The many faces of sarcoma

Sarcoma Awareness Week • 18-24 June 2012

We need your help! Upload/send us your photo to show the wider public The many faces of sarcoma or take part in a fundraising event or challenge during the week of 18-24 June. See page 4.

Research Advisory Committee
We have pledged £100,000 of funding for sarcoma research from April. Find out which projects your money is supporting

Statistics
How do we collect our statistics on sarcoma and what does the data tell us? Matthew Francis from the West Midlands Cancer Intelligence Unit interprets the figures
From the Chief Executive

Sarcoma UK’s key messages

- Sarcoma UK is the main charity in the UK dealing with all types of sarcoma
- Sarcoma UK provides information and support for anyone affected by sarcoma – patients, carers, relatives and friends
- Sarcoma UK’s aim is to achieve the best possible standard of treatment and care for patients with sarcoma. It does this through:
  - Funding scientific and medical research into causes and treatments;
  - Delivering a range of support and information services covering all aspects of sarcoma;
  - Raising awareness of sarcoma amongst the public, healthcare professionals and policy makers;
  - Campaigning on behalf of sarcoma patients for improved treatment and care
- Sarcoma UK relies on voluntary donations and fundraising activities to fund its work
- Sarcoma UK is staffed by a small team, managed by a board of trustees (many with personal experience of sarcoma) and supported by experts in the sarcoma field
- Sarcoma UK works collaboratively with doctors, nurses, researchers and other cancer charities

Impact

Research
- Sarcoma UK has funded over £255,000 of scientific and medical research over 3 years. Grants were awarded to four leading scientists in centres of excellence around the UK

Support
- Sarcoma UK runs three email support groups - for patients, carers and patients with gynaecological sarcomas. Subscribers chat to each other by email and gain valuable support from other patients in the same situation. In a recent survey of subscribers, respondents overwhelmingly found the postings on the site informative
- Sarcoma UK provides supports to 10 local sarcoma groups around the UK, and helps new groups to get set up
- Sarcoma UK has an active Facebook and Twitter page where sarcoma patients, family members and carers are able to communicate with each other in a social online environment – join us today!

Information
- Sarcoma UK’s patient information is rated highly amongst patients and healthcare professionals. Almost 50,000 leaflets about sarcoma are sent out to individuals and hospitals each year

Awareness
- Connect (Sarcoma UK’s publication) is sent out three times a year and distributed to a database of 5000

Campaigning
- Sarcoma UK is an active member of Cancer S2 (the alliance of charities representing less common cancers) and the Cancer Campaigning Group (the alliance of cancer charities representing ‘third sector’ interests in the delivery of cancer services)

What is sarcoma?

Sarcomas are rare cancers that develop in the supporting or connective tissues of the body such as muscle, bone, nerves, cartilage, blood vessels and fat.

There are around 3,200 new cases of sarcoma diagnosed each year in the UK.

Sarcomas are some of the commonest childhood cancers.

Most sarcomas (about 55%) affect the limbs, most frequently the leg. About 15% affect the head and neck area or are found externally on the trunk, while the remainder will be found internally in the retroperitoneum (abdominal area).

Types of sarcoma

Sarcomas fall into three broad categories:
- Soft tissue cancers
- Primary bone cancers
- Gastro-intestinal stromal tumours (a type of soft tissue sarcoma found in the stomach and intestines commonly known as GIST)

There are around 70 different sub-types of sarcoma within the three broad categories. These sub-types are determined by the tissue of origin (the tissue in the body where the tumour originally formed), genetic characteristics or by other molecular analysis undertaken by expert pathologists.

The most common sub-types are:

- Soft Tissue
  - Fibrosarcoma
  - Myxofibrosarcoma
  - Desmoid tumour
  - Liposarcoma
  - Gastrointestinal stromal tumour (GIST)
  - Synovial sarcoma
  - Rhabdomyosarcoma
  - Leiomyosarcoma
  - Malignant peripheral nerve sheath tumour (MPNST)
  - Angiosarcoma
  - Kaposi’s sarcoma (KS)

- Bone
  - Chondrosarcoma
  - Chordoma
  - Osteosarcoma
  - Ewing’s sarcoma
  - Giant cell tumour (GCT)
Size matters

A new sarcoma awareness campaign targets GPs with golf balls!

It is well established that one of the key factors that influences whether a soft tissue sarcoma can be successfully treated is the size of the tumour at diagnosis. The larger the tumour the more difficult it is to treat with the aim of getting a cure. Early diagnosis of sarcoma is therefore vital and a big part of identification falls on GPs to suspect a lump or bump and make the correct referral to a specialist sarcoma diagnostic centre. At the moment, sarcoma patients report at least three visits to their doctor before getting referred for further investigations, and even then, many patients are not referred to a sarcoma specialist centre.

Mr Rob Grimer, one of the country’s leading sarcoma surgeons at the Royal Orthopaedic Hospital in Birmingham, has long been campaigning to improve awareness and early diagnosis of sarcoma by using the concept of a golf ball as a trigger for patients and GPs to seek referrals. He approached Sarcoma UK and the Pan Birmingham Cancer Network with an idea for an innovative project to test out his theory.

The project bears the motto Any Lump Bigger than a Golf Ball should have a Diagnosis. The visually striking awareness campaign is being piloted in the West Midlands by the Royal Orthopaedic Hospital, Sarcoma UK, and the Pan Birmingham Cancer Network.

Launching in Sarcoma Awareness Week in June, the project involves sending a golf ball inscribed with the words ‘Is it sarcoma?’ to over 600 GPs in the Birmingham area, accompanied by a poster of key sarcoma facts and details of how to refer to the Royal Orthopaedic Hospital’s Specialist Sarcoma Centre. Over the next 12 months, Mr Grimer’s team will monitor referrals and the size of lumps at diagnosis to see if there is a reduction in size.

