

Sarcoma UK

Ninth Edition
Autumn/Winter 2007

Email:
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Inside:



Support meetings get warm reception



"YUM!!"



Trust receives its first "big" cheque

TEAM SARCOMA – SUNSHINE AMID THE SHOWERS

Raising spirits, funds and awareness in Torquay

On the weekend of the 13th-15th July, the first Team Sarcoma UK event was held in Torquay. Over 60 patients, carers and family members were involved in the event, which combined walks around the area with the opportunity for those affected by Sarcoma to meet and share their experiences.

After an introductory dinner on Friday night, the activities commenced on Saturday morning with a walk along the Agatha Christie Mile and the chance to explore Torquay. In the afternoon we walked as a group to Cockington Country Park for cream teas and a look at the various craft workshops.

We were lucky to have a beautiful afternoon, as well as a conveniently scheduled game of cricket on the lawns to add to the atmosphere of a summer's day. Unfortunately the



The whole party!

weather was not so kind for the main walk on Sunday, but it did not manage to deter anyone from taking part! 36 people set out for the full 8.5 mile walk from Brixham to Torquay, joined by a further 24 people mid-way at Goodrington, where we stopped for a photo call with the local press before the final stretch. There was a great team atmosphere, with even those who were not able to take part in the walk coming to cheer the walkers on. Somewhat exhausted, we gathered back at the hotel for a final dinner, and some fun with quizzes and presentations.

Team Sarcoma events took place around the world on the same weekend. The UK event was organised by Sarcoma UK and Brian Lewis, who lives in Torquay with his wife Debbie, a sarcoma patient. Brian was extremely pleased with how it went. "When we first started discussing the idea of an event I thought that if we had 10 or even 20 people attend, that would be a great first event, so to have around 60 people taking part in various parts of the weekend was fantastic. The real success for me was the first night. I was slightly anxious about how people would get along with others they'd never met before, but all these worries disappeared very quickly as people started arriving and chatting as if they had known each other for years."

The event raised over £4000 for The Sarcoma Trust through sponsorship and donations. More importantly, many patients were able meet and spend time talking about their experiences. This was the real success of the weekend for Debbie Lewis, "I enjoyed the fact that people were so friendly and very supportive of each other. The sharing of stories helped me to feel that I was not alone in what I have been through."



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The Bad Nauheim Declaration - setting standards for the NHS

More about The Sarcoma Trust

Sarcoma UK

Sarcoma UK is supported by unrestricted educational grants from Novartis Oncology and Pharmamar SA.

This newsletter is published free of charge to sarcoma patients, carers, friends and those who treat this group of rare cancers.

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If you would like to join our email support group please contact us at:
info@sarcoma-uk.org or go to
www.mailtalk.ac.uk/lists/sarcoma.html

We are keen to hear and publish patient stories. Stories we have printed already have proved an inspiration to other patients. Tell us about your sarcoma experiences.

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FIRST NEW TREATMENT FOR 25 YEARS

In July the European Medicines Evaluation Agency (EMA) gave a favourable opinion to Yondelis as a treatment for advanced metastatic sarcoma, the essential first step in the drug being licensed for use.

Yondelis (also known as trabectedin and formerly as ET-743) is derived from the toxin of a primitive Caribbean sea squirt, found in mangrove swamps. It is now synthesized. The research and development work has been undertaken by the Spanish biotechnology company Pharmamar.



It is anticipated that the European licence for Yondelis will be issued by

the end of September and the drug will become available in the UK and Germany shortly after that. The licence will permit its use for adult patients who have failed first-line chemotherapy for advanced or metastatic soft tissue sarcoma. In clinical trials extended periods of remission, or of disease stability, were recorded in significant proportions of patients.

The drug is administered intravenously over 24 hours. This can be done by a small pump so patients do not have to stay in hospital during

treatment. Treatments are repeated every three weeks. There is no build up of toxicity so, if appropriate, treatment can continue beyond the six cycles normally associated with chemotherapy.

There are side effects, notably nausea and fatigue, but one side effect common with chemotherapy is absent, there is no hair-loss. The prescribing guidance will indicate that an anti-emetic to help control nausea is given before Yondelis. Routine monitoring of patients during treatment is similar to that for other drugs. The liver function test was the most frequent cause of withdrawal from treatment during trials.

