

Annual Review 2014-2015



Our year in numbers

239

people visited our new national Rehabilitation hub on our website

£250,000

awarded in research grants

780

people with sarcoma and their families were able to meet and talk to other people similarly affected, through our network of local sarcoma groups

1,100

GPs in England, Scotland, Wales & Northern Ireland were told about the signs and symptoms of sarcoma through our *On the Ball* pack

96%

increase in visits to the Support section of our website

737

people and families affected by sarcoma received our support through phone and email to our head office

900

people were asked about their personal experiences of being diagnosed with sarcoma and how their experience could be improved

260%

increase in the distribution of our Information Standard accredited Guides for people with sarcoma

173%

increase in the number of views on the 'About sarcoma' section on our website

79

people make up our Sarcoma Voices initiative – getting actively involved in improving sarcoma care

15,000

copies of our publication *Connect* distributed to the sarcoma community

Message from the Chair and Chief Executive

As Sarcoma UK approaches the £1 million income level (forecast 2015/16), the Board of Trustees wishes to thank everyone in the sarcoma community for their contribution to our progress during the past year. In 2014/15, we had ambitious plans that were fully delivered with professionalism and commitment by our small team of seven staff. Our income predictions were modest and we were delighted to end the year with an income level that greatly exceeded our expectations. This enables us to commit more funds to research into sarcoma; to support more people affected by sarcoma and their families; and to raise more awareness of sarcoma amongst the public.

The continuing progress of Sarcoma UK as the only national charity for all types of sarcoma was seen clearly in our achievements this year, including many new areas of development for us. We researched and published our first campaign report about the experiences of women with gynaecological sarcoma, raising questions about the quality of treatment and care women receive, and highlighting the difficulties women face reaching sarcoma specialist services. It was a challenging hard hitting report which made waves within the gynaecological professional world. However, it was also a vital piece of work giving a strong voice to women with gynaecological sarcoma. We will continue to build our campaigning voice in 2015/16 with the launch of a report containing results of our first national survey of sarcoma patients in England and Scotland.

We are pleased to report progress towards our strategic goal: "More



Karen Delin
Chair of Trustees

people will survive sarcoma" through the national launch of our *On the Ball* GP awareness campaign during Sarcoma Awareness Week in June 2014. Over 1,000 supporters throughout the UK ordered a pack containing a golf ball key ring and Diagnostic Tool to give to their GP to help them understand more about sarcoma, and we are very grateful for this support and engagement.

Sarcoma UK is the only charity in the UK providing a comprehensive support and information service dedicated to sarcoma. In 2014/15, our services were used by double the number of people than in the previous year. We will invest in 2015/16 to extend this into the provision of expert, specialist and individualised support for people affected by sarcoma.

The Board of Trustees are very aware that Sarcoma UK's ability to deliver our ambitious goals depends on our continued engagement with the sarcoma community. We highly value all our dedicated supporters who help the charity in multiple ways and hope that you will continue to support us in our work over the coming years.

Thank you.



Lindsey Bennister
Chief Executive

About Sarcoma UK

Our mission is to increase knowledge and awareness of sarcoma through ground-breaking programmes that inspire involvement and transform the landscape for everyone affected by sarcoma.

- We initiate change to raise sarcoma **awareness** and improve standards of treatment and care
- We seek answers through **research**
- We provide **support & information** for the sarcoma community

What is sarcoma?

- Sarcomas are rare cancers that develop in the muscle, bone, nerves, cartilage, tendons, blood vessels and the fatty and fibrous tissues
- There are around 100 different sub-types of sarcoma



Sarcoma UK is the only charity in the UK that focuses on all types of sarcoma. That's our purpose; that's why we are here.

- We are here to provide **credible, high quality information** about sarcoma to everyone affected by sarcoma. We are here to lend support and answer questions
- We are here to **improve survival rates** by promoting early diagnosis and ensuring all people diagnosed with sarcoma are aware of their treatment pathway
- We are here to **educate GPs and the public** on the signs and symptoms of sarcoma so people are diagnosed earlier
- We are here to **ensure that people are not alone** during their diagnosis and treatment. By working with all members of the sarcoma community – patients, carers, supporters, health professionals and researchers – we share information and work collaboratively
- We are here to **get sarcoma on the political agenda**. We empower people through our Sarcoma Voices programme, to ask questions about this rare cancer and get their voices heard
- We are here to **guide and inspire supporters** to maximise their fundraising and show them exactly how we spend their money
- **Ultimately we are here to find a cure for sarcoma**. The research we fund adds to the knowledge base in sarcoma, provides evidence to support changes to practice, and supports breakthroughs.