The campaign has a simple message and one we hope will be effective in getting over the idea that any lump or bump should be treated as suspicious and referred to a specialist sarcoma unit for proper diagnosis. We will consider this pilot project a success if the average size of sarcoma referred to us from GPs who have been sent the golf ball, is smaller than in the six months before the study.

The project has attracted support from the professional golf world. The Professional Golfers’ Association (PGA) said: “We are very happy that Sarcoma UK is working in conjunction with the Royal Orthopaedic Hospital in Birmingham and the Pan Birmingham Cancer Network to use a golf ball to remind GPs about the importance of early detection of this form of cancer. Anything that helps to alert attention to the early diagnosis of this terrible illness can only be a good thing and the PGA therefore fully supports Sarcoma UK in this project. Whilst many, if not most people who play golf, often wish that the little white ball they are trying to hit could be a bit bigger, it is certainly not the case when it comes to a lump on or inside our bodies. A lump the size of a golf ball is naturally very worrying. The PGA therefore hopes that this project is a resounding success and is very interested in its findings and future outcome.”

Andrew Cotter
BBC sports commentator

Key fact

- Analysis of data collected over 25 years at the Royal Orthopaedic Hospital has shown that the average size of soft tissue sarcomas at diagnosis is 96mm, a decrease of only 7mm over the last decade.
Two months until Sarcoma Awareness Week ...

and we need your help!

We aim to create a visual montage of anybody touched by sarcoma - patients, carers, friends, family, healthcare professionals – get involved! Log on to www.sarcoma.org.uk and upload your photo today!

We know that sarcoma does not discriminate and that 3,200 new cases are diagnosed every year in the UK. By uploading your photo you will help us to shout louder about sarcoma and raise even more awareness.

It’s so simple!

How to get involved

Log on:
to www.sarcoma.org.uk

Upload:
a portrait photo onto our website

Write:
a short blurb about yourself

Promote:
our link to friends and family, Facebook and Twitter

Donate:
Online: www.justgiving.com/SAW2012
Text message: SAWE12 £10 To: 70070

No computer access?
Don’t worry, send a photo to us in the post along with your name, age, address and phone number to the address below and we will put it up on our website for you.

Please note we cannot return your photo, so please send us in a copy.

Post to:
SAW
Sarcoma UK
49-51 East Road
London N1 6AH
Organise a fundraiser

Get your friends and family together, hold a karaoke night with your neighbours, put on a picnic with your local support group or hold a coffee morning at your work. Ask those who come along for a donation in support of Sarcoma UK.

We can provide you with t-shirts and a fundraising pack to help you along your way. Here is a list of ideas to help you get started!

**Fundraising is only limited to your imagination!**

Raising £10 from cleaning out your copper jar, £100 from selling your homemade cakes or £1000 from taking part in a challenge; they all add up to fund life-changing research into sarcoma.

- **Afternoon tea**
  - One lump or two? Invite your friends round for a catch up, cake and a cuppa!

- **Battle of the bands**
  - Source a venue and ask local unsigned bands to sing for sarcoma.
  - Charge for tickets and make a night of it.

- **Come Dine with Me**
  - Create your very own culinary experience. As host, you decide on the total bill!

- **Fancy dress**
  - Dress up or sponsor someone to wear fancy dress to school/work for the day.

- **Hair today, gone tomorrow!**
  - Raise sponsorship to shave your hair off – it will grow back!

- **Internet auction**
  - Use eBay to sell your unwanted goods.
  - Use the site to donate money to us.

- **Jelly bean jar**
  - Fill up jars with sweets and ask for donations in return for a guess.

- **Karaoke night**
  - The Golden Oldies really are the best!

- **Ladies night in**
  - Get the girls round for a chick flick and pamper night. Donate the amount you would usually spend on a night out.

- **Lose pounds, gain pounds**
  - Get sponsored to lose weight and raise money!

- **Movie night**
  - Invite friends round to watch a film.
  - Charge them for sofa space and snacks.

- **Quiz night**
  - Gather some teams and host your own quiz evening.

- **Races**
  - Why not give your race a theme, such as sack, pancake or egg and spoon?

- **Skydive**
  - Take to the skies for sarcoma!

- **Sporting events**
  - Running, swimming, cycling, canoeing, rafting...
  - Get in touch!

- **Sweepstakes**
  - Organise a sweepstake on this season’s teams (football, horse racing, tennis, rugby). Everyone can get involved!

- **Tournaments**
  - Have teams compete in different activities, from football to Twister and Scrabble.

- **Wax on, wax off!**
  - Separate the men from the boys! A sponsored leg & chest wax – ouch!

- **Wii night**
  - Hold a sponsored computer games marathon in your living room or sports hall.

- **In fact... sponsored anything!**
  - Sponsored swim, silence, walk, slim or climb.
  - The list is endless...

**Sarcoma UK**

The bone & soft tissue cancer charity

49 - St East Road, London N1 6AH • info@sarcoma.org.uk

www.sarcoma.org.uk

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If skydiving is your thing, help us raise funds by making an exhilarating 10,000 feet freefall parachute jump during Sarcoma Awareness Week.

Sign up today by emailing [skydive@sarcoma.org.uk](mailto:skydive@sarcoma.org.uk) and we will send you more information.
Thanks, thanks, thanks!

We rely solely on voluntary donations and are so grateful for all your fundraising efforts. Hear first-hand from some of our recent fundraisers ...

**Brick by Brick**
I am 27, from Chesterfield and I work at Chesterfield College as a lecturer in construction. I was diagnosed with sarcoma in April. Six months later in October, they said I would have until the New Year to live. So to be writing this is amazing.

I held many events in December to raise money for Sarcoma UK. We held a raffle and an auction and raised £6,200. Further to this, we raised more money at Chesterfield College and now have a total of £11,500.