At the time of writing we do not know how costly the drug will be. It will not have approval from NICE for many months so every instance where a doctor wishes to prescribe it will be decided on by a Primary Care Trust.

Yondelis is the first new treatment to be licensed for advanced sarcoma since the 1980s. Although its use will be limited to a particular group of patients it is an important sign that advances in technology are leading to new therapies for sarcoma.

INTERNATIONAL TRIAL PLANNED FOR "TARGETED" DRUG

US biotechnology company Ariad Pharmaceuticals is to start a worldwide Phase 3 clinical trial of a new drug, deforolimus, targeted at soft tissue and bone sarcomas later this year. The trial is aimed at providing the necessary information to allow a marketing licence within the next five years.

Deforolimus is a novel small-molecule inhibitor of the protein mTOR, a "master switch" in cancer cells. Blocking mTOR starves cancer cells by interfering with cell growth and the creation of a blood supply to the tumour. Phase 1 and 2 trials have been successfully completed and the dosage and safety issues are understood.

The new trial aims to recruit 650 patients who have been successfully treated for metastatic sarcoma. They will be randomized to oral deforolimus or placebo. The trial is a "double-blind" trial which means that neither patients nor doctors will know which treatment is being received. Patients will be monitored for relapse and the investigators hope to see that deforolimus significantly cuts the relapse rate.

EUROPEAN COLLABORATION SET TO MOVE FORWARD

Conticanet, the partnership of European research centres which focus on sarcoma, is reaching out to the patient community and encouraging the development of plans for a pan-European patient advocacy alliance. However Sarcoma UK, Das Lebenshaus in Germany, GRAFS in the

southern region of France and newly formed Polish group Sarcoma, are the only European patient groups looking at providing specialist support to the whole spectrum of sarcoma patients. Together with a number of groups supporting patients with specific sarcomas (notably

GIST and Desmoid tumours) we are investigating how a collaboration might be structured and, providing funding can be made available, what kinds of services it might be able to provide to national groups.

TRUST REGISTERED

The Sarcoma Trust was registered as a charity in June (registration number 1119848). The Trustees are Peter Jay, Judith Robinson, Nicky Mellows, Dennis Tye and Roger Wilson. All are patients or carers of cancer patients.

The Trust's objectives are:

- a) to promote and protect the physical and mental health of patients with bone and soft tissue sarcomas in the United Kingdom through the provision of information, support, education and practical advice to them and their carers;
- b) the relief of sickness and the preservation of health in particular by promoting and supporting research with the publication of the useful results thereof and the development of more effective treatment and care for patients with bone and soft tissue sarcomas;
- c) to advance the education of the general public in all areas relating to sarcoma.

The Sarcoma Trust will work alongside Sarcoma UK, which is re-positioning itself more strongly to undertake the work of support to patients and their families, and to undertake advocacy on behalf of the patient community. The Trust will be the focus for donations, and its work will focus on research, and on raising awareness of sarcoma.

We are delighted that Professor Ian Judson, who leads the sarcoma team at the Royal Marsden Hospital in London, has agreed to chair a scientific/medical advisory panel for the Trust. Invitations for other panel members are being made with the aim of achieving a balanced cross-section of research and clinical skills.

The Trust's website is at: www.sarcomatrust.org.uk



NICE FACES THE RARER CANCERS FORUM

The Rarer Cancers Forum, of which Sarcoma UK is a member, has been working with the All Party Parliamentary Group (APPG) for cancer on issues of proper treatment by the NHS for less common cancers. The APPG is a cross-party group with members from both Houses of Parliament and is chaired by the Labour backbench MP, Dr Ian Gibson, himself once a cancer researcher.

At a 'summit' meeting held in July the key issues facing rare cancers were outlined and debated.

The patient viewpoint was clearly put by Linda Taylor (a sarcoma patient) and Gwen Harlow (an oesophageal cancer patient). Diagnostic delay, and even failure, is much more frequent with rare cancers, and access to new drugs is an ongoing problem. The criteria used by NICE for approval of new drugs present particular barriers. The evidence required and available for more common diseases often cannot be gathered for rarer ones. The implementation of Improving Outcomes Guidance is also variable and patients are disadvantaged when proper referrals in line with best practice do not happen.

