

Sarcoma UK

Eighth Edition
Spring/Summer 2007

Email:
info@sarcoma-uk.org

Inside:



Enjoying your family looks 'right' but read Lesley's story.

See page 6

"Those of you going through treatment yourselves, the advice I would offer is get onto the Sarcoma e-mail support group. They are a great bunch of people, all in the same boat, who can offer lots of advice and point you in the right direction with more medical/technical information if you need it." The email list can be found at www.mailtalk.ac.uk/lists/sarcoma.html



Inspirational marathon running from Richard

See page 7

MEETING OTHERS - ADDRESSING THE SENSE OF ISOLATION

Meetings which bring cancer patients together to exchange their stories and help each other have offered support to many patients over the years. The limiting factors facing the rarer cancers are building the contacts and funding group meetings. Only in Manchester and Newcastle are there regular support meetings specifically for sarcoma patients, organised by nurses at these two main treatment centres, knowing how valuable groups can be. We are hopeful that other treatment centres will follow their example.

In addition GIST Support UK has been able to run meetings, principally because specific drugs work well on this particular sarcoma so the pharmaceutical companies concerned are happy to provide financial support.

We know that sarcoma patients feel isolated, it is one of the more common comments made to us. The launch of our email list two years ago gave those who can access it a valued point of contact and small informal contact networks are also developing as a result. Now Sarcoma UK is developing a programme of support meetings for the next two years with two objectives in mind. The first is to extend the networking between patients which gives so much support. The second is to help hospitals, and patients being treated and cared for at them, to identify whether there is a real demand for local meetings in their area.

We are aiming to get to cities large and small. The schedule for this year starts in Norwich and includes London and Manchester. More details inside.

We are also backing Team Sarcoma, an international event taking place from 13th to 16th July 2007. All across the world sarcoma groups will be gathering to increase awareness of this rare disease, to fund-raise, and to get to know others affected by sarcoma. The Liddy Shriver Sarcoma Initiative in the USA founded Team Sarcoma in 2004 and acts as the co-ordinator worldwide, with sarcoma support organisations acting nationally.



Team Sarcoma UK is a weekend event based in Torquay aimed at sarcoma patients and their families, those who are supporting friends and colleagues who are patients with a sarcoma and those treating sarcoma. Our hope is that by the time the weekend finishes everyone will have made new friends, exchanged news, and enjoyed themselves. The central event of the weekend will be a coastal walk (8.5 miles) for those who wish to take part, from Brixham to Torquay on Sunday 15th. Those wishing to use this walk as a sponsored event to raise money for The Sarcoma Trust (see page 2) are invited to do so – the walk will be monitored and certified for sponsorship.

Further details and booking forms for the Support Meetings and for Team Sarcoma UK can be found in the centre of the newsletter.



Also Inside:

The sarcoma professionals meet
GIST – new data published
Rarer Cancers Forum holds first AGM
First moves towards creating a European Sarcoma Network

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.

If you require additional copies of Sarcoma UK or would like to distribute it through hospital, support group, charity etc please let us know by email of the number of copies required and the mailing address.

Email to: info@sarcoma-uk.org

Sarcoma UK is a company limited by guarantee with charitable objectives.

Editor Roger Wilson

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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.

Address:

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NHS FUNDING FOR SARCOMA SURGERY

The cost of soft tissue sarcoma surgery is not being fully met by the NHS to the hospitals who undertake it. Primary Care Trusts pay hospitals according to a fixed price structure and the tariffs which apply to sarcoma surgery are set for procedures which are simpler than most cancer surgery. The hospitals treating the largest number of cases, and those treating the more complex cases, are the ones most affected. Bone sarcoma treatment is funded centrally by the NHS but the centres which treat bone sarcomas also treat soft tissue sarcomas.

It is calculated that the average soft tissue sarcoma patient is underfunded by the NHS to the hospital by about £5000. The patient is not, of course, aware of this. The transaction happens in the background between PCT and hospital, but there is growing concern that long term decisions being taken by hospitals about the new guidance from NICE will take this financial burden into account.

The burden seems to be worst where multidisciplinary treatment teams come from more than one hospital. Sarcoma UK has been told that the directors of one specialist hospital have already questioned why they should continue to subsidise a surgical oncology service when they are also expected to balance their books each year.

Delegates at the recent British Sarcoma Group Conference expressed their concern and their hope that the NHS can resolve the problem. It is not in patient interests for the NICE Improving Outcomes Guidance to come into conflict with funding. Hospitals who wish to develop their sarcoma services, and to be recognised as a specialist centre, should be able to do so without being financially penalised.