We raised money through fancy dress, sponge and stocks, a giant swing and a bricklaying competition, to mention a few.

We had a cheque presentation where I had the pleasure of meeting Peter Jay, Sarcoma UK’s Chairman. The money will help towards the research that is needed and to help and support families affected by sarcoma.

**Mark Lievesley**

**Going for Gold**
Six performances, over 350 dancers and approximately 800 costumes were used over the course of five days at the Hexagon Theatre, Bristol from 14-18 March.

Venus School of Dance held it’s bi-annual show Going For Gold and was inspired by the Olympics to be held in London later this year.

Each performance was dedicated to a different charity and so this year, six charities benefitted. Sarcoma UK was chosen in support of a parent, Clare who suffers from leiomyosarcoma.

Clare said: “I was very pleased and overwhelmed when I went to watch my daughter dance in her show. I recently went to a Sarcoma UK meeting which is run by two of our wonderful nurses. I was shocked at how little money is available to research our illness. I am pleased that with my friends we are able to raise some money to put back what I have taken.”.

**Kathryn Millchamp**

**Endurance 9**
I like a challenge. I always have. In years gone by I have run marathons and ultra marathons in the hope of beating a previous time or simply for the challenge of the event.

This year, something else has challenged me – to support a close friend, Jo Bryant. Twelve months ago she was diagnosed with a cardiac sarcoma. In February she was given 6-12 months to live. She is 29.

Jo is an extremely positive person and has set out to prove the doctors wrong. Through completing a number of endurance events, I hope to support her.

To date I have raised over £3,000 for Sarcoma UK and the sponsorship keeps coming in!

**Nick Chouksey**

**Nick’s nine events**
- Brighton Half-Marathon: 19 Feb (1hr 29mins 50secs)
- Cambridge Boundary Run Marathon: 4 March (3hr 35mins 17 secs)
- Manchester Marathon - April
- London to Brighton night ride - May
- Warrior Dash - June
- Mont Blanc Half Marathon - June
- London Duathlon - September
- Men’s Health Survival of the Fittest - October
- Tough Mudder - November
When my husband Malcolm retired in March 2010, we celebrated by going on a fabulous cruise to the Caribbean. I knew I had a bowel problem and I was finding it difficult to breathe through my left nostril, but I didn’t let this put me off. When we returned, I saw a bowel doctor and a colonoscopy and biopsy confirmed that the tumour was cancerous. I had the operation in June 2010 and thankfully the cancer was contained and I, therefore, did not have any further treatment.

I knew I still had something wrong with my nose, but I couldn’t deal with both problems at once. When I did go back to see my GP, who had originally prescribed me a nasal spray believing the problem to be a polyp, he eventually referred me to the ENT department at our local hospital. I was getting awful nose bleeds that would start without any warning and would go on for two or three hours. I went into A&E on numerous occasions and had my nose plugged and cauterised. It was just terrible, I felt insecure about going out on my own.

The hospital discovered the tumour, which lay between the roof of my mouth and my left nostril, and sent a biopsy to two further hospitals for diagnosis. In January 2011 I was diagnosed with an angiosarcoma, a very rare cancer of the blood vessels. I was told that the cancer was life threatening with a poor prognosis, and that if I did not have an operation to remove it I would bleed to death. I had no choice.

The operation was to be done at Guy’s Hospital, by Mr Richard Oakley. From the middle of January I would travel to London to see him every Friday and each week he would reveal a bit more detail about the horrific surgery. When I was told that it was a very disfiguring operation and I would lose my nose, my upper lip and most of my teeth I was with my husband and daughter, and we all cried.

In February 2011, I underwent the 16 hour operation to have the tumour removed. The tissue for my face and palate together with the veins and arteries, were taken from my right thigh. It took Mr Oakley 12 hours to remove the tumour and 50 lymph nodes from my face, then the plastic surgery team reconstructed my face and palate as best they could, which took a further four hours.

When I was able to get up out of bed, I would brush my teeth in the ensuite bathroom. One day I looked in the mirror and, although Mr Oakley had warned me, I was shocked. But I have got used to it now. My close friends say they see me how I am, and I have got used to it now. I was shocked. But I have got used to it now. My close friends say they see me how I am, and I have got used to it now.

My thigh did not heal as quickly or as well as expected so I underwent three more operations to have the wound reopened and drained. The healing of my scar was imperative because it was delaying the commencement of chemotherapy. In June 2011 at UCLH I started chemotherapy, but was only able to take nine of the 18 recommended doses, as I developed oedema.

After a short holiday I commenced six weeks of radiotherapy in September involving 20 minutes of radiation for five days a week. The treatment was gruelling and it left me with a badly ulcerated mouth and tongue, so I was unable to eat and barely able to drink. The pain in my mouth was awful. Every day brought more treatment, more ulcers and more pain but with the help, support and prayers of my husband, family and friends my days were made bearable. I have four children, three sons and a daughter, and seven grandchildren and they visited an awful lot. We are Christians and have been members of the Mormon faith for 45 years, and I have relied on God so much over the past two years. I also have friends I have known, inside and outside the church, for 40, even 50 years. To know that I am loved brings strength in itself.

It has been a long journey to get this far with many ups and downs and I have often felt isolated and alone. Sarcomas are very rare so one does not meet many people who know what they are. I wanted to do something to raise money for Sarcoma UK to help them with their research funding programme and to promote awareness of this charity. I organised a charity musical concert, with the help of my friends as I love music and singing. The concert was a great success and we raised over £2,200. I’ve also been on ITV’s This Morning to promote awareness of sarcoma.

I do not know what the future holds for me. The doctors have just found angiosarcoma in my jaw and chin and I am awaiting further radiotherapy. Nevertheless, I live each day to the full and enjoy everything that I do. Every day I wake and feel grateful to be alive.