Eric Low, Chief Executive of Myeloma UK, expanded on the drug access issue. Only two new treatments have appeared in 20 years for myeloma. The recent difficulty in getting velcade approved by NICE illustrated how the high price needed by a pharmaceutical company to cover

research and development costs for a drug which has few potential patients, can threaten patient welfare in a discriminatory way.

Professor Sir Michael Rawlins, the chair of NICE, responded well to the criticisms, both explicit and implied, of NICE and its processes. He accepted criticisms of lack of openness, saying that NICE appraisal processes will become public hearings during 2008. On the issue of the evidence limitations of trials of new drugs in rarer cancers, he called for a less 'myopic focus' on randomised controlled trials and for more innovative research studies, including case series and reports of clinical experience. He also acknowledged the weakness of the 'Quality Adjusted Life Year' (QALY) as a mechanism for guiding appraisal recommendations but added that it is the only tool available - "tool not rule" should be the NICE watchword.



One of NICE's ongoing problems is that it only has capacity for 30 to 40 Technology Appraisals each year. Prioritising what is appraised is also an imperfect exercise and ensuring that rare cancers are not discriminated against can probably best happen by taking decisions on priorities out of the hands of politicians.

TEAM SARCOMA CONTINUED...




The photo competition over the weekend was won by **Angela Carter**. Her photo of a Devon cream team came with the short, simple and very descriptive title "Yum".



Brian and Debbie's families - the local planning and backup team - **Roger, Brian, Debbie and Sheila Lewis, Hazel and Janine Clarke**



Peter Jay and Brian Lewis enjoy dinner.



Nicole Biddulph, disabled after surgery for a fibrosarcoma on her spine, completed the walk with her father **Allan**, flying the flag for younger patients.

View from the Front Line of Team Sarcoma

By Peter Jay

I just have to tell you about Torquay. The organisers, Brian and Debbie Lewis, together with our amazing Roger and his gorgeous daughter Flora (with background help from his wife Sheelagh) really pulled it off. For those who could not make Torquay can I just try to put some of it on here so that those who were unfortunate to miss it will, hopefully, pick up on some of the atmosphere of it all.

You need to remember that most people had never met each other before. Most people had been through (and many were either still going through or about to go through) the nightmare that is sarcoma. Within hours of arriving at the hotel we were all in a room for a buffet dinner seated at large round tables. Within no time at all it seemed we had all known each other for years - there was a warmth and friendliness that seemed totally out of place in a room full of enormous horror stories lurking in the background. We just bonded instantly and I lost count of the number of people who said to me "I can't believe this". We ate, drank and talked till late. The children that came were just perfect - all happy, well behaved and great fun to be with. The young, the old, black and white, gay and straight, patients and carers all reacted as if they were part of a very close family. I just cannot explain it any better. There were no awkward moments - but there were some emotional moments. You cannot escape those and I wouldn't want to anyway.

Saturday was organised for those who wanted to stay local whilst others trotted off to do their own thing. More bonding and talking took place on Saturday evening and then, on Sunday, was the big event. Some of those who completed the eight miles were amazing - I wimped out by taking the shorter route! Being totally chuffed with ourselves we went into the buffet dinner that night on a high. Roger and Brian had organised a quiz night. The main competition was won by a team calling themselves the 'Veggie Table' and I can't work out how it was that so many know-all's managed to seat themselves at the same table!! I'm proud to say, Di, that I won one of your delightful cards - thank you for donating these. Oh, and Shirley, thank you from everyone for the 'Shirls' - ribbons we all wore for the weekend.

It concluded with endless requests for this to be repeated - we will do it, for sure. I won't forget this one, I met some truly amazing people.

(from an original email sent by Peter to the Sarcoma Maitalk email list)

BAD NAUHEIM DECLARATION

At the end of June delegates representing support and advocacy groups for patients with GIST attended a weekend conference in Bad Nauheim supported by Novartis Oncology. The aim was to catch up on the latest developments in treatment and improve understanding of the rapid advance in surgical approaches and drug technologies which are helping GIST patients.