The bone & soft tissue cancer charity

The current sarcoma landscape

- About 3,800 new cases of sarcoma are diagnosed each year in the UK which makes up approximately 1% of all cancer diagnoses
- 3,330 people are diagnosed with a soft tissue sarcoma (including GIST)
- 500 people are diagnosed with a bone sarcoma
- In general, patients with a bone or soft tissue sarcoma diagnosis are younger than the majority of cancer patients
- 16% of bone or soft tissue sarcomas are diagnosed in patients less than thirty years of age, compared to around 2% of all cancers
- 37% of bone or soft tissue sarcoma patients are aged less than 50 years
- Sarcomas make up 15% of all childhood cancers (0-14 years)
- Sarcomas make up 11% of all cancer diagnoses in teenagers and young people (15-24 years)
- The five-year relative survival rate for all sarcomas is only 55% and overall survival is still poor compared to other countries, e.g. Scandinavia and Italy, and other cancer types.

Objectives and activities

Sarcoma UK is the only cancer charity in the UK focusing on all types of sarcoma.

Our Mission

To increase knowledge and awareness of sarcoma through ground-breaking programmes that inspire involvement and transform the landscape for everyone affected by sarcoma.

Our Goals

1. More people will survive sarcoma.
2. More will be known about the causes of sarcoma.
3. Everyone affected by sarcoma will have access to the best treatment and care.

Achievements and Performance

Sarcoma UK's achievements against objectives for the year are set out below. Our activities and income increased significantly during the year with £964,709 raised compared to £760,967 in 2013/14. The Trustees wish to thank everyone who has supported the charity this year and contributed to its achievements.

Strategic priorities for the year and achievements

Priority 1: Initiate change to raise awareness and improve care

Sarcoma cancer is not widely known by the public. In our first market research poll carried out in January 2015 (of 1,000 people), we found that 53% of the public had never heard of sarcoma; and only a quarter of the public were able to identify sarcoma as a type of cancer. This is why our priority is to increase awareness of the signs and symptoms of sarcoma with the public and health professionals. Earlier diagnosis will ultimately save lives and GPs play a vital role in helping to make this happen. The poll will be carried out annually to track public awareness of sarcoma against this baseline information.

The experiences of sarcoma patients provide us with important insights into how care can be improved within the NHS, and these experiences inform all of our work.

