

A chance ...of life

It all started in December 1999 as I kept falling asleep in the afternoon, and had funny aches and pains in my legs. I went to see my GP in the New Year, who examined me and noticed I had a large lump in my stomach and so I was sent for an ultrasound scan. They found I had an enlarged spleen and did some blood tests that showed I had a high white cell count, the highest they'd seen in a long while.

At the hospital, I was diagnosed as having Chronic Myeloid Leukaemia (CML) – a disease I knew nothing about, but was very scared of all the same. I was examined by loads of student doctors too, as my spleen was so unusually large, which was really strange, being looked at by so many strangers! At first I couldn't believe it, I was numb and in shock. Then I got angry – I'm quite an independent person and I hated being stuck in hospital having to take so many tablets at set times. I felt like all my choices had been taken away. It seemed like a whirlwind of treatment, but I realise now how vital early diagnosis and treatment can be.

Worried about hair loss

I was sent to see Dr Marks at the Bristol Hospital for Sick Children, who kindly explained every option to me and recommended I have a full bone marrow transplant (BMT). I was put on the list and they found two possible matches straight away! However, I was got myself so worked up about possible side effects that I chose not to go ahead with a full BMT, even though my partner, Etienne, wanted me to. Looking back, it was the best option really and I wish I'd been more positive about it. I was so worried about losing my hair then – it's amazing how much I didn't know about leukaemia, but it's something that you only find out

about when you've got it. I thought it was the leukaemia that caused hair loss... I didn't realise it was the chemo!

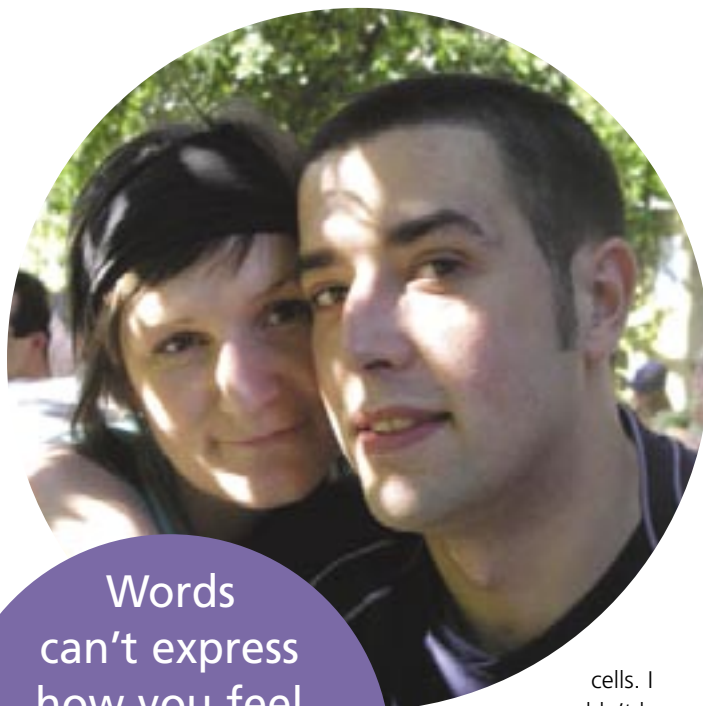
I was lucky enough to be given the chance to go on the new Glivec trial with Dr Milligan at Birmingham Hartlands Hospital. It seemed like the best option at the time and in August 2000 started on the trial. I was warned, though, that a BMT was likely to my only long term solution.

Life carried on fairly normally for two years. I was tired sometimes, and a bit nauseous, but on the whole Etienne and myself just carried on. I had lots of support from my family and I was working part-time, which was enough for me.

Mini-transplant

In 2003, I went back to see Dr Marks. Since I first saw him, there had been many more successful mini-transplants, and this was an option he put to me. Although the success rate was slightly lower, I felt this was right for me, so in November 2003, I went into hospital. I stayed in for four weeks, and although I lost my hair, I was so pleased it grew back again within six months. I was happier with this treatment and wasn't sick once, but think now that I was a bit of wimp about the treatment.

