

Sarcoma UK is supported by an unrestricted educational grant from Novartis Oncology.

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 or to sarcoma@dflair.demon.co.uk

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



Editor: Roger Wilson

Design: Chris White

The newsletter Sarcoma UK is printed by:

Pearson Print,
Dale Street,
Craven Arms,
Shropshire.

Sarcoma UK

Fourth Edition
Spring/Summer 2005

Email:
info@sarcoma-uk.org

ABOUT SARCOMA UK

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

- 1 To provide information and support to sarcoma patients, their carers and families
- 1 To support the development of a coherent national network of specialist centres to treat sarcoma in line with the best identified clinical practice
- 1 To support research which leads to better treatment and better outcomes for sarcoma patients

We have been generously supported in the development of Sarcoma UK with unrestricted grants from Novartis Oncology and Pharmamar SA.

Our immediate aim is to continue publishing this newsletter as a means of creating contact with sarcoma patients and their families and carers. We now have information leaflets for newly diagnosed patients and a more general leaflet for wider awareness.

There is an email support group with about 40 patients and carers subscribing. If you would like to know more, or would like to register as a subscriber, please contact us at info@sarcoma-uk.org.

We have already received a number of requests for information on how to support sarcoma research. We have a research fund and a clinical advisory group so that we can ensure proper use of donations. If anyone wishes to support research into sarcoma we would be happy to hear from you.

The Sarcoma UK website was re-launched in 2004

To stay in touch with us please complete the form at the centre of the newsletter on contact us at the address above. You are already on our mailing list if you received this copy of the newsletter direct by post.

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

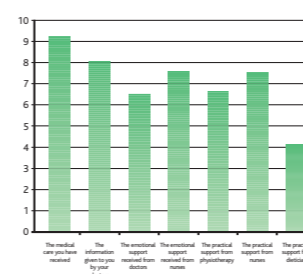
Address:
Sarcoma UK, PO Box 128, Ludlow, Shropshire SY8 1YL
Email: info@sarcoma-uk.org

Inside:

Meet Harry and his Little Beastie



Reporting your response to our first questionnaire



New Support Group

Manchester's Christie Hospital and Royal Infirmary work together to treat sarcoma patients from a wide area of north west England, north Wales and parts of the west Midlands. The first meeting of a patient support group was held at the Christie Hospital in January with patients attending who are being treated at both hospitals. About 20 patients and carers came to the first meeting. It is hoped that the group will start to meet regularly during 2005 and become another valued part of the service offered to patients by the two hospitals. Support groups are already well established in Newcastle and Birmingham. If you want to know more about the Manchester group please contact Merian Denning (Christie) or Sue Hamby (MRI). They can be found at the regular out patient clinics.

NICE Guidelines

Work on the development of guidelines for the NHS provision of sarcoma treatment is now well advanced. The first public consultation documents will be during May and June. Anyone can respond with comments and those from individual patients, are welcomed. If you do not wish to comment directly but would like to make your viewpoint known Sarcoma UK is a respondent in the consultation and we would be happy to collate and forward any representations ensuring anonymity if requested. The consultation documents will be downloadable from the NICE website shortly after May 9th – www.nice.org.uk

New guidelines for GP referral of suspected cancer include new guidance on sarcoma. These guidelines are shortly to be put in place. Following patient representation one of the new guidelines states that patient concern about a lump which is growing should now be acted on with an immediate urgent referral.

The Cost of Cancer

Macmillan Cancer Relief, together with CancerBACUP, are researching the financial issues faced by patients with cancer. The 'Better Deal' campaign wants to hear real life stories of patient experiences (anonymously if preferred).

If you would like to help them you can get in touch with the Macmillan campaign team on 020 7840 7807.



AN EXCITING TREATMENT STORY CONTINUES

In November 2004 the National Institute of Clinical Excellence (NICE) published guidelines for the use of imatinib for the treatment of gastrointestinal stromal tumour (GIST) in the NHS. Imatinib, which is more commonly known as Glivec, has revolutionised treatment of this sarcoma of the stomach and intestines. GIST was first treated with the drug, which is taken daily as a tablet or capsule, in 2000. Before November's decision UK patients were treated through clinical trials and a centrally funded programme, but now local Primary Care Trusts must provide the funding.