Sarcoma UK is joining its voice to those of the clinicians at the specialist centres to make the NHS aware of the problem. Finding the right solution will be a matter for the Department of Health, PCTs and hospital trusts but both professional and patient groups will be watching carefully to ensure that services improve as planned by NICE.

HORMONE TESTING

Many gynaecological sarcomas have shown themselves to be hormone sensitive. Shirley Collings' article in Sarcoma UK (autumn 2006 edition) told her story about seeking appropriate treatment once that sensitivity was confirmed. Following an internal review the Royal Marsden Hospital is now automatically testing all gynae sarcomas for hormone receptor status. The information can help oncologists decide on the most appropriate treatment in follow-up and in the event of recurrence.

THE SARCOMA TRUST

The Sarcoma Trust has been formed with the aim of becoming the first registered charity to take a national role working for those concerned with sarcoma. The Trust was formed in January 2007 and has applied for registration with The Charity Commission. The founding Trustees include four people affected by sarcoma.

The Trust will work with Sarcoma UK, which is a trading company limited by guarantee, where it is appropriate to do so. Sarcoma UK will support the Trust in fund-raising and will ensure that unsolicited donations offered for research are routed to The Sarcoma Trust. The extensive range of medical, scientific and commercial contacts developed by Sarcoma UK will also be made available.



RARER CANCERS FORUM AGM

The first AGM of the Rarer Cancers Forum was held at the Parish Hall, Eaton Square, London on Wednesday, 4th October 2006. I didn't expect any specifics for sarcoma, but was pleased (if that is the right word) to be one of six sarcoma patients present.

RCF Co-ordinator, Penny Wilson-Webb explained the aims of the Forum, and covered the subject "Access to Care & Knowledge", highlighting lack of knowledge of rare conditions at GP level, reluctance by newly diagnosed patients to question doctors "who know more than me" and thereby delaying referral to specialist centres. Ask, ask, ask was her message. She also highlighted cost of travel involved getting to specialist centres and brought our attention to the Macmillan webpage which has a section on travel to hospitals and parking costs.

Penny stressed not to believe everything on the internet and if you do searches, check the dates of the articles, some are over ten years old; medical advancement has been huge over ten years. She discussed the possibility of getting a consultant to approach the PCT ethics committee if there is a drug on trial that can be used on compassionate grounds for named patients. Everyone can ask their consultant about this. She ended by stressing an important aim of RCF: To provide a bespoke service to individual patients with any rare cancer, by assisting them to find information and available services for care and treatment.

Two other speakers were present. Louise Soanes, a paediatric cancer nurse from the Royal Marsden explained the role of nursing for rarer cancer patients. She outlined: supportive care between consultants, patients and families; management and administering

of treatment such as chemo, injections etc; psychological, social and physical support as and when necessary, support in, and providing resources for, education and information for patients and also being the ministering angel at the bedside.



The second speaker was Dr Frank Saran, an oncologist from the Royal Marsden on the subject "what a patient should know". He outlined the journey from GP to secondary referral, onward to a tertiary institution and even to a fourth level of "super dooper" institution. He suggested the Rarer Cancer Forum compile a list on the website of clinicians with relevant specialisms in various parts of the country as a point of reference for newly diagnosed patients. He suggested that the RCF create links on Google or other search engines, so that anyone "googling" their particular cancer can find a link to the RCF or other support groups relevant to their conditions.

It was very humbling to be in the company of 50+ patients/carers dealing with rare cancers and the support each and everyone was willing to give, information exchanged with openness and compassion and email addresses exchanged!

Shirley Collings

<http://www.rarercancers.org.uk/>

NEW CHILDREN'S CANCER ORGANISATION

In August 2006, the two main children's cancer research organisations in the UK, the UK Children's Cancer Study Group (UKCCSG) and UK Childhood Leukaemia Working Party (UKCLWP), merged to form a new organization - the Children's Cancer and Leukaemia Group (CCLG). The UKCCSG has run clinical trials for children with bone and soft tissue sarcoma for many years. The work of both groups has helped to substantially improve survival rates for children with cancer in the UK. The merger will have a number of benefits, including optimising the administration of clinical trials, sharing expertise, and the creation of a united national research voice for all children with cancer.



Further information about the new group can be found on their website

www.cclg.org.uk

BRITISH SARCOMA GROUP CONFERENCE

The British Sarcoma Group, the association of specialist clinicians, met in Manchester in February 2007 for its 3rd annual conference. Over 130 delegates, including a group of patients and carers, were informed by a range of high quality presentations and discussions.