I was out before Christmas, but by April needed to have regular top-ups of white



Words
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how you feel
about your donor...
you owe them
everything

cells. I wouldn't be here today if it wasn't for the lady who donated her bone marrow. I found out later that she came from Newcastle and was in her early thirties, like me. Words can't express how you feel about your donor... you owe them everything and no amount of flowers or presents would be enough to tell them what a truly marvellous thing they've done... to give someone a chance of life.

Public speaking

I was asked to do a talk at the CML Conference in Bristol by Dr Marks as he wanted me to share my experiences with others. I've never done any public speaking before, but even though I was panic stricken, I got up and spoke in front of 200 people. I did it for Dr Marks to say thank you for all he's done for me. I'd also like to thank all the nursing staff who've cared for me during my treatment. They really treated me like I was special and made it all bearable.

Above all, Etienne helped me tremendously. He wouldn't let me get down and kept me positive. He is a real inspiration to me and I'd like to thank him for showing me the way.

Maria Drew



Listening to Dr Ian Gibson, MP - Chair of the All Party Parliamentary Group on Cancer, and representing Leukaemia CARE, are (left to right) Raymond Knox, Roland Maturi, Chris Matthews-Maxwell, Tony Gavin, Clive Hatt, Ann Ashley and Neil Gillespie.



Call for fairer deal for lymphoma patients

Every hour of every day one person in the UK is diagnosed with lymphatic cancer. Around 45,000 people in the UK are living with the disease and incidence is rising.

Given the appropriate treatment at the appropriate time, many lymphoma patients can have their disease managed effectively or even be cured. There have been huge advances in treatment which have resulted in more patients surviving, and with a better quality of life.

However much remains to be done. This is the first time that groups – the Lymphoma Association, Leukaemia Research Fund, CancerBACUP and Leukaemia CARE – have come together as the Lymphatic Cancer Alliance to propose a unified plan for helping lymphoma patients.

Patients, trustees and staff from Leukaemia CARE attended the launch of the Lymphoma Manifesto at a reception at the House of Commons in November 2005. The Lymphoma Manifesto demands accurate diagnosis, timely access to the best treatment, high quality supportive care and information, and investment in research as the cornerstones of the UK's approach to the condition.

The manifesto identifies the changes that are required throughout the patient



Sharing experiences are (l to r) Eve Martin, Tony Gavin and Ken Campbell of the Leukaemia Research Fund.

journey if all today's lymphoma patients, as well as the growing numbers who will have the disease in the future, are to receive the best treatment. If these changes are to be delivered, then greater resources will need to be allocated for lymphoma care.

Each of the patient groups are committed to the belief that all patients with lymphatic cancer have a right to:

- 1 Accurate diagnosis**
- 2 Universal access to the best treatment**
- 3 High quality nursing care, support and information throughout diagnosis and treatment**
- 4 Investment in research today**

announcements

Christmas baby!



Nicky Sargent, our Fundraising Executive, has had the best present delivered that she could ask for – a healthy new baby boy! Elliot Daniel, 9lb 8oz(!)

was born at 3.35pm on Wednesday 28th December 2005. Nicky describes it an epic journey, but one she would repeat tomorrow!

Welcome to our new staff

We have had numerous new members of staff joining Leukaemia CARE since the last issue of Focus.

George Home (pictured left) has joined us as PR & Marketing Assistant. She has a background in photography and graphic design, with writing being a favourite pastime too. Her first day will always be memorable as she agreed to promote the Christmas Fun Run by jumping around in the freezing cold while being photographed for the local paper, dressed as Mrs Claus!

Alice Watts, Events and Sponsorship Assistant (right), was also thrown in at the deep end due to the Christmas Fun Run. Alice has been involved in fundraising since attending Exeter University and has worked previously for a charity in Bath, and for a corporate events company in London. She is currently arranging her sister's wedding, so certainly has the organisational skills needed to work in the fundraising department.

Sally Everton (pictured right) started with us in November and is settling in very well at One Birch Court as our part-time receptionist.



Lastly, Clare Brooks, CARE Team Administrator (left), is the newest member of staff. She has come to us from a residential home for adults with learning disabilities. Clare thinks

the role of CARE Team Administrator is a great career move for her.