Glivec at 400mg daily is the recommended daily dose. The drug works for about 80% of GIST patients with advanced disease but resistance to the drug can build up after a period, which might be many years, and

patients can relapse. Now the good news is that another new drug, Sutent (previously called SU11248), is showing positive results for many patients for whom Glivec does not work, or who have relapsed.

A worldwide clinical trial was halted at the end of January and patients on the non-treatment arm were transferred to treatment with Sutent. In the trial about 65% of patients responded to treatment. The European drug regulator EMEA has awarded Sutent 'orphan drug' status, opening the way to further large scale trials and a full marketing license application, possibly in 2006.

Both Glivec and Sutent are members of a new class of targeted therapies for cancer. They attack the molecules on the cancer cells which are responsible for triggering growth and reproduction of the cells. There can be many such

molecules and the scientists are still developing their understanding of how they work, and of how these drugs can best be used.

Glivec is also effective against chronic myeloid leukaemia while Sutent is also showing good results with certain kidney cancers. Trials with Glivec on other sarcomas have not shown the same dramatic improvement in treatment as with GIST although some of the molecular targets it attacks are present. All this development has rapidly accelerated the biological understanding of GIST and other new treatments are known to be in the pipeline. It is to be hoped that some of them will also make a wider impact on the whole range of sarcomas.

(See comment on Page 5)

CLINICAL TRIALS FOR SARCOMA

We are occasionally asked about the availability of clinical trials in the UK for treating sarcoma. The following are the trials currently available at a number of treatment centres nationally. There are also trials available at individual hospitals, which local oncologists will know about. There is not a single trials database yet in the UK, although there is now significant patient group pressure to make one available on the Internet. The Sarcoma UK website carries links to the databases of trials available through NHS hospitals – www.sarcomauk.org/trials.htm

Trial Title	Description
EORTC 62991	Phase II pilot of moderate radiotherapy for inoperable aggressive fibromatosis (Desmoid tumours)
EURO-E.W.I.N.G. 99	Phase III pan-European Ewing's sarcoma treatment study
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.
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 of uterine origin. Only available at centres in London.
EURAMOS 1	Due to start in 2005 - a Phase III randomized trial of the European & American Osteosarcoma Study Group - strategies for resectable osteosarcoma based on response to pre-operative chemotherapy

If you want to know whether a clinical trial might be applicable to you, you should talk to your consultant.

GETTING INFORMATION

We know that patients have very different needs regarding information. Sources of reliable information on sarcoma are improving all the time and on this page we try and give you a picture of what is available.

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

General sarcoma information is available from Cancer BACUP. They have good booklets, which have recently been revised, on Soft Tissue Sarcoma and on Understanding Primary Bone Cancer. There are also good booklets on treatments such as Radiotherapy and Chemotherapy. Your hospital information centre may have them, if not call Cancer BACUP (phone number below) and they will post them to you straight away. Some hospitals have also produced their own information which may be available from a nurse specialist or their information centre.

If you have access to the Internet there is a wide range of information available from around the world. Even if you cannot access the Internet yourself there may be someone who can do it for you and print out the pages they find. It could be quite a lot of paper !

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, though it may be of a different kind. Treatments such as chemotherapy have a lot of mystique about them and raise fears of their own. Rather than listening to old stories about side effects it is much more valuable to hear about how treatments have changed and how modern medicine, and some complementary therapies too, can help you through a demanding treatment.

It is also important to understand that if you do not want to learn too much about your disease you don't have to. The choice is yours.

Contact telephone numbers and useful websites

CANCER HELP UK

Cancer Help is Cancer Research UK's website for patients. Excellent sarcoma material including "Questions for Your Doctors". Click the link to 'Specific Cancers' and also use the search function as there are further references within the site.

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

CANCERBACUP

Cancer Bacup's free helpline is staffed by experienced nurses who can answer many questions. The web link leads to booklets on sarcoma and other cancer related issues - all available free by phoning Bacup.

<http://www.cancerbacup.org.uk/catalogue/sarcomas.htm>
0808 800 1234 - freephone helpline
020 7696 9003 - publications

MACMILLAN

Macmillan works to improve the quality of life for people living with cancer. It offers information and practical advice over the phone and its web site is extensive. Macmillan also has information on local support groups.

<http://www.macmillan.org.uk/>
0808 808 2020 - freephone helpline

SARCOMA UK

We are the new kid on the block and our web presence is being worked on. The main page offers links to a range of further Internet resources and you can download our first two editions of our newsletter if you missed them.