Key headline presentations on the first day looked at the role of PET/CT scans, at inhibiting angiogenesis (blood supply to tumours) and at the treatment of retroperitoneal (internal) sarcomas. The meeting also gives younger doctors undertaking research projects as part of their training the opportunity to present their work to a distinguished and expert audience.

Dr Mike O'Doherty from Kings College London made a strong case for the use of PET/CT (combined positron emission tomography and computed tomography) in diagnosis, staging and follow-up for some sarcomas. Professor Ian Judson gave a clear description of angiogenesis and the part it plays in tumour development and growth. He talked about new treatments, discussing what is known about their effectiveness in treating sarcoma and their progress in clinical trials. Mr Andrew Hayes, one of the specialist surgeons from the Royal Marsden, looked at advances in the management of retroperitoneal sarcoma. He emphasised the importance of a complete resection as the first surgical procedure, it is a major factor which affects the outcome.



Other sessions during the first day looked at work on improving diagnosis and at research. Two current clinical

trials were reported and discussed – EURAMOS (the international osteosarcoma study) and VORTEX (a trial of adjuvant radiotherapy for extremity sarcoma). Dr Jeremy Whelan also reported on trials for children and young adults.

Day two started with parallel sessions on surgery and oncology. Delegates to the surgical session reviewed pelvic surgery with Mr Steve Cannon from Stanmore, treatment of lung metastases with Mr Alan Kirk from Glasgow, and were given a thoughtful view on



how the best patient outcome can be achieved following amputation.

The oncology session focussed on the science of sarcoma and GIST in particular. Mutational analysis was described by world leader Dr Maria Debiec-Rychter from Leuven University in Belgium. The management of GIST is one of the fastest moving fields in oncology today, as Dr Mike Leahy explained. Dr Paolo Casali, of Istituto Nazionale Tumori in Milan, took the theme towards all sarcomas, identifying that targeted treatments as well as traditional chemotherapies are

becoming relevant and that future development will probably be in combination therapies. The conference moved on to look in greater depth at Ewing's sarcoma and neurofibromatosis, a condition which can lead to sarcoma. There was also discussion about the introduction of the NICE Improving Outcomes Guidance and methods for auditing its implementation.

BSG Conference 2008 is 31st January/1st February 2008 in Sheffield

The Royal College of Radiologists has launched a web-based discussion board exclusively for the use of sarcoma clinical staff. The system allows doctors who are facing diagnostic or case problems to consult quickly with distant colleagues. The system is free of charge and aimed at all clinical disciplines, not just radiologists. It allows any subscribing member to start a discussion thread and to post images (scans or pathology slides). Automated email notification alerts other members and their opinions or experiences can then be added to the thread. The system archives discussions so documents, images and past threads so remain accessible. Clinical staff wishing to find out more should contact peter_lumb@rcr.ac.uk

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.sarcoma-uk.org/trials.htm

If you think a trial might be valuable for your treatment please talk to your consultant.

Trial Title	Description
EORTC 62991	Phase II trial of moderate radiotherapy for inoperable aggressive fibromatosis (Desmoid tumours) http://www.ncrn.org.uk/portfolio/data.asp?ID=874
VORTEX	Phase III randomized trial comparing two volumes of post-operative radiotherapy for adult patients with extremity soft tissue sarcoma. http://www.ncrn.org.uk/portfolio/data.asp?ID=1070
EURO- EWING 99	Phase III pan-European treatment study for Ewing's sarcoma and Primitive Neuro-ectodermal Tumours (PNET) http://www.ncrn.org.uk/portfolio/data.asp?ID=1188
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 62061	Randomized phase II study of brostallicin (PNU-166196A) versus doxorubicin as first line chemotherapy in patients with advanced or metastatic soft tissue sarcoma. For patients ineligible for EORTC 62012.
EORTC 62024	Phase III study of adjuvant imatinib (Glivec) 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.
EORTC 62043	Phase II study of GW786034 in patients with relapsed or refractory soft tissue sarcoma.

TOWARDS A EUROPEAN SARCOMA NETWORK

Sarcoma patient groups from France, UK and Germany met with Professor Jean-Yves Blay, the current chair of the sarcoma group of the pan-European research organisation (EORTC) in December 2006 to discuss European networking.

Professor Blay, France's leading sarcoma specialist medical oncologist, heads a working group of researchers from academic centres and industry (Conticanet) looking at how Europe can best bring its research work together so that advances in sarcoma treatment can be speeded up for the benefit of patients.