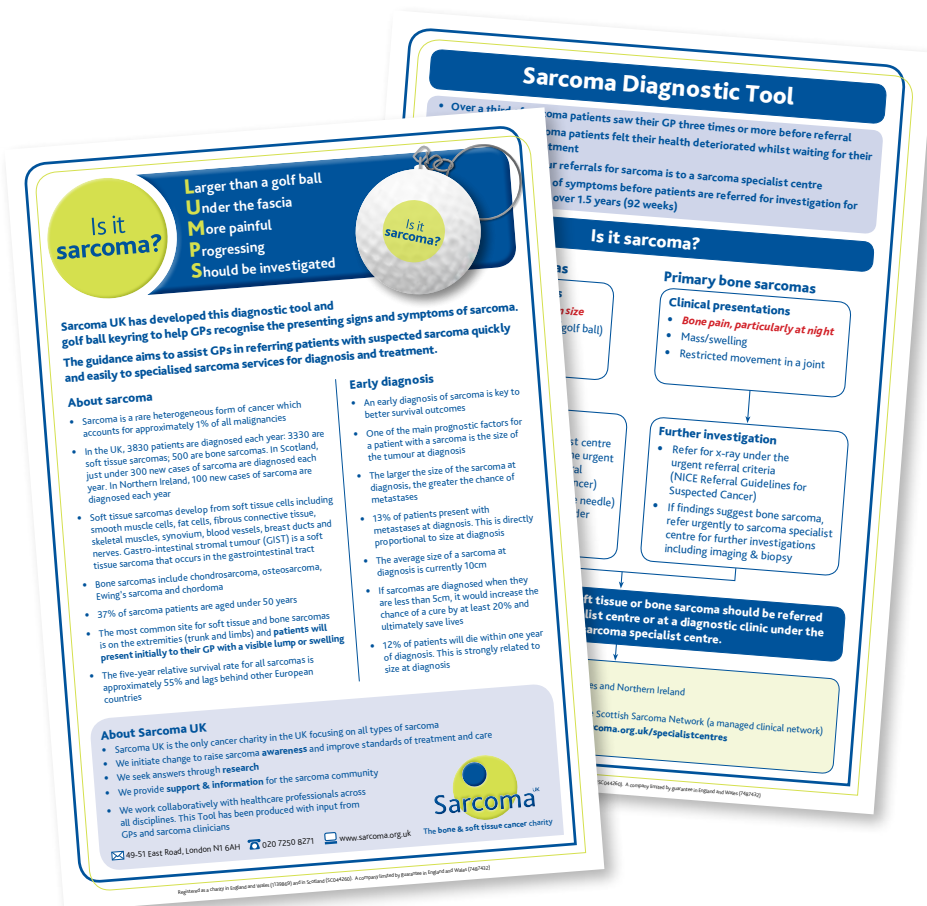
Objective

Launch a national GP education programme to bring about earlier diagnosis of sarcoma, building on the learning from a regional pilot project in 2013/14.

What we achieved

Sarcoma Awareness Week 2014 marked the launch of our national GP awareness campaign. We asked the sarcoma community to individually take an **On the Ball pack to their own GP at their next appointment.**

The pack contained a personal letter from the patient; clinical information about sarcoma; a Diagnostic Tool to help GPs identify the red flag symptoms of sarcoma; and a golf ball key ring as a reminder of the size of a lump that may indicate sarcoma. The campaign, backed by Sarcoma UK Patron, Paralympic gold medallist Richard Whitehead MBE and sarcoma patients, achieved TV, radio and press



coverage including local BBC, ITV and the *Daily Mail*.

1,034 On the Ball packs were distributed throughout the whole of the UK

In 2015/16, we will expand our work on early diagnosis to provide and participate in GP training and Continued Professional Development programmes.

