

Sarcoma UK

Seventh Edition
Autumn/Winter 2006/7

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Inside:

Primary Care Trusts and New Treatments

Administrators in ivory towers remote from the reality of cancer have no part to play in deciding how patients should be treated

Approval for the funding of new treatments by the National Institute of Health and Clinical Excellence (NICE) rarely seems to be out of the newspaper headlines. The issues about such funding however do not only involve NICE. The front line of NHS decision-making about funding new treatments for individual patients is the Primary Care Trust. Cancer patient groups are becoming increasingly aware that Primary Care Trusts are responding to their over-spends by making new treatments more difficult to access.

The Secretary of State, Mrs Patricia Hewitt, told PCTs on 25th October 2005 that their decisions should not be based solely on cost. However, there is growing concern about the ability of Primary Care Trusts to fairly assess new cancer drugs when doctors request one for a patient.

Each PCT has an Exceptional Treatment process for reviewing funding where new treatments are not covered by NICE guidance. The process calls on non-specialist people to make judgements about specialist treatments. They are guided by an analysis of evidence - usually summarised by someone without oncology knowledge. There is no expert oversight of the summariser's work. The review process is then conducted in private with no representation for the patient, either in person or by a doctor. The process is chaired by an executive from the PCT, who is probably under management pressure to deliver savings. The outcome is that a patient can be denied treatment which could extend their life.

Many of the new generation cancer drugs act in ways that have not been seen before. Diseases which had been almost untreatable are becoming treatable and although it may yet be too early to understand how long some of these effects last, the important thing is that patients are being given hope. The PCT process is being used to deny that hope. Lame excuses about lack of efficacy, equity and fairness are wrapped around their decisions in an attempt to hide the fact that cost alone is the reason for refusal.

To add insult to injury no PCT uses an ethical 'bad news' procedure to convey their decision. Bromley PCT, for example, sends a letter to the patient's home to convey their decision impersonally. Of course, it is expressed "with due consideration and sympathy for your situation". No emotional support is offered. Appeal processes are equally secretive and impersonal. Convicted criminals are treated better and have more rights.

The process will soon break down completely. More people are turning to the courts and there have also been active demonstrations at PCT meetings and on ministerial visits. MPs are getting an increasing amount of correspondence about it. Yet the Government seems oblivious to the injustice and immorality being perpetrated in the name of the NHS.



Barry and Shirley entertain...
...and read Shirley's story
See page 3



"Its your age" she was told
See page 6

Also Inside:

Implementing NICE Guidance
New treatments - a fast changing world
Current clinical trials
A questionnaire on support meetings

Sarcoma UK

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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

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If you would like to join our email support group please contact us at: info@sarcoma-uk.org

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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Guidelines - the benchmark to improve treatment for patients

The new Guidance to those in the NHS who commission and pay hospitals for treating patients with sarcoma is now being implemented. Sarcoma UK will be keeping a careful eye on development in the coming months to see that the recommendations are implemented.

There are worrying signs. Some hospital trusts have a casual approach to rare cancers and if a consultant diagnosing a patient does not know who to refer a patient to, inappropriate treatment may result. In many cancer networks there has never been a formal pathway for sarcoma treatment and even though the guidance is mandatory, delay because of cost seems a likely excuse.

A recent patient complaint about poor treatment made to Barking, Havering and Redbridge Hospitals Trust was dismissed by the Chief Executive with the statement that the surgeon "informs me that he treats many patients with breast sarcoma locally and has referred some of them for second opinions to a sarcoma specialist".

The incidence of sarcoma in the breast (often a side effect of previous radiotherapy treatment) is so rare that on average this hospital might see two cases every five years. Telling lies to patients could get a doctor into trouble. It is also inappropriate for Chief Executives. Specialist care by a multi-disciplinary team is also a key factor in getting a good outcome in sarcoma but this surgeon is clearly either too arrogant or just plain ignorant about observing that basic duty of care. The fact that the Chief Executive did not question the statement made to him is equally worrying.

The kind of behaviour which lies behind that complaint is what Guidelines are there to prevent. They give us a benchmark against which the occasional horror stories we hear about treatment can be set. Sarcoma UK will not hesitate to ensure that NHS regulatory authorities will get to hear these stories too.

