
Additions				6,447
Disposals				(664)
At 31 March 2022				15,738
Depreciation				
At 1 April 2021				7,692
Charge for the year				2,636
On disposals				(166)
At 31 March 2022				10,162
Net book value				
At 31 March 2021			£	2,263
At 31 March 2022			£	5,576
12. DEBTORS				
12. DEDITORS		2022		2021
		2022 £		£021
Due within one year		~		2
Trade debtors		600		49,000
Rent deposit		8,125		8,125
Recoverable Gift Aid		· -		5,047
Prepayments		4,933		7,111
VAT debtor		3		3
	£ 1	3,661	£	69,286
		-,		,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,

NOTES TO THE FINANCIAL STATEMENTS For the year ended 31 March 2022

13	CREDITORS: AMOUNTS FAL	I ING DUF W	ITHIN ONE YI	FΔR			
	ONEDITORIO. AMOUNTO I AL	LING BOL W	٥١١٢	- A11	2022		2021
					£		£
	Trade creditors				16,469		11,126
	Provision for FBC Trading Ltd				500		360
	Deferred grant income				13,500		-
	Social security and other taxes				3,483		4,011
	Other creditors				-		657
	Accrued expenses				2,695		3,226
					£ 36,647	£	19,380
						~	70,000
	Deferred income						
	Amount deferred in the year				13,500		
	Balance at 31 March 2022				£ 13,500	£	Nil
14.	STATEMENT OF FUNDS						
					Transfers and		
		Brought	Incoming	Resources	investment		Carried
		Forward	Resources	Expended	gains/(losses)		Forward
		£	£	£	£		£
	RESTRICTED FUNDS						
	Patient Booklets	-	15,830	(14,180)	-		1,650
	Contact Cards	24,454	-	(5,579)	-		18,875
	Exemplar	2,773	115,008	(84,046)	-		33,735
	Patient Advocates	7,676	1,858	(19,207)	9,673		-
	Website Support	3,734	2,909 408	(15,367) (25,565)	8,724 25,157		-
	Research	_	510	(7,916)	7,406		_
	riesearch	_	310	(7,910)	7,400		_
		£ 38,637	£ 136,523	£ (171,860)	£ 50,960	£	54,260
	SUMMARY OF FUNDS						
	General Funds	144,106	239,839	(187,519)	(51,460)		144,966
	Restricted Funds	38,637	136,523	(171,860)	50,960		54,260
		-,	-,-	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	,		,
		£ 182,743	£ 376,362	£ (359,379)	£ (500)	£	199,226

NOTES TO THE FINANCIAL STATEMENTS

For the year ended 31 March 2022

CTATEMENIA	OF FLINIDS	CONTINUED	2021
SIAIFWENI	UF FUNIS	CONTINUELL	- /()/

STATEMENT OF FUNDS CONTINUED - 2021									
				Transfers and					
	Brought	Incoming	Resources	investment		Carried			
	Forward	Resources	Expended	gains/(losses)		Forward			
	£	£	£	£		£			
RESTRICTED FUNDS									
Patient booklets	34,005	20,000	(54,005)	-		-			
Contact Cards	26,118	-	(1,664)	-		24,454			
Exemplar	-	40,000	(37,227)	-		2,773			
Patient Advocates	-	10,000	(2,324)	-		7,676			
Website	-	14,788	(11,054)	-		3,734			
	£ 60,123	£ 84,788	£ (106,274)	£ Nil	£	38,637			
0/4/4/5// 05 5/4/50 000/									
SUMMARY OF FUNDS - 2021									
General Funds	137,949	219,188	(218,009)	4,978		144,106			
Restricted Funds	60,123	84,788	(106,274)	-		38,637			
	£ 198,072	£ 303,976	£ (324,283)	£ 4,978	£	182,743			

Description of funds

Patient booklets

A new initiative to develop, produce, launch, and distribute a suite of ten patient information booklets designed to support patients on every step of their bladder cancer pathway.

Health Professional Contact Cards

Personalised business cards for nurses and other health professionals to give to patients, with the charity's support services and their own contact details.

Exemplar

The project seeks to define what exceptional services for people affected by bladder cancer would look like.

Patient Advocates

The recruitment, training, and support of people affected by bladder cancer to share their insights and lead the work of the charity.

Website

Refreshing fightbladdercancer.co.uk to ensure that it contains current and accessible information about the diagnosis, treatment, and care of bladder cancer.

NOTES TO THE FINANCIAL STATEMENTS

For the year ended 31 March 2022

15. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted Funds			
	Designated Funds £	General Funds £	Restricted Funds £	Total Funds £
Tangible fixed assets Net current assets	<u>.</u>	5,576 139,390	- 54,260	5,576 193,650
	£ Nil	£ 144,966	£ 54,260 £	£ 199,226

16. OPERATING LEASE COMMITMENTS

The charity had no operating lease commitments (2021 - the same).

17. OTHER COMPANY INFORMATION

Fight Bladder Cancer is a registered non-company charity, charity commission registration number 1157763. The registered office is 51 High Street Chinnor Oxfordshire OX39 4DJ. The accounts are presented in GBP to the nearest £1.



High Street Chinnor Oxon

01844 351 621

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