Patricia Searle tells us her experience of angiosarcoma, including appearing on This Morning to raise awareness

My journey with angiosarcoma

www.sarcoma.org.uk

“I looked in the mirror and I was shocked. But I have got used to it now. Close friends say they see me how I used to be.”

Malcolm and Pat Searle on This Morning’s settee with Eamonn Holmes and Ruth Langsford

Personal experience
In 2007 a few sarcoma patients from Dorset and Hampshire met each other at a national Sarcoma UK event. It was so good to be able to talk to each other and we shared so many things in common. Most of us had had delayed diagnoses, felt isolated, were being treated at distant centres, had lacked psychosocial support and wanted to learn more about sarcoma.

We wanted to set up a support group to help ourselves and to try and find other patients and carers who we felt were out there and feeling isolated. The thought of setting up a group was, frankly overwhelming at times. Many of us were having to deal with whatever sarcoma continued to throw at us and it was not easy. You really do need proper help and information to get started and the partnerships we formed were vital. Two patients belonged to the Dorset Cancer Network (DCN) and the Central South Coast Cancer Network (CSCCN) and in 2008 approached the Networks Involvement Facilitators and Paula Bond, the Macmillan Community Networks Development Co-ordinator for help to set up a support group. Planning meetings followed and we discussed what we wanted from the group, how it would be structured, where it would be held and how often, and how we were to fund the group.

Paula explained that we needed to have a constitution before we could apply for any funding from Macmillan. Once that hurdle was achieved, a start up grant from Macmillan enabled the group to create and have published leaflets advertising the group. The leaflets were sent to hospitals in both networks and also tertiary centres as one of the challenges was to reach out to find sarcoma patients to inform them about the group. This is an ongoing process and Sarcoma UK have kindly funded reprints of updated leaflets. Since 2009, with the appointment of a part-time Sarcoma clinical nurse specialist (CNS) Louise Sharif at Southampton, Louise has been able to signpost patients to the group, which has helped.

A development grant from Macmillan has enabled the purchase of a pull-up banner advertising the group which has been used in the out-patients clinic in Southampton and a Survivorship conference in Bournemouth.

The group members have participated in focus groups to devise a Sarcoma Patients Experience Survey which has been used in Southampton.

The group is made up of patients and carers and is growing slowly. Not every person can come to every group; many patients have had recurrences and needed further treatments and, sadly, three patients have died.

Many thanks to Macmillan, Wessex Cancer Trust, DCN, CSCCN and Sarcoma UK for support, advice and funding. We could not have done it without you.

“Most of us had had delayed diagnoses, felt isolated, were being treated at distant centres, had lacked psychosocial support and wanted to learn more about sarcoma.”
Join the sarcoma community!

Scotland - Glasgow
Meets: Third Wednesday of every month, 2:30 – 4pm
Venue: Maggie’s Centre, The Gatehouse, Western Infirmary, 10 Dumbarton Road, Glasgow G11 6PA
Gillian Hailstones, Maggie’s Centre - 0141 330 3311

Newcastle and Tyneside
Meets: First Monday of every month, 7 – 10pm
Venue: Education centre, Freeman’s Hospital
Cuth Earl, Group secretary - 0191 520 1824

Manchester
Meets: Last Tuesday of May, Sept and Nov, from 5pm
Venue: Manchester Royal Infirmary, Seminar Room 1 (adjacent to Ward 1)
Helen Murray, Clinical Specialist Sarcoma Nurse (MRI) - 0161 276 6187
(Pager 07659 596823)
Maxine Cumbo, Specialist Sarcoma Physiotherapist (MRI) - 0161 276 6845
Lena Richards, Specialist Sarcoma Physiotherapist (Christie) - 0161 446 3795 or 0161 446 3000 (Bleep 12539)

Sheffield (and surrounding areas)
Meets: Second Friday of May, July, Sept and Nov, afternoon
Venue: Cancer Support Centre, 23 Northumberland Road, just behind Weston Park Hospital, Sheffield or Royal Hallamshire Hospital
W: www.sheffieldsarcomasupport.org.uk

East Midlands (and eastern counties)
Meets: Third Tuesday of every month, 5 – 7pm
Venue: Helen Webb House, 35 Westleigh Road, Leicester, LE3 0HH
E: emssg@live.co.uk

Merseyside and Cheshire
Meets: 3 - 4 times a year, 4-6pm
E: mcsarsup@gmail.com

Oxford (inc Thames Valley, south and parts of south west England)
Meets: First Thursday of every month, 2-4pm
Venue: Tebbit Centre, the Nuffield Orthopaedic Centre, Windmill Road, Oxford
Pip Large - 01865 737861; philippa.large@noc.nhs.uk
Helen Stradling - 01865 738282; helen.stradling@noc.nhs.uk
W: www.oxfordsarcoma.co.uk/2011/01/oxford-sarcoma-support-group-2011

Exeter
A new group is meeting at the FORCE cancer centre in Exeter; for more information contact Sarcoma UK 020 7250 8271

Bristol and South West England
Meets: Third Monday of every month, 4 – 6pm
W: www.bristolsarcomasupport.co.uk

South of England
Meets: 9 May, 11 July, 12 Sept, 14 Nov, 23 Oct – 4.30pm
Venue: Wessex Cancer Trust, Bellis House, 11 Westwood Road, Southampton SO17 1DL
Louise Sharif, Sarcoma Clinical Nurse Specialist - 07769 234598 and 02380 796752
E: louise.sharif@suht.swest.nhs.uk

Contact
vicki.smith@sarcoma.org.uk for help with marketing materials like leaflets and banners for your area.