Speakers included Professor Jean-Yves Blay (France), Professor Peter Hohenberger (Germany) and Dr Peter Reichardt (Germany). In addition there were workshops on clinical trials, creating strategic alliances, fund-raising and some of the psychological issues of being a patient. The important topic of access to new drugs was also high on the agenda and the GIST patient group, many of whom face problems with accessing both imatinib (Glivec) and sunitinib (Sutent), agreed on a common position.

The Bad Nauheim Declaration sets out a clear minimum position which GIST patient groups wish to see in place everywhere for the treatment of patients. It calls for patients to be treated in specialist centres using evidence-based guidance developed from consensus among clinicians, regularly reviewed and updated. It calls for all treatments to be fully funded and for an end to national and local treatment variations, wherever the patient lives.

Both Sarcoma UK and GIST Support UK are among the 16 organisations from 14 countries who have signed the Declaration.

For the full declaration go to: http://www.sarcoma-uk.org/docs/Bad_Nauheim_declaration.pdf

WARM RECEPTION FOR SUPPORT MEETINGS

Meetings have been welcomed by sarcoma patients in Norwich (June) and London (September) and by GIST patients at a meeting in Manchester in May. Specialist doctors from the local treatment centres have supported the meetings and were ready to answer a wide range of questions from patients, their families and friends.

The Norwich meeting, attended by 34 people, heard the whole clinical team from the Norfolk & Norwich University Hospital answer a range of questions on treatment and diagnosis, as well as explaining some very complex cancer issues on pathology and MRI/CT imaging.

A meeting specifically for GIST patients held in Manchester (and supported with grants from Novartis and Pfizer) was attended by over 70 people. Dr Michael Leahy (Medical Oncologist - Christie Hospital) and Dr Bill Newman (Clinical Geneticist) addressed a wide range of questions, though **"Tears were shed and friendships made and renewed and it was a great event"** on understanding genetic mutations of GIST and the value of differing treatments. A further GIST meeting is being held in London in October.

"It was interesting to share experiences, before this meeting I'd never met anyone with sarcoma"



Delegates from Romania, Belgium, USA, Israel, Netherlands, Norway, Hungary, Switzerland, UK, Italy, Canada, Germany, France and Poland gathered at Bad Nauheim to agree and sign the Bad Nauheim Declaration.



The London sarcoma meeting brought together 44 patients and carers, some of them meeting other patients for the first time. Dr Jeremy Whelan and Dr Beatrice Seddon from University College London Hospital answered a wide range of questions covering genetic issues, diagnosis, side effects of treatment, development of new treatments, follow-up and the management of recurrences. The meeting also discussed the potential for creating a regular self-support meeting in London and a small group of those attending agreed to look at how this might be arranged.

TO HAVE ONE SARCOMA IS UNLUCKY, BUT PAMELA HAS HAD TWO!

PATIENTS STORY



Pamela Waterhouse, who lives in Norfolk, has had the rare experience of two primary sarcomas. Pamela came to the support meeting in Norwich in May. She tells her story simply, but her frankness hides the worries, doubts and anxieties which every patient and carer can recognise.

My problems started in December 2002 when I was diagnosed with a 'GIST' in my small bowel. Fortunately it was a low grade cancer and has given me no further trouble. Then, in February 2003 my left thigh became painful and swollen. I visited my General Practitioner four times in the next 4 months. At first he thought it was a strain, the second time sciatica, the third time a definite lump could be felt so he arranged for me to have an X-Ray. By the fourth visit, in June, I was feeling pretty desperate and asked for a scan. He reluctantly agreed, but added "you will find it is only fibrous".

I arranged for the scan privately through the specialist who had removed the GIST in my small bowel the previous year. The verdict after an Ultra Sound, a CT Scan and an MRI, was a large, approximately 6 inches x 3 inches soft tissue sarcoma, highly invasive Grade 3.

I then had several frantic weeks of telephoning and pleading before I finally, privately, had it removed in August 2003. It was followed in November 2003, after a long waiting list again, with 6 weeks radiotherapy.