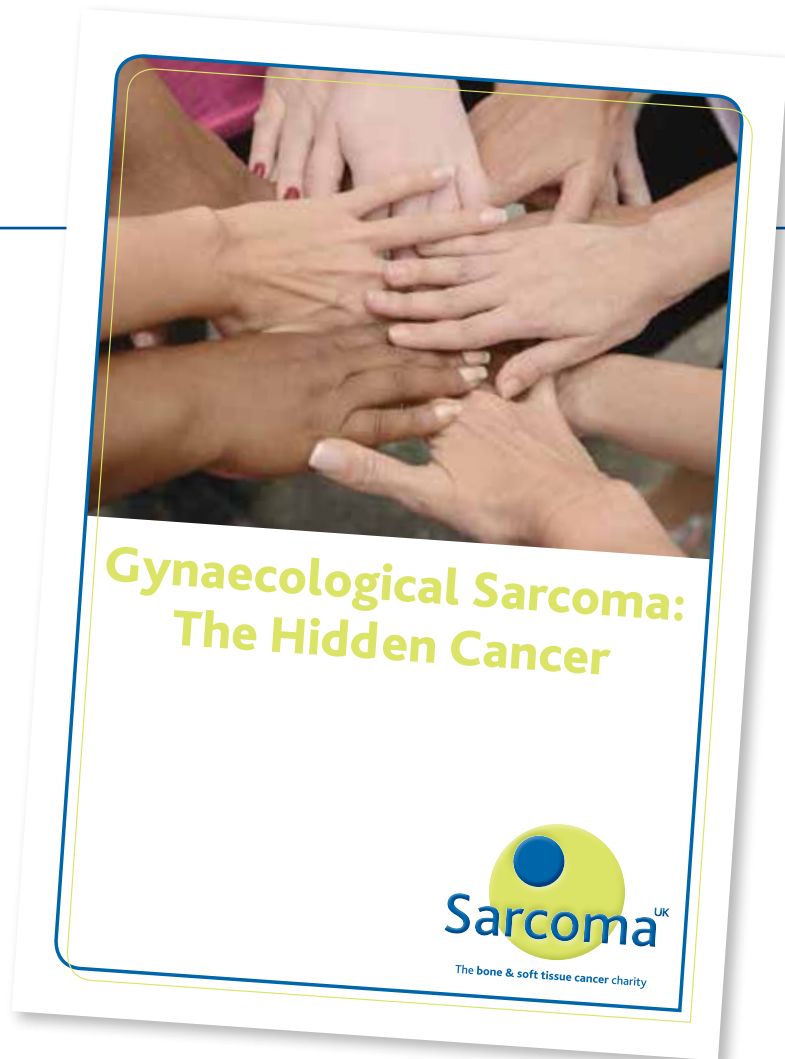
Objective

Increase our understanding of sarcoma patients' experiences and provide expert patient input to NHS sarcoma services

What we achieved

We had become increasingly aware of the often devastating impact of gynaecological sarcoma (a sub-type of sarcoma affecting almost 300 women each year) through **hearing the experiences of women and their families** who use our support and information services. Anecdotal evidence indicated that many women were not able to access the best treatment and experienced delays in referral to sarcoma specialist services until the cancer was too far advanced for treatment. In 2014 we carried out an in-depth survey of women with gynaecological sarcoma, leading to the production of our first campaign report ***Gynaecological Sarcoma: The Hidden Cancer*** in early 2015.

The report was presented at **the British Sarcoma Group annual conference and distributed to gynaecology and gynaecological oncology professionals, and health policy makers**. The experiences of



women in the report also informed an investigative news story by Channel 4 News, involving Sarcoma UK's Chief Executive.

In 2015/16, we will continue to campaign for a consensus between gynaecological oncology and sarcoma specialist health professionals on the treatment and care of women with gynaecological sarcoma.

In 2014, we engaged Quality Health (a company that delivers the National Cancer Patient Experience Survey – NCPES) to carry out **a large scale survey of sarcoma patients** on behalf of Sarcoma UK. We were able to talk directly to 1,000 people living with all types of sarcoma in England and Scotland and ask them questions to understand more about their experiences. A steering group of patients, clinicians and statisticians helped shape the content of the questionnaire.

In 2015/16, we will publish a detailed report of sarcoma patient experiences in England and Scotland, which will act as a comprehensive evidence base to inform our work.

Through our **Sarcoma Voices** programme, we supported people with personal experience of sarcoma to participate in sarcoma research and policy groups including the NHS England Sarcoma Clinical Reference Group, the National Cancer Research Institute Sarcoma Clinical Studies Group, and the National Cancer Intelligence Network Sarcoma Site Specific Clinical Reference Group. Members of Sarcoma Voices contributed to the many policy responses that Sarcoma UK produced during 2014/15.

Priority 2: Seek answers through research

Sarcoma is a complex disease which requires high levels of investment to bring about breakthroughs in understanding the causes, developing new treatments and ultimately preventing sarcoma. We invest in high quality, innovative research throughout the UK.

Objective

To expand our sarcoma grants programme.

What we achieved

Sarcoma UK runs a UK-wide grants programme dedicated specifically to sarcoma. We are committed to funding high-quality, peer-reviewed research that benefits sarcoma patients.

This year, we awarded £250,000 - our largest call for proposals to date.

The aim was to attract larger applications and also to fully fund selected applications. This resulted in five new grants awarded in the first quarter of the financial year (2014/15), bringing the total amount of research funded by Sarcoma UK to £675,836, with 16 projects funded.