Readers will recall our Patient Story in the Spring 2006 issue by Sally Young. For full follow-up her online blog can be found at www.sallyyoung.blogspot.com

Getting a better deal for patients

Macmillan Cancer Support is calling for cancer patients to be entitled to free hospital parking and help with travel costs. Macmillan is urging supporters to make their voices heard and sign up to its Better Deal Campaign.

Macmillan's research showed that patients in Scotland spent an average of £636 on travel and parking throughout the course of their cancer treatment while those in Wales spent £318. Patients in England faced an average of £477 in the South West, £424 in London and the South East and £371 in the rest of the country. These figures are averages so many patients paid a lot more.

The survey also found nine in ten (91%) cancer patients' households suffered a loss of income and/or increased costs as a direct result of their cancer diagnosis. Four in five (78%) of these people received no financial help at all.

The Better Deal Campaign calls on government to ensure all cancer patients get free hospital parking and help with their travel costs.. Currently, only patients on certain benefits are eligible for help although many are unaware of the scheme's existence.

You can find out more at www.macmillan.org.uk/Get_Involved/Campaigns/Home.aspx

HAVE YOUR FINANCES BEEN AFFECTED BY CANCER?

If so, Macmillan Cancer Relief would like to hear from you.

As part of our **Better Deal** campaign, we're looking for people to share their experiences of financial difficulties caused by cancer.

Costly travel and parking costs for cancer treatment appointments? Increased heating or laundry bills?
Extra child care costs? Difficulty in accessing benefits?
Had to give up work? Denied travel insurance?

We want to hear your story (anonymously if preferred) to help other people dealing with cancer and campaign for change.

If you have an experience you can share please get in touch with the Campaigns Team on 020 7840 7807 or write to Macmillan Cancer Relief, 99 Albert Embankment, London SE7 7LQ, or email mystery@macmillan.org.uk Thank you!

A better deal for people dealing with cancer
Call: 0800 600 600 or visit www.macmillan.org.uk/betterdeal
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**WE ARE
MACMILLAN.
CANCER SUPPORT**

Patient story

Uterine sarcoma and HRT

Shirley Collings tells how her search for information led to changes in her treatment

After my total hysterectomy and subsequent uterine leiomyosarcoma diagnosis (Sept 2003), lung metastases diagnosis (Jan 2005) and surgical removal of local recurrence (April 2005), I was advised to carry on with HRT by two GPs. Both my oncologist and the Royal Marsden assured me that my HRT (Tibolone, known as Livial, a synthetic HRT which mimics the activity of the female hormones oestrogen and progesterone in the body) was OK as LMS was not normally hormone receptive. I never asked whether the tissue from both my cancer surgeries was tested for hormone receptors and was never told.

By April 2006, I was getting more and more worried about whether or not I should stop HRT (after careful 'surfing' of a reliable and informative LMS site). My oncologist arranged for the tumour removed in April 2005 to be tested for hormone receptors - and the results showed that it was oestrogen receptor positive. It wasn't tested for progesterone but should it have been? I am now on a course of letrozole and, of course, have stopped HRT.

After receiving the confirmation of the oestrogen receptor test I was at first devastated, then very angry, but now I am feeling positive because this result may open a new avenue of treatment for me. I asked my oncologist if the outcome of the test and treatment with letrozole could alter my prognosis. He said **if** letrozole was effective and **if** it stabilised or even shrank my lung mets, then maybe my prognosis would change (no guarantees), but it would not be a cure (I accept that). I asked if HRT had been a factor in the increase and growth of lung mets. He said no-one would really know for definite because of the rarity of both LMS and its being hormone receptor positive, and the lack of a large enough patient population for statistical analysis.

I've recently read a couple of PubMed research papers on hormone receptor expression in patients (23 in total) with uterine LMS. (1999 and 2003). Conclusions for both were similar, in that these studies observed that hormone receptors can be expressed in uterine LMS. Overall, even though HRT did not seem to have a pronounced adverse effect on LMS outcome, caution is certainly needed until more studies can be done with larger numbers of cases to verify a correlation between uterine LMS and HRT.

My personal view would be to err on the side of caution and have LMS tumours of gynaecological origin routinely tested. The results of this test has opened up a new direction of treatment for me, and that is a positive thing, whether it works or not. But how many other women could this have happened to? An important factor is that not all sarcoma patients have the capacity to analyse and question.

The moral of this tale is listen to your instincts. If things don't add up or don't make sense, question your oncologist – repeatedly!