<http://www.sarcoma-uk.org>

GIST SUPPORT UK

The UK's GIST support group with online information about Glivec.
<http://www.gistsupport.co.uk>

CLINICAL TRIALS

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

<http://www.nelh.nhs.uk/clinicaltrials/>

INDUSTRY SITES

Novartis manufactures Glivec®, the radical new treatment for GIST, an intestinal sarcoma.

<http://www.novartis oncology.com/home.jsp>

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

<http://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.

INFORMATION AND SUPPORT

In the last edition of Sarcoma UK we carried a questionnaire. Thank you to everyone who responded.

In all there were 45 replies. Of these 27 came from women and 18 from men. The age range is shown in Table 1.

Age	Female	Male	All
Under 25		1	1
25-45	8	2	10
45-65	16	9	25
65+	3	6	9

We asked you to score out of 10 the quality of the healthcare you have received. It is encouraging that everyone gives praise to the medical teams who handle their treatment though many people wrote in comments describing the difficult pathway they suffered in order to reach a diagnosis.

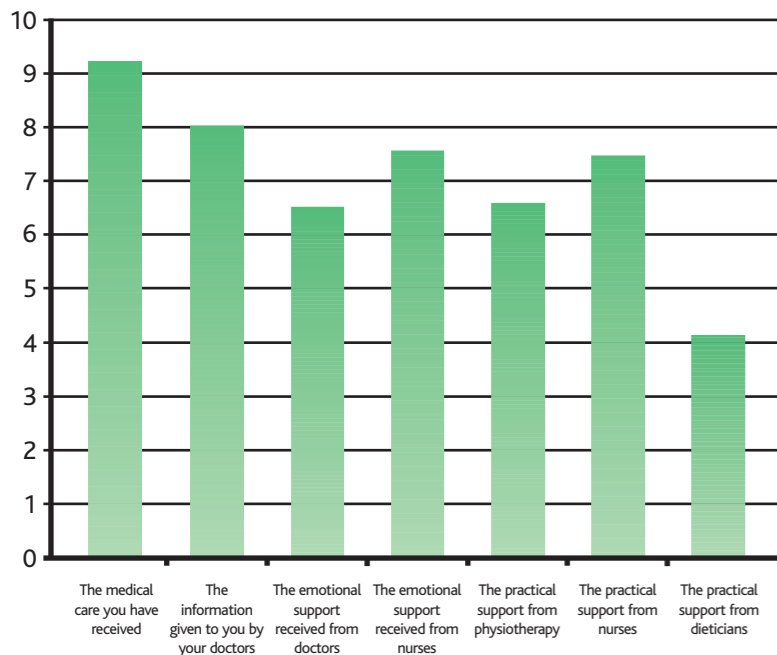


Figure 1 – quality scores

their doctors, although doctors were good at giving the information about individual situations which patients need (Figure 1).

The last two groups of questions were about contact with other patients and patient support groups. Those saying they have had no contact with other sarcoma patients totalled 20 (44%). Of the 21 who reported contact with other sarcoma patients the majority were at hospital clinics. We know there are very few sarcoma specific support groups but nonetheless 7 people (15% of the whole sample) had been to such a group.

How did you find your contact with other patients? The majority found it 'useful', 'encouraging', 'reassuring' or 'supportive' with the frequency of those responses ranging from 76% down to 52%. Four people found the contact experience was difficult, ticking between 2 and 5 of the more negative responses offered – although 2 of these four also ticked more positive ones as well. Another four ticked one problem response along with more positive responses. The responses indicating problems came equally from men and women and across all the age ranges.

The score for diet advice is striking. Only 20 people (44%) offered the dieticians a score, suggesting that advice is not generally available and several people gave them zero, suggesting advice was not relevant.

The replies on counselling also suggest that in many places it is not available. Only 17 people (38%) were offered counselling and 6 took it up (3 out of 8 women and 3 out of 9 men). A further 9 people (7 women) sought counselling when it was not offered. You were also asked to score the value of the counselling you received. Ten people did so and the average score was 8.7 (out of 10) with four of the ten giving it 10 out of 10.

Asked if you sought information on the Internet 31 of you (69%) said yes. The largest group saying no was among 45-65 year olds with 12 (48%) (5 men and 7 women). Only 2 of the 65+ age group said no (both female). Of other sources of information Cancer BACUP came top - 12 people (27%) had sought information from the charity. However only 8 people (18%) said they had received general information about sarcoma from the hospital or from

So what does this tell us ?