Always check with your local group direct before attending, in case details have changed.
This information is provided by the individual support groups, and is the latest we have received from the groups.
If you don’t have a local support group, and would like to set one up, get in touch - call 020 7250 8271 or email info@sarcoma.org.uk
Support

‘Live Life to the Full’

Scat’s campaign looks forward to helping future Paralympians

The bone cancer trust Scat (Skeletal Cancer Action Trust) is dedicated to the advancement of bone cancer research, to providing the best possible care and support at each stage of treatment, and to improving the quality and dignity of life for all patients. Research and practical support play key roles in the advancement of diagnosis, treatment and care.

In the last year Scat has provided £300,000 to progress advanced research on bone tumours. In March the charity contributed to the discovery of the abnormality which causes the majority of cartilage tumours (chondrosarcomas) and a new drug therapy is already being developed.

Surgeons at Royal National Orthopaedic Hospital and University College Hospital work with a dedicated team of oncologists and other specialists to provide a special package of care for each patient. Unfortunately certain tumours may require amputation of a whole or part of a limb. Approximately 30 to 40 children have amputations each year as a result of bone cancer.

Scat’s Live Life to the Full campaign offers support to those who have suffered an amputation as a result of bone cancer, so that they achieve maximum mobility post treatment. Funding ranges from the provision of the best technology available in the manufacture of artificial limbs to maximum mobility post treatment.

In 2011 Scat assisted with two special wheelchairs. One of these was for Edward Holt, 19, a Lloyds TSB Local Hero who had a below-knee amputation due to osteosarcoma in 2009 at the age of 17. Edward had been playing tennis since the age of eight and his ambition now is to compete in the 2016 Paralympics in Brazil. In May 2010 Edward was picked out for wheelchair tennis at the Bath Paralympics Talent Day and he has not looked back. Following extensive chemotherapy and two further operations, Edward is now at Leeds Metropolitan University studying Sports Performance and training hard with a serious tournament plan for this year.

Scat funded a special day chair, which facilitates Edward’s mobility when he’s not playing tennis. Edward now uses this chair for his studies at university and also when he goes to his wheelchair tennis tournaments as his stump swells after a game and it becomes very difficult for him to put on his prosthetic limb.

Edward said: “I have found myself in a parallel world that I didn’t know existed. Nonetheless I’m willing to make the most of it. Losing my leg and playing wheelchair tennis has enabled me to meet a variety of people and inspired me even more to make the 2016 Paralympics.”

Edward in his new day chair

Research funding is only possible because of you, our committed supporters of Sarcoma UK’s research who have raised the money to fund the projects. The Research Advisory Committee (RAC) was very aware of supporters’ contributions and were committed to ensuring that the projects to be funded were of the highest quality and that each has the potential to advance scientific knowledge of sarcoma, to the real benefit of sarcoma patients. The most important criteria for selection was the quality of the proposal. We focus here on the four new projects that Sarcoma UK will be funding:

1. Genomic and expression profiling of recurrent well differentiated and de-differentiated liposarcomas
   Dr Janet Shipley, Team Leader and Dr Anastasia Constantinidou, Clinical Research Fellow from the Institute of Cancer Research, Sutton. Sarcoma UK is providing £25,000 to this project over two years for consumables.

   Consumables are the ‘basics’ of science, just like the ingredients in a kitchen cupboard, or the pots and pans in your family home. Give them to Jamie Oliver and great things happen! Give the same things to someone else and… well… you might have to order a takeway. For Janet’s project, Sarcoma UK is funding her excellent idea by paying for the tools needed for her research. Consumables are vital kit for the end result of top quality science but can be mundane in themselves, such as disposable pipettes for handling fluids or plastic tubes that fit in centrifuges.

   Janet’s project is in liposarcoma. Liposarcomas are a type of soft tissue sarcoma that arises in fat cells. Well-differentiated (WD) liposarcomas have clear cell walls and a regular appearance under the microscope. De-differentiated (DD) liposarcomas are much messier and irregular. Both are the most frequent subtype of liposarcomas in adults. Well-differentiated liposarcomas can recur looking more like the DD type, which is associated with increased aggressiveness. In contrast,
Research grants for 2012

In the last edition of Connect, we reported on what happens next for the charity’s research programme. Following the call for proposals in September 2011, Sarcoma UK’s Research Advisory Committee met in January to consider all the grant applications that were received.

If one day we can identify individuals at high risk of developing sarcomas, this could lead to earlier detection and more effective treatment. Sarcoma studies involving families have so far been limited to work in children, but the 90% of sarcomas that arise in adults have not been represented. The International Sarcoma Kindred Study (ISKS) has been set up to identify, validate and quantify genetic risk in patients with adult-onset sarcoma. This is an international initiative, with nine major international sarcoma centres in USA, Europe and Asia taking part, to ensure genetic diversity. This gives sarcoma patients and their families the opportunity to take part in, and potentially directly benefit from, this original study. The study will be of direct and immediate benefit to patients in the investigation and identification of their risk of developing further sarcomas or other cancers, and the associated risk to their family members. All participants will be offered full support and referral to counselling services.

Sarcoma UK is funding the UK arm of this study for two years.

3. Studies in angiosarcoma using canine tumours
Dr Robin Young from Sheffield University. Sarcoma UK is providing £17,500 to this project over one year.

In humans, angiosarcomas are rare, aggressive tumours of blood vessels. Angiogenesis is the process of new blood vessel formation and it is controlled by a number of different growth factors. The researchers think it is likely that these growth factors are important in the development of angiosarcoma and that treatments targeting these factors will be useful for patients with angiosarcoma. While human angiosarcoma is rare, the tumour is common in dogs and will be seen by vets in their surgeries, whereas the chance of your GP seeing a case of angiosarcoma is unlikely. This means that samples of tumour from dogs are available for study, potentially to the advantage of dogs and people. Doing this will promote better understanding of angiosarcoma in humans and in dogs. As angiogenesis is important in the growth of other sarcomas these studies will also be relevant to the treatment of other sarcoma subtypes. It is expected that results from these studies will lead to clinical trials in both humans and dogs.