All seemed well other than a hernia repair to the GIST wound in mid 2004, until August 2005 when again, I realised 'lumps' had returned and an MRI confirmed this. These were removed in October 2005, but the operation had to be repeated in December 2005, as not enough affected area had been removed. I then had chemotherapy in March to July 2006, but again, in October 2006 I realised the Cancer had returned.

I immediately asked for an MRI but could not get one until January 2007. I was operated upon in February 2007, but what was a tumour the size of a marble in October 2006, had become at least the size of a golf ball. I am now hoping for the best, but it is a struggle to get appointments exactly when you need them, you just have to persevere.

I am treated at the Royal National Orthopaedic Hospital at Stanmore, Middlesex which is a three and a half hour car journey from my home and often with a two to three hour wait when you get there. It is worth it, they are always so positive, and a real tonic to me. I hope the sarcomas will now give me a break.

CHARLIE REVISITS BIRMINGHAM A HARD WAY...

Charlie Parish was treated for sarcoma four years ago at the Royal Orthopaedic Hospital in Birmingham. He works at a college in Winchester and decided, with a colleague Andy Pond, to celebrate the college's 400th anniversary with a 400 kilometre cycle ride, just the right distance to the Royal Orthopaedic, and back.

Four years ago I had been a patient in Ward 12 in the Royal Orthopaedic Hospital and was very impressed with the care and expert treatment that I received there for my sarcoma, so we thought that it would be appropriate to ride to the hospital and raise some money for cancer charities while doing so.



Journey over at the Royal Orthopaedic – or at least the first half of the journey.

We rode from Winchester to Birmingham on 21st June keeping to small roads as far as possible. This route was 232km long and took us about 11 hours, including stops for food. We stayed overnight at a bed and breakfast and that evening we enjoyed a large curry in one of the excellent restaurants in Moseley. The following day the weather was less welcoming; heavy rain and a slight head wind meant that we decided to choose a slightly more direct route home, cutting out the challenging Lickey Hills. Luckily the rain eased off after a couple of hours and we completed the return 208km ride in a similar time as day one.



Charlie and Andy at the College before setting off.

So we managed 440km (275 miles) in the two days, and collected a grand total of over £2,000 from friends and colleagues. We have split that equally between The Sarcoma Trust and the oncology Ward at the ROH.

THE FIRST OUTSIZE CHEQUE...

The Sarcoma Trust received its first 'outsize cheque', a £5000 donation from the customers of The Nags Head, Woodborough, Nottinghamshire, in early August. The fund-raising lasted all year and was in memory of Simon Mellows, who captained the local village cricket team and died from sarcoma in 2005. Events during the year included quizzes, draws and competitions as well as individual sponsored events including a bike ride and marathon runs.

The cheque was presented by Nottinghamshire and England cricketer Paul Franks at a celebratory evening at the pub attended by several of his county colleagues.



Photo L to R: **Chris Read** (Notts and England wicket-keeper), **Charlie Shreck** (fast bowler), **Roger Wilson** and **Nicky Mellows** (Sarcoma Trust trustees), **Paul Franks** (Notts and England all rounder), **Will Jefferson** and **Jason Gallian** (opening batsmen), **Steve Derry** and **David Mellows** (fund-raising organisers).

We acknowledge with gratitude various donations received by Sarcoma UK and by The Sarcoma Trust to help with the work of informing and supporting patients, and to contribute to funding research projects.

Some people aren't very well
And you may not be able to tell
Right next to you is something you should see
Could even be on your knee
Ow you might say if you touch it
Maybe if you leave it you could need a crutch
Always keep aware.

Poem by Michael Abraham, age 11



Michael came to Team Sarcoma UK with badges made to represent The Sarcoma Trust. Over the weekend he raised over £68. Thank you **Michael**, and well done.