- 1. Dr Tim Forshew, University College London:** Assessing the potential of circulating tumour DNA as a new biomarker for low grade bone and soft tissue neoplasms
- 2. Dr Paul Huang, Institute of Cancer Research:** Dissecting the mechanisms of pazopanib resistance in soft tissue sarcoma



- 3. Dr Barbara Tanos, Institute of Cancer Research:** Role of TTBK2 and cilia in sarcoma progression
- 4. Dr Clare Turnbull, Institute of Cancer Research:** Studies of genetic susceptibility using exome sequencing in patients with sarcoma and an additional primary tumour
- 5. Dr Gareth Veal, Northern Institute for Cancer Research, University of Newcastle:** Study to investigate correlations between age-dependant pharmacokinetic variation, side-effects of

chemotherapy and biomarkers of toxicity in Ewing's sarcoma

We continued to fund previous research grants that have made some great progress, from presentations at the British Sarcoma Group (2015) and the Scottish Sarcoma Network, as well as publications.

In 2015/16, we will continue to increase the amount of funds invested into research, and improve our communications to supporters about the research we fund, including holding a national event showcasing Sarcoma UK's funded research.

Priority 3: Support the sarcoma community and provide information

Sarcoma can make many people feel isolated and afraid. We provide both regional and online sarcoma support groups. Our information booklets break down the language barriers to guide people easily through their diagnosis to treatment.

Objective

Reach more people affected by sarcoma through our information and support services

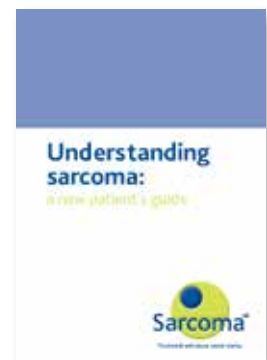
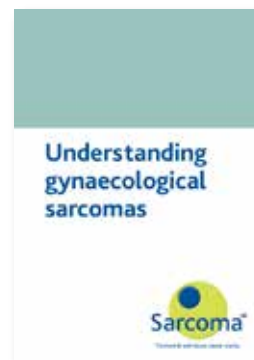
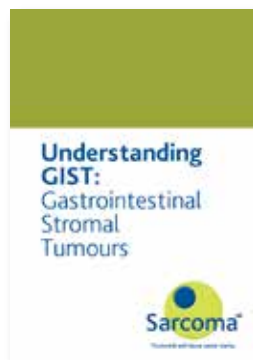
What we achieved

We significantly increased our range of information and support for people affected by sarcoma and the ways that it can be accessed, resulting in many more people using our services.

An increasing number of people are using our **'About Sarcoma'** pages on the website to help them learn about their diagnosis and treatment. The number of people using our website sarcoma information increased by 75% to over 68,500.

In addition, our printed booklets remain very popular, with **over 3,000 copies** of our three guides for people with newly diagnosed sarcoma; GIST; and gynaecological sarcoma being ordered. The guides are Information Standard accredited, a mark of quality in health information, and offer people space to keep notes about their treatment.

We also expanded our range of patient information. As part of an innovative collaboration between patients, support groups, health professionals,



bone sarcoma specialist centres, and rehabilitation specialists, Sarcoma UK's website became the host of a **national 'information hub' on rehabilitation** for people with sarcoma. Since its launch in November 2014, **over 2,000 people have visited the hub** to find out about rehabilitation services available to them.

This year, Sarcoma UK was involved in 20 events held during the year which provided information and support to patients, including *Living Well with Sarcoma* events in conjunction with sarcoma specialist centres, sarcoma support group meetings, regional sarcoma conferences, and patient/professional education events in Scotland, Northern Ireland and England. We provided face-to-face information and support to over 500 people affected by sarcoma.

We also saw a significant increase in

personal and individualised requests for support by telephone and email. This year, enquiries to Sarcoma UK from patients and their families doubled from the previous year.

We strengthened and expanded our network of regional sarcoma support groups across the UK with the aim of having a support group associated with each sarcoma specialist centre. Through this thriving network, **we supported 600 people affected by sarcoma**. We also helped one new regional sarcoma group to get established, and provided financial support and advice to 13 existing groups.

In 2015/16, we will expand our support and information services to provide tailored, individualised support and information to people with sarcoma, their families and supporters.

Communications

Media

Our reputation is growing within the media as the first organisation to contact for expert comments on all sarcoma-related issues. This year, we have received many more enquiries from local and national journalists in TV, radio, press and digital news. Highlights of the year include: Channel 4 News; *The Times* (Aberdeen research project); Guardian Online (Miniature Ink); and digital media support from Premiership League rugby unions clubs, Saracens and Northampton Saints.