The quality of care received in hospital is high. Doctors are not as good as nurses at emotional support – hardly a new story – but with a score of over 6/10 it suggests they are doing a lot better than history tells us they used to do. The score for diet support is very disappointing and one we would hope that hospitals and cancer units will address.

This survey confirms the information we already have about support groups. They are not for everyone but for those who wish to meet other patients they can be very positive. However there are few sarcoma specific support groups and contact at clinics is not enough to address the sense of isolation which many sarcoma patients report. At the same time there is a lack of counselling availability, although it is interesting that only 6 (35%) of those offered counselling took it up. Its importance is highlighted by the fact that 9 (32% of those not offered it) sought it independently. Again, counselling is clearly not for everyone, maybe only one-third of patients, but the score it was given shows that for some it is extremely valuable.

Cancer BACUP's booklets are clearly valuable and we will be able to give them some feedback. The importance of the Internet as a source of information is also well illustrated. The 69% using the web is in excess of the average of internet use in the general population.

Thank you to all who responded. We will use these results as part of our approach to raising sarcoma awareness and pushing for improvements in care.

Editorial Comment – is it NICE enough?

The National Institute of Clinical Excellence was set up to decide which treatments should be paid for by the NHS in England and Wales. It was an attempt to eliminate 'post-code prescribing' where patients in different parts of the country receive different treatments.

NICE processes are consultative. It makes its decisions on the basis of research evidence and it considers evidence or comments submitted by patient groups as well as medical researchers. The Technology Appraisal of imatinib (Glivec) for the treatment of advanced or unresectable GIST took almost 20 months to complete. Among the problems it faced is that there was little research on GIST before imatinib was available. The most important result is that imatinib can be prescribed on the NHS by oncologists treating GIST patients. However there is also guidance for the NHS about ceasing treatment even though there is no evidence base to support this guideline. NICE also made recommendations for further research, which are impractical. The guidance will be reviewed in October 2007.

Research and treatment for GIST has moved so fast that the guidelines for ceasing treatment are already less-than-best practice. The review date, if it remains unchanged, also presents a problem because of the new treatments which are rapidly becoming available. Should the treatment of GIST patients with advanced disease in England and Wales be the best in the world? If we wait until the end of 2007 to start a review of the situation that will be unlikely - despite the UK having some of the best doctors in the world.

NICE is genuinely trying to do its best. However its processes are inflexible - it seems incapable of adjusting to accommodate rare diseases or potentially fatal situations, a fact recently recognised by one of its own consultative groups. The experience of the imatinib/GIST appraisal tells us that all is not well. We hope that has been noticed in the NHS corridors of power.



Harry with his grandson

THE LITTLE BEASTIE

A poem by John Harry Ayers

A while ago I found a lump that didn't look too bad,
 "Now, should I see the Doctor, dear?" My wife said, "Better had".
 The doctor said, "Don't worry", on that he did insist,
 "We'll check again in four weeks time, it's probably a cyst"
 Now just as luck would have it, a specialist I'd to see...
 ... next day to get my scan results about my damaged knee.
 I took the opportunity to show the lump I'd found,
 He didn't seem to like it much, arranged an Ultrasound.
 Well over several weeks and months more scans and tests took place,
 Then finally I got the news, they told me to my face.
 Myeloid Chondro Sarcoma is what the beastie was,
 "An operation's what you need, it must come out, because...
 ...if left there unattended to, the thing will grow and grow,
 and then you'd need to have your leg removed from top to toe."
 The operation was arranged and me confined to bed,
 More checks and tests but happily, the beastie hadn't spread.
 I understand the op went well but blimey it was sore,
 And whilst still in recovery ward, who should come in the door?
 Two "sympathetic" physios to get me out of bed,
 They were a day ahead of time; you'll guess just what I said!
 From next day on they did their job, it helped I have no doubt,
 And even though on crutches, in four days I was out.