Clinical Trials for Sarcoma

The following are treatment trials currently available. There may also be trials available at individual hospitals, which local oncologists will know about. A very good on-line trials database is at www.cancerhelp.org.uk/trials/trials/default.asp. If you want further information about trials there are also links on the Sarcoma UK website – www.sarcomauk.org/trials.htm

Trial Title	Description
EORTC 62991	Phase II pilot of moderate radiotherapy for inoperable aggressive fibromatosis (Desmoid tumours)
VORTEX	Phase III Randomised trial of single agent doxorubicin versus doxorubicin plus ifosfamide in the first line treatment of advanced or metastatic soft tissue sarcoma.
EURO-E.W.I.N.G. 99	Phase III pan-European treatment study for Ewing's sarcoma and Primitive Neuroectodermal Tumours (PNET)
EURAMOS 1	A Phase III randomized trial of the European & American Osteosarcoma Study Groups - strategies for resectable osteosarcoma based on response to pre-operative chemotherapy. http://www.ncrn.org.uk/portfolio/data.asp?ID=1433
EORTC 62012	Phase III randomised trial of single agent doxorubicin versus doxorubicin plus ifosfamide in the first line treatment of advanced or metastatic soft tissue sarcoma.
EORTC 62024	Phase III study of adjuvant imatinib (Gleevec) versus no further therapy after complete surgery for intermediate and high risk GIST. http://www.ncrn.org.uk/portfolio/data.asp?ID=1504
Gemcitabine and docetaxel in leiomyosarcoma	A Phase II trial to assess the activity of gemcitabine and docetaxel as first line chemotherapy in patients with unresectable leiomyosarcoma.

GETTING INFORMATION

Sources of reliable information on sarcoma are improving all the time and on this page we try to offer guidance on what is available.

The first stop for information about your case and treatment should be your doctors. The hospital specialist will be able to tell you most about the treatment appropriate for you. Your GP may have some information too but remember that on average a GP will only see one sarcoma patient in his whole career! Sarcoma is that rare!

Information can help you decide what questions you want to ask. Doctors or nurses don't mind being asked, they would rather hear all the questions you want answered and they will spend time answering them. Their focus is on you, the patient.

If you have been diagnosed with advanced sarcoma, information is just as important as it is for the newly diagnosed. Treatments such as chemotherapy have a lot of mystique about them and raise fears. It is therefore valuable to hear how treatments have changed and how modern medicine, and some complementary therapies too, can help you through a demanding time.

It is also important to understand that you only need to learn as much about your disease as you wish. The choice is yours.

Contact telephone numbers and useful websites

CANCERBACKUP

Cancerbackup's free helpline is staffed by experienced nurses who can answer many questions. The website includes online versions of booklets on sarcoma and other cancer related issues.

www.cancerbackup.org.uk/

0808 800 1234 - freephone helpline

020 7696 9003 - for publications

MACMILLAN CANCER SUPPORT

Macmillan works to improve the quality of life for people living with cancer offering information and practical advice including information on local support groups.

www.macmillan.org.uk/

0808 808 2020 - freephone helpline

CANCER HELP UK

Cancer Research UK's website for patients. Click the link to 'Specific Cancers' and use the search function as well because there are further references within the site.

www.cancerhelp.org.uk/

SARCOMA UK

Our website offers an introduction to understanding sarcoma. Extensive links to a range of further Internet resources.

www.sarcoma-uk.org

GIST SUPPORT

The UK's GIST support group with online information about Glivec.

www.gistsupport.co.uk

Be cautious when using the Internet to look for information on any cancer. Just because a website exists it does not mean that those responsible have any expertise. Information can only be general and can not be specific to a particular patient.

CHILDREN WITH SARCOMA

CCLG co-ordinates the work of 22 specialised children's cancer centres across the UK.

www.cclg.org.uk

TEENAGERS WITH SARCOMA

Teenage Cancer Trust

www.teenagecancertrust.org

CLINICAL TRIALS

If you are considering entering a clinical trial this site gives good general information about clinical trials.

www.nelh.nhs.uk/clinicaltrials/

SUPPORT GROUPS

There are sarcoma specific support groups at the following hospitals:

Royal Orthopaedic, Birmingham (ROHBTS)

Christie Hospital and Manchester Royal Infirmary, Manchester

City Hospital and Freeman Hospital, Newcastle

EMAIL SUPPORT GROUP

Provided by Sarcoma UK

www.mailtalk.ac.uk/lists/sarcoma.html

ESUN

Online newsletter from USA with lots of valuable articles

tinyurl.com/2dkcsy

Sarcoma UK leaflets can be downloaded from www.sarcoma-uk.org or contact us via email at info@sarcoma-uk.org

We also have information available to help explain clinical trials.