There were five patient organisations attending (two from UK, two from France and one from Germany) and another five or six small groups are known about. The potential of a forming a network which allows these groups to become more widely known, and which can encourage groups to form in other countries, was discussed.

A key issue for the medical researchers is getting patients in Europe to agree to enter clinical trials, where these are available. The rapid advances being made by scientists will, it is hoped, lead to a growing number of new treatments needing to be trialled, and there was some debate about how a growth in patient numbers can be encouraged.

Back row: Mariek Podevin (SOS Desmoid – France), Dr Simon Bacconnier (Conticanet), Kai Pilgermann (Das Lebenshaus - Germany), Roger Wilson (Sarcoma UK), Estelle Le Cointe – (Ensemble contre le GIST – France), Vincent-Olivier Beldon (Grafs – France)



Front row: Markus Wartenberg (Das Lebenshaus – Germany), David Robinson (GIST Support UK), Professor Jean-Yves Blay (Conticanet), Judith Robinson (GIST Support UK)

POST CODE LOTTERY

In late 2006 NICE agreed with Sarcoma UK's representation that there was a need to review its guidance for using imatinib (Glivec) for the treatment of GIST. The regulator consulted with researchers and with Novartis and will decide its timetable for review after the publication of research results due in summer 2007.

The most pressing problem is that patients who show progression while taking 400mg of Glivec have to get specific approval from their PCT to receive either the 800mg escalated dose indicated in clinical guidelines or the alternative drug Sutent. There are postcode differences around the country with some patients refused treatment and others receiving it. In Scotland 800mg of Glivec is funded by the NHS but Sutent is specifically refused.

ADJUVANT STUDIES

Among the latest results already made available by Novartis is the first indication from an American study of adjuvant Glivec for fully resected GIST. Patients were randomised to receive either Glivec or a placebo and took the treatment for one year. The study was designed to demonstrate recurrence-free survival. The first interim analysis shows that 97% of the treatment group showed no recurrence compared with 83% of the placebo group.

The difference is regarded as 'significant' and the National Cancer Institute, which sponsored the trial, has decided to close it. Novartis has offered Glivec for one year to all

participants in the trial currently taking placebo.

The results as announced are unlikely to result in a rapid change of use in Europe. A European trial of adjuvant Glivec for patients who have had surgery and are categorised as at 'high' or 'intermediate' risk is still open to new patients. This trial looks at overall survival rather than onset of a relapse, is likely to offer more complete data for European regulators. Patients on this trial are randomised to two-years of Glivec, or standard monitoring (no treatment). However the publication of such positive interim results from the USA puts pressure on European researchers to analyse their data as soon as possible.

GIST SUPPORT UK MEETINGS

GIST Support UK is holding two support meetings during 2007. The first, in Manchester on Monday May 21st, hopes to attract GIST patients from the north who find a journey to London too demanding. The second meeting will be in October in London. If you are a GIST patient and have not received an invitation but would like to come please contact us at sarcoma@uk2.net



PATIENT STORY

Many sarcoma patients have a delayed diagnosis. Lesley Abraham kept a careful record as she searched for the truth about the lump on her arm.

My journey with sarcoma began on January 19th 2006 in the fracture clinic of Bangor hospital. It was the final stage of a long hard-fought journey to get to a diagnosis. Let me explain.

In August 2004 I noticed a lump on my right forearm which the doctor put down to a swollen muscle. Fair enough, however by November it had not gone away and although it was not troubling me, if my children leant on it (as they often do!) it was very painful. Another visit to the doctor - told these things take a long time to recover. January 2005, return to doctor (a locum) who referred me to the local hospital and I received a letter in March telling me I was on an 18- month waiting list.

The first anniversary came round and the lump was still there. Nothing had changed except that all of a sudden I was getting a lot of pain and chewing pain killers every few hours. Yes, you guessed it, back to the doctor to ask for a private referral (I had no insurance but just needed to get the first appointment). The doctor did not want me to go private and said she would see if she could get me seen early by the consultant. But a refusal there!