4. Analysis of osteolysis in Ewing’s sarcoma and the effect of resorption inhibitors on tumour growth
Prof. Nick Athanasou, Prof. of Musculoskeletal Pathology from Oxford University. Sarcoma UK is providing £17,500 to this project over two years, for consumables.

Ewings sarcoma is a highly aggressive bone tumour that predominantly affects children, adolescents and young adults. It is a tumour that causes extensive bone destruction and can spread rapidly. The bone destruction in Ewing’s is caused by osteoclasts, specialised bone cells which normally breakdown bone in balance with osteoblasts which build it up. This study aims to look more closely at the way Ewing’s cells promote osteoclast formation, which then knocks normal bone biology out of kilter, increasing bone destruction. This study may then open up a new avenue of additional treatment of Ewings and other bone sarcomas such as osteosarcoma. Sarcoma UK is funding the equipment needed for this study.

University of Sheffield
Sarcoma UK is also funding the final year of a three year PhD project at the University of Sheffield from a previous grant round. The project, Defects of DNA repair gene and cell cycle regulators as a predisposing cause of sarcomas is laboratory-based research looking for defects in the genes that make us what we are, and that in sarcomas become altered to not behave as they should. It is hoped in the later stages that the findings will translate into new treatments.

Facts and figures
- £100,000 was available for research funding
- 14 applications were received, totalling over £500,000
- Sarcoma UK is fully funding one grant, and part-funding three grants
- Sarcoma UK will be running a new call for proposals in September 2012, for further research funding in 2013
- Since 2009, Sarcoma UK has awarded over £355,000 of scientific research grants. (For more information see the website.)

Future editions of Connect will carry a more in-depth focus on each new grant awarded.

Do you have any questions you would like answered about how sarcoma research works? Email them to research@sarcoma.org.uk or send by post to Sarcoma UK, Research Questions, 49-51 East Road, London N1 6AH and we will answer them in the next edition of Connect.
Clinical trials in sarcoma

If you feel that a clinical study might be of value you should talk to your doctors.
Most of the trials below are multicentre studies.
See our website for more information: [http://sarcoma.org.uk/Looking-for-research-to-join](http://sarcoma.org.uk/Looking-for-research-to-join)

<table>
<thead>
<tr>
<th>Trial Name</th>
<th>Description</th>
<th>Status</th>
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<tbody>
<tr>
<td><strong>ADULT SOFT TISSUE SARCOMA</strong></td>
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<tr>
<td>VORTEX</td>
<td>Phase III randomised trial – volume of post-operative radiotherapy in adult extremity soft tissue sarcoma.</td>
<td>Open</td>
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<tr>
<td>VORTEX BIOBANK</td>
<td>Prospective sample collection for the VORTEX randomised radiotherapy trial.</td>
<td>Open</td>
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<tr>
<td>TRUSTS</td>
<td>A Phase III study of the safety and effectiveness of trabectedin versus doxorubicin-based chemotherapy in first line for patients with untreated metastatic or advanced sarcoma.</td>
<td>Open</td>
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<tr>
<td>Axi-STS</td>
<td>Axitinib in patients with advanced angiosarcoma and other soft tissue sarcomas: a phase II open-label parallel-group (non-randomised) study.</td>
<td>Open</td>
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<tr>
<td>CASPS</td>
<td>Phase II study of cediranib (AZD2171) in the treatment of patients with alveolar soft part sarcoma.</td>
<td>Open</td>
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<tr>
<td>PICASSO</td>
<td>A study to evaluate the clinical benefit of palifosfamide tris administered with doxorubicin in combination, compared with single-agent doxorubicin for patients with unresectable or metastatic soft-tissue sarcoma.</td>
<td>Open</td>
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<tr>
<td>Eribulin 3rd Line</td>
<td>A randomised open label Phase III study to compare efficacy of eribulin versus dacarbazine in third line for patients with advanced soft tissue sarcoma.</td>
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<tr>
<td><strong>ADULTS AND YOUNG PEOPLE SOFT TISSUE SARCOMAS</strong></td>
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<tr>
<td>GeDDIS</td>
<td>Phase III randomised – gemcitabine+docetaxel compared with doxorubicin as first line treatment in previously untreated locally advanced, unresectable or metastatic soft tissue sarcoma. Eligibility age 13 +.</td>
<td>Open</td>
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<tr>
<td>VIT</td>
<td>Phase II randomised study of vincristine and irinotecan plus/minus temozolomide in advanced rhabdomyosarcoma patients aged &lt;50 years.</td>
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<tr>
<td><strong>PAEDIATRIC SOFT TISSUE SARCOMAS</strong></td>
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<tr>
<td>EpSSG RMS 2005</td>
<td>Treatment of children and young people presenting with non-metastatic rhabdomyosarcoma.</td>
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<tr>
<td>EpSSG non-Rhabdo</td>
<td>Treatment of children with non-rhabdomyosarcoma soft tissue sarcomas. Open to adults aged up to 21.</td>
<td>Open</td>
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<tr>
<td>BERNIE</td>
<td>A study of avastin (bevacizumab) in combination with standard chemotherapy in children and adolescents with metastatic rhabdomyosarcoma or non-rhabdomyosarcoma soft tissue sarcoma. Randomised Phase II design.</td>
<td>Open</td>
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<tr>
<td><strong>GIST</strong></td>
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<tr>
<td>NILOTINIB IN GIST</td>
<td>A randomized, open-label, multi-centre phase III study to evaluate the efficacy and safety of nilotinib versus imatinib in adult patients with unresectable or metastatic gastrointestinal stromal tumors (GIST).</td>
<td>Closed</td>
</tr>
<tr>
<td><strong>PRIMARY BONE SARCOMAS</strong></td>
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<tr>
<td>EURO-EWING</td>
<td>Multi-modal therapies treating patients with Ewing’s sarcoma.</td>
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</tr>
<tr>
<td>EURAMOS 1</td>
<td>Phase III – strategies for resectable osteosarcoma based on response to pre-operative chemotherapy.</td>
<td>Closed</td>
</tr>
<tr>
<td>OTIS</td>
<td>A Phase II Study to determine the efficacy and safety of conventional dose oral treosulfan In patients with advanced pre-treated Ewing’s Sarcoma.</td>
<td>Open</td>
</tr>
<tr>
<td>Denosumab GCT</td>
<td>Safety study of denosumab in patients with recurrent or unresectable giant cell tumor of bone.</td>
<td>Open</td>
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</tbody>
</table>
News round-up