Study calls for more research

At the ASCO conference in June 2006 (ASCO is the largest oncology conference in the world) a short paper from a French research team reported on the treatment of eight patients with uterine sarcomas, including leiomyosarcoma, with aromatase inhibitors. All 8 responded to some degree and after two years the majority were still free of progressive disease. The study authors call for a large-scale clinical study.

Aromatase inhibitors are highly effective in uterine sarcomas expressing estrogen receptors. J. Fayette, I. Ray-Coquard, E. Bompas et al: Journal of Clinical Oncology, 2006 ASCO Annual Meeting Proceedings Part I. Vol 24, No. 18S (June 20 Supplement), 2006: 9576

Letrozole is one of a family of drugs called aromatase inhibitors. They are commonly given to menopausal women with breast cancer. The drug blocks the body's process (aromatisation) which creates oestrogen and thus reduces the amount in the body which can encourage the tumour to grow.

NEW TREATMENT FOR SARCOMA

Advanced sarcoma is not easy to treat and the chemotherapy drugs used have unpleasant, but manageable, side effects. Research has identified new ways of developing drugs and a new generation of treatments is beginning to appear. The very first of these is Glivec, manufactured by Novartis, which has changed the prospects for GIST patients. Now we are beginning to see the first signs of similar drugs for other sarcomas.

Gastrointestinal stromal tumour (GIST) is the commonest sarcoma and has a high rate of recurrence. When Glivec was shown to give extended survival to patients with advanced GIST it changed their prospects almost overnight. Glivec began trials for GIST during 2000, was licensed in 2002, and was approved by NICE for use in 2004. Glivec is now being used to shrink tumours before surgery and has an important clinical trial to see whether it can also reduce the risk of advanced disease developing after surgery.

The range of GIST treatments grew this summer with the licensing of Sutent. This is manufactured by Pfizer and it was licensed for patients who have failed initial therapy with Glivec. Some advanced patients who relapse also respond to an increased dose of Glivec although, like Sutent, this has not yet been reviewed by NICE.

A range of new drugs for other sarcomas are in early stages of clinical trials around the world. They are mostly inhibitors, like Glivec and Sutent, blocking the ability of tumour cells to reproduce themselves.

Yondelis, manufactured by Spanish company Pharmamar, is the drug for soft tissue sarcoma likely to be the first to be licensed. An application was submitted in the summer. This will not make Yondelis readily available on the NHS as Primary Care Trusts and Health Boards will have to be individually approached for funding, and it is a costly treatment.

US biotechnology company Ariad published results of a large Phase 2 trial of its drug AP23573 at the world's largest oncology conference, ASCO, in June. Ariad is planning a randomized, worldwide Phase 3 clinical trial of oral AP23573 in patients with advanced sarcomas in preparation for an application for a licence.

Glaxo Smith Kline has a Phase 2 trial of GW786034 underway and some Sarcoma UK readers are participating. This trial is supported by the European Organisation for the Research and Treatment of Cancer (EORTC) and by trial organisations in the USA.

All this activity is a major change in the world of sarcoma treatment and it has been badly needed. Two researchers from Essen in West Germany recently published a review of the state of sarcoma treatment, especially for patients whose disease becomes advanced. The absence of effective treatment concerns patients and the doctors who treat them but the researchers struck a final optimistic, if cautious, note:

"With the vastly improved understanding of the biology and pathology of soft tissue sarcoma, an era of opportunities seems to have begun and the recent success in the treatment of gastrointestinal stromal tumors impressively shows how fast a gain in the understanding of oncogenic mechanisms may translate into a highly efficient, clinically useful treatment."

Locally advanced and metastatic sarcoma (adult type) including gastrointestinal stromal tumors. Bauer S, Hartmann JT: Critical Reviews in Oncology/Hematology: August 2006.

- **Yondelis** (trabectedin) works by blocking the DNA in tumour cells. It has been developed from a primitive marine sea squirt. It is delivered as an intravenous drip. Pharmamar published results of its major clinical trial in September 2006.
- **Ariad's** large Phase 2 trial of AP23573 showed that clinical benefit was achieved in 29% of patients and 24% had achieved stability at six months. Side effects were generally mild or moderate and all were treatable. AP23573 is an inhibitor (mTOR)
- **GSK's** GW786034 is also an inhibitor (VEGF) taken as a daily capsule. Depending on the results of the Phase 2 trial currently running in the USA and Europe a large scale pre-licensing Phase 3 trial may be anticipated.
- **Nilotinib** (AMN107), developed by Novartis the maker of Glivec, has been in early clinical trials in the USA and Europe. The drug is also an inhibitor. A report at ASCO, in June suggested that it has "relevant activity" for GIST patients and trials will continue.