In total we generated **180 individual articles** which represents an average of three mentions a week and a total audience reach of over 30 million. This is mainly down to our supporters using our key messages and **sharing their personal story** with their local media, in turn raising public awareness of sarcoma. By providing supporters with the tools to contact their local media, we can maximise awareness and minimise the funds spent on PR activities.

In October, **Channel 4 broadcast an exclusive feature** about power morcellation (a treatment used for gynaecological problems that may be linked to the spread of undiagnosed gynaecological sarcoma) which included an interview with our Chief Executive, Lindsey Bennister. Channel 4's Health Correspondent, Victoria MacDonald worked with Sarcoma UK to produce this powerful feature using our case studies and evidence from our report "Gynaecological Sarcoma: The Hidden Cancer". It was aired on prime-time Channel 4 news (22 Oct).

Digital

We made digital media a priority this year, strategically planning relevant content using our website and social media as a platform. **We focussed on storytelling** to celebrate and promote our supporters' activities, efforts and achievements.

Our supporter-centric and personalised approach in our Facebook and Twitter accounts has led to a 45% increase in followers.

Social media proved the most effective way of promoting our *On the Ball* campaign with 29% of supporters ordering a GP pack because they had seen the call to action on Facebook or Twitter. The largest *On the Ball* social media post reached 9,752 people with 123 shares.

The number of visits to the Sarcoma UK website increased by 41%. This shows the increasing need of our website as a way of engaging with the charity and sourcing information and support.

Print

We aim to reach as many people as possible through our printed quarterly publication *Connect*, in order to inform and inspire newly diagnosed patients and help them feel less isolated. Throughout this year, **sign-ups to *Connect* increased by 33%.**

*In 2015/16, we will invest significantly in our website, so that it provides greater support and is more responsive to the needs of people with sarcoma, their families and our supporters. We will engage with our readers about the content and distribution of *Connect* to ensure it reflects their needs and preferences; and we will introduce new ways to communicate with our supporters to keep them informed about our work.*



Priority 4: Build a strong charity

The commitment and dedication from our current supporters, and the increasing number of supporters who are new to the charity, has helped us to surpass our income target for the year. We cannot do the work we do without this support from the sarcoma community. From head-shaves to fancy dress; from open water swims to shaking a tin at sporting events; and personal challenges like climbing the world's tallest mountain, our supporters are highly successful in raising much needed funds and awareness of sarcoma.



Paula Magnus raised over £21,000 at a glamorous ball at Epsom Racecourse in memory of her husband, Dean.



Our connection with the rugby world was a consistent theme in 2014/15. Northampton Saints Rugby Club fan, Luis Ghaut was diagnosed with osteosarcoma. Luis' story touched everybody he met and funds were raised by his local community towards his treatment and charities including Sarcoma UK. Sadly, Luis passed away in September. His

family maintain close links with Sarcoma UK and visited us to present a cheque for £10,000. They continue to take part in events and challenges in Luis' memory and to play a significant role in raising the profile of sarcoma.



Sarcoma UK was nominated as match-day charity by Saracens Rugby Club at an Aviva Premiership game against Bath by a supporter with personal experience of sarcoma who worked for Saracens. Our team of volunteers talked to fans and collected donations throughout the event.



To meet increased demand from supporters, we have extended our events and challenges portfolio. After careful analysis, we committed to buying 14 official places in the London Marathon and 24 places in the Prudential Ride 100. This has resulted in a good return on investment with both events exceeding expectations, raising a total of £76,000. The London Marathon in particular is very popular and Team Sarcoma is boosted each year by runners who have acquired their own places in the ballot, thereby adding extra value and saving the charity the cost of the place. In 2014, we held our first post-marathon party at the wonderful rooftop terrace of the Transport for London building close to the finish line, where the space was made available to us at no cost through a Sarcoma UK supporter.



The 17-strong Sarcoma UK team taking place in our first Prudential Ride London-Surrey in August 2014 bravely battled through hurricane conditions to complete the gruelling circuit, cheered on by friends and family at cheering posts along the route. We would particularly like to thank the Super C's, who take up this challenge annually in memory of Derek Watkins.