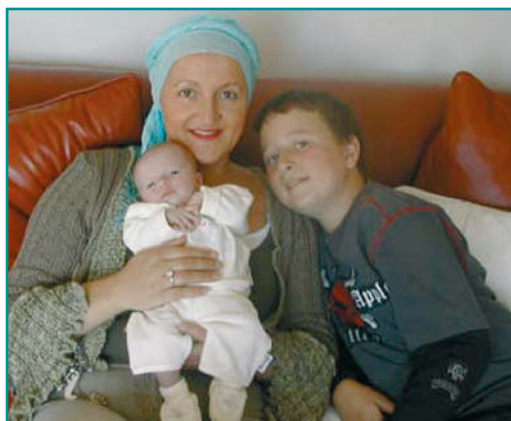
So I took myself to A & E who said, and this became my catch phrase! "OH THAT DOES NOT LOOK RIGHT" and guess what – they sent me home telling me there was nothing they could do. Back to GP who tried the consultant again. Refused to see me once more but offered a multidisciplinary appointment which, when translated into plain English, was a physiotherapist. Treatment before diagnosis, new one on me. The physio looked hard and told me she had seen nothing like it

before. She did a thorough examination and told me she would report that I should be seen. Four days later I received a phone call from her to tell me the consultant had once again refused to see me! Back to GP to get a referral to a private consultant. So on September 24th 2005 I was seen and told I would need an ultra sound and CT scan that would be a 6 to 8 week wait. To me by now that was nothing, so I asked to be transferred to his clinic on the NHS. Should not have believed them. It took many phone calls and eventually I received a cancellation appointment for Friday 13th January 2006. The doctor who did

the ultra sound sent me straight through for an MRI scan. I felt such relief as I would not have to wait for another appointment and now the consultant would have all the results for my appointment with him in February.

Well this now brings me back to my first paragraph. Six days later I was in the fracture clinic. Aged 41, married and mother to 2 children of 9 and 7, on my own and an hour drive from home, I was told by the registrar (the consultant had been called away) that I had an aggressive cancer that needed treating straight away. Shock does not describe my feeling but I remember the one overwhelming thought was that I finally knew what was wrong with me. So over the next few days I set about making sure I was treated as quickly as possible. My treatment has been at Birmingham's Royal Orthopaedic Hospital by the 'blue' team of Mr Tillman and Mr Grimer. My care is now also shared with Mr Gollins, my oncologist at the North Wales Cancer Treatment Centre. My treatment from diagnosis onwards has been second to none and I am grateful for all the care, from surgery through radiotherapy and chemotherapy.

I now feel fine and am slowly building up the energies that the chemo sapped and I am trying to decide if I like my new curly look! I never had curly hair, one of the great side effects of chemo.



Lesley with son Michael and baby granddaughter, Madison



FUND RAISING FOR SARCOMA

Many special people have run marathons, held dinner parties, refused Christmas presents, and held social events to help support work with sarcoma. The Kyokushin Karate Club in Nottingham held a social evening to fund raise to send members to compete in World Championships, and supported us too. The Southwell Running Club ran a New Year Road Race. We have also received donations in memory of loved ones.



Ian Morton (lower with thumbs up) sky-dives over Nottinghamshire.



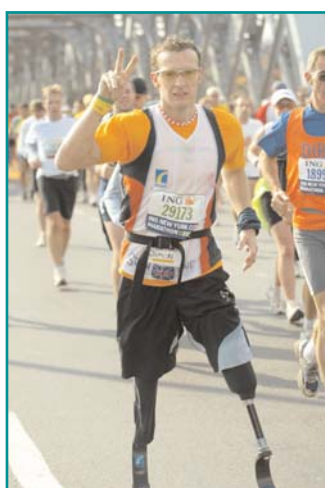
Sheila Eardley (right) and her friend Jayne Hulme organised a social evening in Stoke.

We offer our grateful thanks to all those who have supported the work of Sarcoma UK and who have fund-raised to support research into sarcoma. Donations specifically mentioning research have been made over to The Sarcoma Trust (see page 2) part of whose work will be to develop a research support programme.

Richard Whitehead who ran the New York Marathon in November 2006 to support Sarcoma UK was born without lower legs. Despite this disadvantage he has become one of the UK's leading disabled sportsmen, taking part in a number of sports and representing England at international level in some of them. He

was voted Trent FM Radio's Inspirational Personality of the Year recently. His support for Sarcoma UK stems from losing a close friend, Simon Mellows, to sarcoma in 2005. Richard also

competed in the London Marathon in 2007 and brought his personal best time down to 3.49.59. He works as a sports development officer for disadvantaged youngsters in Nottinghamshire.



Richard Whitehead completes the New York Marathon

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

THE LIFERAFT GROUP

The Liferaft Group is a US support group for all GIST patients. Excellent monthly downloadable newsletter.

www.liferaftgroup.org

CHILDREN WITH SARCOMA

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

www.cclg.org.uk

THE NATIONAL ALLIANCE OF CHILDREN'S CANCER PARENT ORGANISATIONS

www.naccpo.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

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.