CLINICAL TRIALS

Phase1 trials assess the safety of a new drug.

Phase2 trials assess the effect a new drug has on a disease or a range of diseases.

Phase3 trials compare a new treatment with the existing standard treatment

Phase4 trials look at issues following acceptance of a drug into regular use.

A leaflet explaining clinical trials is available from the UK Clinical Research Collaboration

www.ukcrc.org

RESEARCH INTO CAUSES OF SARCOMA

Researchers in Newcastle have analysed nearly a quarter of a century of data to look at the space-time clustering of certain childhood cancers, including soft tissue sarcomas in boys and osteosarcoma in girls. They were looking for the possibility of an environmental cause of the disease based on factors other than the environment itself. The principal suspect, if such clustering appeared, was likely to be infection.

The combination of geographical and temporal clustering of childhood acute lymphoblastic leukemia (ALL) and all the sarcomas analysed does suggest a role for infection as a cause. The statistical analysis also suggested that this clustering effect was evident in less densely populated areas for soft tissue sarcomas, and in both dense and less dense areas for osteosarcoma.

The report in the International Journal of Cancer says "Space-time clustering is highly suggestive of a role for an infectious component to etiology. Whilst infectious mechanistic hypotheses have been proposed for leukemia and ALL, there is a lack of such hypotheses for soft tissue sarcoma and osteosarcoma."

The research team is hoping to undertake a similar study which would include adult sarcomas. Although the kind of infection which could be a cause is not known, any confirmation of this suspicion from a further study would open up new lines of research into causes for sarcoma.

However the researchers concluded, "In the long-term, better understanding may hopefully lead to better treatment and prevention (it must be stressed this is a long-term goal)."

Space-time clustering of childhood cancer in Great Britain: a national study, 1969-1993. McNally,RJQ Alexander,FE Bithell,JF : International Journal of Cancer Vol 118 No11 2840-2846

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 trial of moderate radiotherapy for inoperable aggressive fibromatosis (Desmoid tumours)
VORTEX	Phase III randomized trial comparing two volumes of post-operative radiotherapy for adult patients with extremely 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.
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 (Glivec) versus no further therapy after complete surgery for intermediate and high risk GIST.
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. <i>Only available in UCH London.</i>
EORTC 62027	Phase II trial of imatinib for the treatment of unresectable and or metastatic dermatofibrosarcoma protuberans (DFSP) and giant cell fibroblastoma (GCF). <i>Available at the Christie, Manchester.</i>
EORTC 62043	Phase II study of GW786034 in patients with relapsed or refractory soft tissue sarcoma.

Where a trial is only held at one location a referral can usually be arranged. If you think a trial might be valuable for your treatment please talk to your consultant.

"It's your age", she was told...

Patient story

I have to admit it – I am a large woman. I am six foot tall and have a hefty bone structure. In many ways this has been an advantage in life; I've never had to struggle to be noticed, and I was able to terrorise classes of 'remedial' teenage boys effortlessly. My height and weight did, however, have the disadvantage of concealing a terrible time bomb.

Ten years ago I had a hysterectomy, and although everyone said I'd feel better after the statutory 6 weeks I didn't pick up at all. A year later a lump in my breast proved to be breast cancer. When I'd finished the six months of chemotherapy no-one could understand why a year or so on I still had no energy. When complaining to my oncologist of 'unnatural' tiredness and a pain in my chest when speaking I was told – "Oh, it's your age (50), and you probably have arthritis in your rib-cage."

I found sleeping on my side increasingly difficult, and had to attempt to prop my chest 'open', not wishing to have the weight of my arm pressing on my rib-cage. I used to do yoga, but increasingly found that if I leaned forward I would feel strange and dizzy. I had to let out all my waistbands and cut the top band of my tights, as any pressure around my middle became unbearable. Sometimes at night a bout of indigestion would have me silently writhing on the carpet of the bedroom, trying not to waken my husband. Neither he nor I could understand why even travelling in the car was so tiring; I had to have a pillow and wind the seat back to find a comfortable angle.