This year, we have started to diversify our income streams including building links with corporate organisations and entering into partnerships with other charities. We are privileged to receive annual support from investment company, The Analyst, who pledge a percentage of their annual profits to Sarcoma UK, in memory of their founder Jonathan Scriven.

We highly value the ongoing partnership with our friends at The Boom Foundation in Northern Ireland. This thriving charity, founded and run by Leona Rankin in memory of her fiancé Philip, provides support to people affected by sarcoma in Northern Ireland. The Boom Foundation pledge 50% of their fundraising to Sarcoma UK to support our research programme, and in 2014/15 donated £25,000 to Sarcoma UK.



Sarcoma UK receives some financial support from pharmaceutical companies. Sarcoma UK's Board of Trustees have approved a policy setting out the framework and principles behind Sarcoma UK's relationship with the pharmaceutical industry, which is available publicly on the charity's website. Donations from pharmaceutical companies in 2014/15 represent 1% of Sarcoma UK's income for the year.

For every £1 spent on fundraising £5.53 was raised. We strive to keep costs to a minimum.

We would like to thank all the people who have fundraised for us during this year (and beyond). Your involvement is helping us to transform the landscape for everyone affected by sarcoma.

In 2015/16, we will further diversify our fundraising streams to ensure a sustainable funding base is in place for the charity, as well as increase the communications with our supporters to keep them fully informed of our work, achievements, and how their donations have been used.

Accounts

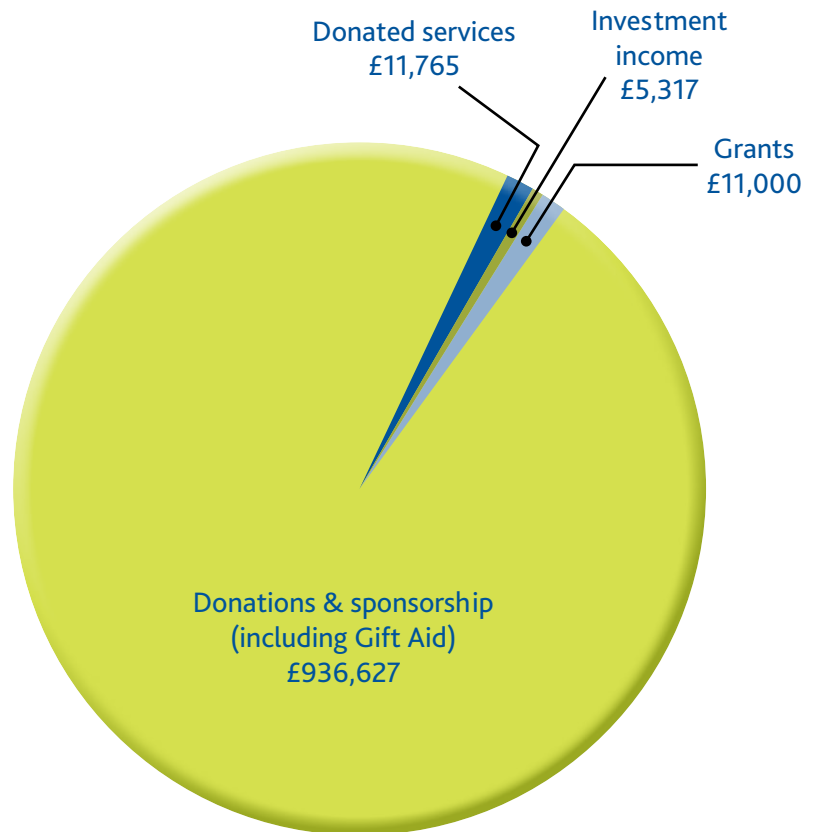
For every £1 spent on fundraising £5.53 was raised

Income

Our financial year runs from April 2014 to March 2015.

Thanks to you we have grown income significantly from £760,967 to £964,709, an increase of 27%.