The latest sarcoma-related news from around the country

**British Sarcoma Group conference 2012**

The annual British Sarcoma Group (BSG) conference took place in Oxfordshire from 29 February – 2 March 2012. It is the main educational and networking event for all UK healthcare professionals treating patients with sarcoma, and was attended by almost 200 delegates. This eighth meeting started with workshop sessions on topics such as ‘What can be learnt from veterinary medicine?’, pathology, clinical trials, oncology, and a special session for nurses and allied healthcare professionals.

The first ever BSG public session was held for patients and their families. An inspirational lecture by Peter Kapitein, a cancer patient from Inspire 2 Live in the Netherlands, was followed by a Q&A session with a panel of experts and patients and an interactive voting system. Sarcoma UK was represented at the conference and it was a great opportunity for us to display our new information and awareness materials.

**Sarcoma UK launches new Personal Guide to Sarcoma folder**

At the BSG conference in 2011, a workshop session led by Sarcoma UK identified the need for improved information for sarcoma patients. The workshop, attended by patients, support group representatives, healthcare professionals and researchers, recommended that a personalised folder for sarcoma patients was developed. The folder would be tailored to the information needs of the individual patient, utilising nationally and locally produced sarcoma information, as well as enabling healthcare professionals to include details of local sarcoma health services. During the following nine months, the folder was designed and input obtained from patients, members of Sarcoma UK’s Information Review Panel, and sarcoma specialist nurses, clinicians and allied healthcare professionals. The Guide was launched at the BSG conference in March 2012 and has been received with great enthusiasm by healthcare professionals and patients. The folder can be ordered for free in bulk by healthcare professionals via our website (www.sarcoma.org.uk) or by emailing info@sarcoma.org.uk. Information sent out direct to individual patients by Sarcoma UK will also be in the new folder.

**Cancer Campaigning Group**

One of Sarcoma UK’s objectives is to raise awareness of sarcoma amongst policy and decision makers, to ensure that the needs of sarcoma patients are represented nationally. As a small charity, it is difficult to do this on our own. Instead, we work collaboratively with some of the larger cancer charities such as Macmillan Cancer Support, as well as part of alliances like the Cancer Campaigning Group (CCG) and Cancer 52. Below is a brief focus on two key issues that Sarcoma UK has been involved in supporting recently through membership of the CCG.

**New study from coalition of leading cancer charities supports the critical role of cancer networks in improving patients’ care**

Developing Excellence in Cancer Networks a new report from the CCG, calls for the NHS Commissioning Board to establish cancer networks as Strategic Clinical Networks. The report also recommends a series of quality markers for what cancer networks can achieve when the networks are working at their very best.

The CCG hopes that this will be a useful contribution to the reformed NHS.

**Support and information**

The latest sarcoma-related news from around the country

“Cancer networks are crucial to ensuring integration into the reformed NHS.”
ongoing Department of Health work considering the role and responsibilities of clinical networks in the future.

Commenting on the report, Lindsey Bennister, Chief Executive of Sarcoma UK and member of the CCG, said: “Sarcoma UK fully supports the recommendations of this report. Cancer networks are crucial to ensuring integration into the reformed NHS, and this report sets out the critical role of cancer networks in improving patients’ care.”

Welfare Reform Campaign
The proposed new Welfare Reform Bill contained measures to reform the Employment and Support Allowance (ESA) which could impact on cancer patients’ ability to claim welfare benefits. However, following extensive and co-ordinated lobbying by cancer charities, large and small, during a debate in the House of Lords on 14 February, the Work and Pensions Minister, Lord Freud, announced some important concessions that should protect many cancer patients from the full impact of the government’s proposed reforms of ESA.

Votrient: new treatment for sarcoma
New treatments for advanced sarcoma have been few and far between. In recent years trabectedin (Yondelis) has been the only addition to the range of treatments available. Last year we had the news that a new drug, pazopanib (Votrient), had seen positive results in a large-scale clinical trial treating some advanced sarcomas and that GSK, the manufacturer, was seeking regulatory approval. The regulators processes in the USA and Europe move slowly, so the news that the US Oncologic Drugs Advisory Committee (ODAC) has given a positive recommendation to pazopanib was welcome. The ODAC recommendation goes to the Federal Drugs Administration (FDA) and although full regulatory approval is not automatic, it is a promising sign. In Europe, the European Medicines Agency (EMA) is expected to make a decision within the next few weeks. At the same meeting of ODAC the drug ridaforolimus, trialled for maintenance therapy in sarcomas in the SUCCEED trial, was not recommended.

Sarcoma UK joins the Olympic Torch Relay
We are delighted to announce that Pippa Hatch, 17, and Jordan Anderton, 19, are bearing the Olympic torch for sarcoma after being selected as London 2012 Torchbearers.

Two years ago, Pippa was diagnosed with Paediatric Wild-type GIST and has raised over £16,000 for Sarcoma UK. We are very grateful to Pippa and for the long-term support of her family and friends.