Some post-op Radiotherapy was my next port of call,
 With a daily trek to Christies for a full 6 weeks and all.
 "Now Mr. Ayers, what's your address? That's right now come this way,
 And take socks, shoes and trousers off and on that table lay".
 Two thin green lines were generated, crossing at the spot,
 From which all measurements were made, and there were quite a lot.
 The first whilst lying on my back, ignoring how it feels,
 A two and twenty centimetres, gap between the heels.
 They next made sure the line was checked, through ankle, knee and shin,
 Now 4 point 1 moved to the right, and 2 point 9 moved in.
 Now elevate by 1 point 6, just two more things to check,
 The distances from gun to leg, when angled to the deck.
 The beams were from two-twenty, and then three-thirty (two),
 Oh by the way I should have said, I had to wear "the shoe".
 A simple plastic mould designed to keep the ankle set,
 At angles worked-out best for aims of treatment to be met.
 With all the checks completed, the roggies* smiled to leave,
 And in anticipation, my chest began to heave.
 With entry warning system armed, the lights first off, now on,
 And lighting-up the ceiling tiles, just like the morning sun.

The picture was quite soothing, a canopy of trees,
 The background music classical, T'was all designed to please.
 Then warning signs flashed on and off, and whirring sounds occurred,
 "Elekta" did its job as planned; the time just went, quite blurred.
 In minutes all the treatment's done, there's nothing seen - no pain,
 "Be back same time tomorrow", and we'll do it all again.
 Now some days were quite different, with extra checks to do,
 They'd look for signs of swelling, and irritation too.
 On Thursday's I'd be earlier, the Doctor I'd to see,
 He liked to keep an eye on things, my ankle, scar and knee.
 He said that all is going well, when he walked in the door,
 But as the end of treatment neared, I'd get a little sore.
 I don't give two brass monkeys though, for when all's said and done,
 I'll be a happy bunny, if the little beastie's gone.

It just remains to give my thanks to each and every one, The Roggies*, Docs and Physios, for a splendid job - Well Done!

* Roggies - my endearing term for the radiographers.

PATIENTS TALK TO PATIENTS – SUPPORT AT ITS BEST

Our sarcoma email support list has been running for about 18 months. There have been some truly helpful and supportive message during that time. With Peter Jay's agreement one of his recent messages, slightly edited, is reproduced below.

There's lots I can tell you about my journey through all this. To begin with I didn't trust the doctor - everytime he told me something I thought 'he would say that wouldn't he?'

I convinced myself that if I was going to die he wouldn't tell me anyway. It took time to build a relationship with him and I was lucky to have a good consultant. I even went to see the pathologist, that was my own idea but it was after I had researched as much as I could about my lump. My pathologist sat in his office, pocket handkerchief matching his tie and speaking 'awfully, awfully nicely'. He seemed terribly prim and proper. His secretary produced tea and biscuits and we had a long chat. He was really straight with me.

His final words I will never forget (bearing in mind the 'la-de-da' he was). He said, "Peter, there's only one thing I can say to you now. Whatever happens from hereon there's f*** all you can do about it!" I was stunned but as it sunk in I realised he was right. I was in their hands entirely and provided I understood (and questioned where necessary to satisfy myself) I had to trust the medical profession.

They told me if it came back it would be on my chest.

"I was in their hands entirely and provided I understood (and questioned where necessary to satisfy myself) I had to trust the medical profession."

I had to have chest scans at frequent intervals and each of those scans would be preceded by two weeks of discomfort and pain in my chest. After each scan I had to wait a week for the result - the pains continued. As soon as he saw me in the waiting room (and before my appointment) my consultant would



Peter Jay

shout at me "Your scan's clear" and give the thumbs up. Instantly my chest pain would melt away! It was all in the mind.

Strange things may happen to you along the way and there will possibly be disappointments (I called them hurdles to get over) - but you can either lie on the floor, kick your legs in the air and cry "why me" or you can stand up and fight. Not much choice really!!! Be positive, be bright with your friends and try not to be hurt by those friends who don't know how to handle you and therefore steer clear. That invariably happens.

I'll always try to respond quickly if I can and on this site you can be honest. We have all been there and there's no need for you to be lonely in this.

If you would like to join the sarcoma email list it is free and easy to access. There is no obligation to send messages, and at times the list can be very quiet. Go to www.mailtalk.ac.uk/lists/sarcoma.html and follow the path to register.

Booklist

Warmly (highly) recommended read:

"The Anatomy of Hope" (How People Find Strength in the Face of Illness)

by Dr. Jerome Groopman published by Simon & Schuster UK 2005

ISBN 0-7432-6390-1 Price £10

Jerome Groopman has been a doctor for almost thirty years. He has seen the astonishing effects that hope, or lack of it, can have on an illness. Here, with great wisdom and compassion, he reveals what he has learned about hope and its ability to triumph over disease, both emotionally and physically.