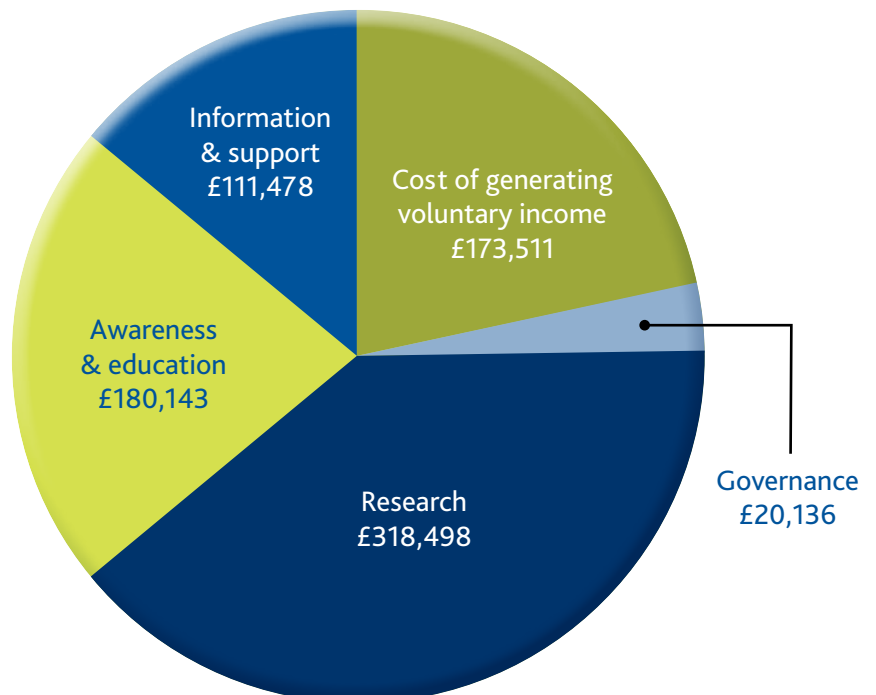
Voluntary income from individuals and families who have a personal connection with sarcoma represents 97% of Sarcoma UK's funding. This large percentage demonstrates how vital your fundraising is in supporting our work.



Expenditure

Our expenditure for the year increased by 65% to £803,766. This amount reflects our expanded activity and success in achieving our charitable activities.

Sarcoma UK awarded £251,521 to research grants during this financial year. A further £335,493 has been designated to research grants in 2015/16.



The summary financial information shows the income and expenditure for our charity. The information is taken from the full accounts which were approved by the trustees on 17 September 2015. In order to gain a full understanding of the financial affairs of the charity, the full accounts, including the trustees' report and auditor's report should be consulted. Copies can be obtained from Sarcoma UK.

Signed on behalf of the trustees
Karen Delin, Chair

Acknowledgments

The Board of Trustees wishes to acknowledge the following people for their outstanding support of Sarcoma UK during the past year:

PATRON - Richard Whitehead MBE

HONORARY PRESIDENT - Roger Wilson CBE

Sarcoma UK Research Advisory Committee

Professor Ian Judson (Chairman) BSc MB BS MA MD FRCP (Chairman)

Head of Sarcoma Unit and Professor of Cancer Pharmacology, Royal Marsden Hospital, London

Professor Penella Woll (Vice Chair) BMedSci MB BS PhD FRCP

Professor of Medical Oncology, University of Sheffield

Professor Adrienne Flanagan MB PhD FMedSci

Professor of Musculo-Skeletal Pathology, University College London

Consultant Histopathologist, Clinical Lead, Royal National Orthopaedic Hospital, London

Professor Bass Hassan BSc DPhil FRCP

Professor of Medical Oncology, University of Oxford

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Consultant Orthopaedic Surgeon, New Royal Infirmary, Edinburgh

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Dr Paula Wilson BSc MBChB (Hons) MRCP FRCR

Consultant in Clinical Oncology, University Hospitals Bristol

Mr Lee Jeys MB ChB MSc FRCS

Consultant Orthopaedic Surgeon, Royal Orthopaedic Hospital Birmingham

Individuals who have provided professional support

The following people have provided valuable professional support and advice to Sarcoma UK on a pro-bono basis.


- Kate Donachie (HR Business Partner, Work Services Directorate, Department for Work and Pensions)
- Edelman PR
- Mark Gould (Director, The Systems Management Company)
- Jonathan Rennison (Mentor, Institute of Fundraising)



The bone & soft tissue cancer charity

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