For nearly six years this state of affairs continued. Every six months a visit to the oncologist who had saved my life with the clever combination of drugs would end unsatisfactorily with my being told "It's your age".

I staggered through Christmas 2001 feeling weird and in the New Year of 2002 became increasingly disturbed by a rapidly growing lump protruding between my ribs in the region of my stomach. For the first couple of days I thought 'Oh, drat! I've inherited my Dad's problem – a hiatus hernia.'

Then I began to panic as it grew larger day by day. I managed to get an appointment to see the doctor whose face confirmed my fears, although he had no idea what the growth was at that stage. So between us we set up investigative surgery after the weekend. This lasted 9 hours, with two surgeons struggling to remove a monster liposarcoma weighing nearly 14 lbs.

When I said at the beginning of this piece "I am a large woman", the fact that I was carrying an extra stone of tumour behind my stomach was not that noticeable. A woman carrying twins of roughly the same weight usually looks quite large. I normally weigh about twelve stone, so one stone more is purely academic! A Tesco bag packed with seven 2 lb bags of sugar is about what the tumour weighed, but with it when it came out was one of my kidneys, my spleen, half my pancreas and a foot of colon. The thing had wrapped itself around these organs, and pushed my stomach up towards my left shoulder.

"Shouldn't eat freshly baked bread", I'd been telling myself for the previous couple of years. Along with the refrain "Oh, it's my age." Two years later a colon cancer developed, for which I had surgery too. I've become known to my family as The Incredible Hollow Hulk. I prefer, though, what one of my brothers called me recently: "Hil, you're a beacon of hope to other cancer sufferers." Two years on from the last cancer I'm still alive and I plan to stay that way.



*Hilly Cansdale (centre)
with her brothers and sisters*

Hilly Cansdale

TEAM SARCOMA



Team Sarcoma is a US led initiative to raise awareness worldwide. In summer 2006, forty-nine people were the core of the central event, a week long cycle tour of Denmark. Around the world at least a further 770 people took part in various events, usually cycling, lasting for one day or longer. In Essen in Germany 30 people took part in a 30km 'race' over hilly terrain around the beautiful Lake Baldeney. They all finished the course! (see picture).

Worldwide the event raised over \$120,000 for research into sarcoma.

If we can find a route to use in the UK which is safe for a cycle event, and someone to act as organiser, Sarcoma UK would be happy to support involvement in future Team Sarcoma events. Please contact us if you are interested.

Doing amazing things...

Sarcoma UK would like to thank the many people who have given donations during the last six months to help our information and patient support work. We would also like to thank those who have given donations to our research fund.

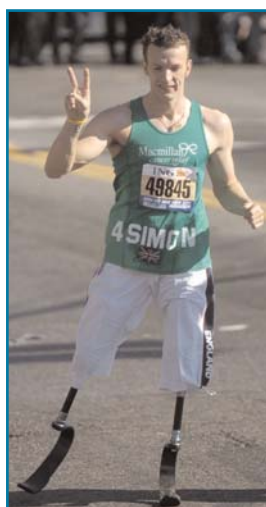


Barry and Shirley Collings entertaining his colleagues on the occasion of Barry's retirement. Shirley's story is on page 3



Sheralyn Pattison underwent a modified hairdo with the help of some friends, raising money for Sarcoma UK and Cancerbackup in memory of Andrew Skinner.

Richard Whitehead (left) and Ian Morton (right) sky-dived over Nottinghamshire one Saturday afternoon to celebrate their 'significant' birthdays and to remember their friend Simon Mellows. Richard is a limbless athlete with a remarkable record of fund-raising and his support for Sarcoma UK continues with his entry in the New York Marathon in November 2006.



A group in Nottingham are organising a fund-raising event and dinner at the East Midlands Conference Centre to support four local youngsters who will be representing the UK at an international karate competition. Two of the girls are nieces of Simon Mellows, who died of chondrosarcoma in 2005, so they are also supporting Sarcoma UK.

If you are in the East Midlands on 27th October 2006 contact Diane Doran on 01773 775020 and she will be glad to provide tickets for a black tie night out to remember.

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

www.liferaftgroup.org

CHILDREN WITH SARCOMA

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

www.ukccsg.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 information about clinical trials.

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

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.