Pippa said: “I’m grabbing life by the horns and living it to the full! I am currently half way through a nine month Executive PA Diploma course in Oxford and am loving being a normal 17 year old, albeit dealing with the uncertainties that go with living with a rare form of cancer.”

Four years ago, Jordan was diagnosed with myxoid liposarcoma and used our support services to get a bit more information and understanding about sarcoma, which helped him feel more confident and less isolated.

Jordan said: “I am now in my first year studying International Hospitality and Events Management at Cardiff Metropolitan University. I have been given the greatest opportunity to carry the Olympic Torch.”

Bone and soft tissue sarcomas
Sarcomas are an exceptionally rare form of cancer which can arise in either bone or connective tissue. Connective tissue includes fat, muscle, cartilage and nerves. There are over 100 different types of sarcoma.

Soft tissue sarcoma
The most common types of soft tissue sarcomas are leiomyosarcoma (which originates from the smooth muscles), liposarcoma (which originates from fat tissues), fibrous sarcomas (which arise within fibrous tissue) and dermatofibrosarcoma (which originates from the fibrous tissue within the skin). Kaposi’s sarcoma arises within the blood vessels and is associated with HIV infection.

Bone sarcoma
Bone sarcomas can arise within any bone of the human body. The most common types are osteosarcoma (bone), chondrosarcoma (cartilage), chordoma (notochord) and Ewing’s sarcoma (which can arise in both bone and soft tissue).
Statistically speaking

The collection of sarcoma data and statistics is still in its infancy, but knowledge is growing all the time due largely to the work of the West Midlands Cancer Intelligence Unit (WMCIU), the cancer registry responsible for collecting national sarcoma information. In this article, Matthew Francis from WMCIU describes how sarcoma statistics are collected, and gives a summary of what the current sarcoma data tells us.

**Incidence statistics**

Primary bone sarcomas account for only 0.2% of all malignant tumours. Around 380 people were diagnosed with bone sarcomas annually in England between 1985 and 2009. Bone sarcomas affect males more than females, with a male/female ratio of 1.3:1.0. In 2009, 437 patients (261 males, 176 females) were diagnosed with bone sarcomas. More than a third (34%) of bone sarcomas occur in the long bones of the lower limb.

Soft tissue sarcomas are more common than bone sarcomas, but still only account for 1% of all malignant tumours. Around 2,800 people were diagnosed with soft tissue sarcoma in England in 2009. There are no significant differences in incidence rates between males and females. More than 65% of cases occur in people aged 50 and over. Approximately 60% of soft tissue sarcomas are assigned to the local organs where they occur (gynaecological organs, skin, breast, stomach, peripheral nervous system). The remaining 40% are assigned to the general site ‘connective and soft tissue’, which is subdivided according to the location in the body (leg, arm, head & neck, pelvis, abdomen, thorax and trunk).

Unlike bone sarcoma incidence rates which remained fairly stable between 1985 and 2009 (Figure 1), soft tissue sarcoma incidence rates have risen significantly by 26% (Figure 2). However, it is uncertain if this is due to true increases in incidence, improved awareness and diagnosis, or better reporting and coding.

**GIST**

GIST (gastro intestinal stromal tumour) has only just started to be coded separately, with its own morphology code. Previously, GIST was coded as leiomyosarcoma or mesenchymoma. This makes it difficult to know the true incidence of GIST in the UK, and this will be the case for the next couple of years until accurate data have built up.

**Coding issues**

The general coding and classification systems used by cancer registries for all cancers mean that it can sometimes be difficult to obtain accurate information on the incidence of some rarer forms of sarcoma. For instance, if a patient is diagnosed with a bone sarcoma of the facial skeleton, this would be recorded by the registries as ‘malignant tumour of bones of skull and face’. In order to determine the number of bone sarcomas of the facial skeleton, the WMCIU examined locally held pathology data and operational information found in Hospital Episode Statistics (HES) for words indicating a tumour’s occurrence in facial bones, such as maxilla, nose or orbit. Extrapolating the results from the West Midlands to England as a whole, gives an average of 26 facial sarcomas each year over the 19 year period 1990-2008 (range 13 to 39). This equates to an incidence rate of 0.5 cases per million population.

**Further information**

- [www.wmpho.org.uk/wmciu/BSTS01.htm](http://www.wmpho.org.uk/wmciu/BSTS01.htm)
- [www.ncin.org.uk](http://www.ncin.org.uk)
- [http://info.cancerresearchuk.org/cancerstats/](http://info.cancerresearchuk.org/cancerstats/)
- or email Matthew at the WMCIU at matthew.francis@wmciu.nhs.uk

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**Figure 1: Bone sarcoma incidence rates (1985 – 2009)**

**Figure 2: Soft tissue sarcoma incidence rates (1985 – 2009)**

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**Matthew, I collect statistics for Sarcoma UK**
Donate

We rely solely on voluntary donations to fund vital sarcoma research, information and support

**Online:** www.sarcoma.org.uk

**By cheque:** Make payable to Sarcoma UK and post to us at 49-51 East Road, London, N1 6AH

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**Resources**

www.sarcoma.org.uk
Keep up to date on research, information and support.

**Pocket Guides**
Key facts about sarcoma.

**Personal Guides**
Keep all your information in one place.

**Fundraising materials**
T-shirts, running vests, fundraising ideas, leaflets, stickers, donation envelopes – we can send these out to you.

To order any of the above materials, email vicki.smith@sarcoma.org.uk

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**Sarcoma UK**

The bone & soft tissue cancer charity

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**Connect editorial and production team**

Editorial: Vicki Smith, Lindsey Bennister, Linda Gibson, Glyn Wilmshurst & Roger Wilson
Design: INQ Design Ltd 020 7737 5775

Chair of Trustees
Peter Jay

Chief Executive
Lindsey Bennister

Honorary President
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