Giving back to our Vol

Our Volunteer Conferences are always an enjoyable and rewarding event for Leukaemia CARE staff, as we get to meet and catch up with so many of our Volunteers. It is our chance to thank them face-to-face, to hear all about their experiences out 'in the field', and to listen to their ideas about how we can improve our care and support services.

On 12th November 2005, around 40 volunteers, plus various staff and trustees, attended the first Volunteer Conference to be held at our new offices at Birch Court, Worcester.

The theme for the day was 'Giving back to our Volunteers'.

The Trustees and staff of Leukaemia CARE wanted to thank all those who have volunteered for the Charity over the years, for their commitment, the support they have given and to show how much their efforts are appreciated. Without our Volunteers, we simply couldn't exist.

After some welcome refreshments, where new Volunteers had the opportunity to meet their colleagues, the conference was opened with a welcome speech from Clive Hatt, followed by a presentation by Tony Gavin on his role and the work he is now responsible for.

Tony introduced and explained the little known but vital role of patient advocacy, in which the

groups he is involved with are making great progress. He is also constantly developing alliances with other cancer charities. Tony has developed

further our exposure to the corporate world, resulting in successfully securing some substantial sponsorship that is mainly being used to furnish our new CARE facilities.

Following Tony there were presentations from the teams. They all introduced themselves, particularly the new team members, and explained their roles and what exciting initiatives they have planned for the future.



**"Thank you Leukaemia CARE. Amazing work since last year."
Angela Colsell**



Eve Martin, National CARE Manager, presents plans for improving future CARE services



unteers

Training programme

We were very pleased to hear presentations from Regional Co-ordinators Neil Gillespie, Elspeth Brewis and Suzanne Riley. They explained about our comprehensive training programme, developed in conjunction with a professional bereavement counsellor, and outlined the various benefits available to both Volunteers and healthcare professionals.

After a break for lunch, we heard from the key speaker Eve Martin, our National CARE and Support Manager. Eve covered a broad spectrum of relevant CARE issues, including a campaign to increase the number of Volunteers across the UK. She asked for the Volunteers' support and made suggestions to improve our ability to get literature into the right places - hospices, GP surgeries and health centres, and on ward.

Telephone supporters

Eve announced plans for recruiting further patient support through telephone supporters. Telephone supporters will be prepared to maintain contact with people they are supporting and also with the CARE team. They will feed back vital information that will enable us to support those carers and patients more effectively. They will be bound by current protocols and given training.

Website live forum

She outlined plans for a new website facility, where doctors and nurses would be available to answer questions from patients in a 'live' forum, and also hear patients talking about their experiences.

Patient Conferences

Eve updated the Volunteers on the exciting plans to hold four patient conferences across the UK aimed at specific patient disease groups. The first will cover chronic lymphocytic leukaemia, Hairy cell leukaemia and non-Hodgkins

"Great building, fantastic staff and a very good format for the day, thanks"
Keith Lister



lymphoma and will be held on 6th May 2006 in London. We are currently contacting eminent speakers, medical personnel and relevant professionals who will carry out various workshops on the day.

Constructive workshops

We split into five groups, which consisted of a good mix of staff, trustees and Volunteers. Each group discussed and gave their views on a number of issues, many of which we have already put into action. These workshops provide an ideal platform for 'getting to know' colleagues and for sharing ideas and learning new ways of making the Volunteer's life easier!

Invitation to all our Volunteers

Tony Gavin closed the conference by thanking all those who attended, expressing the hope that they had gained as much as he had from the day. He also hoped many more Volunteers would attend the next regional Volunteer Conferences, as the feedback from those who had attended showed that there is much to be gained by meeting fellow Volunteers and staff face to face. There will be two conferences, one in the North and one in the South towards the end of 2006. We really look forward to seeing all our Volunteers there.

In the evening we were able to treat our Volunteers to a dinner and disco party as a gesture of thanks for all their efforts!



The workshop was very interesting and informative.



The Fundraising team give their update to Volunteers.



Volunteers get the chance to feedback their ideas.

Don't forget
Mother's Day!
Sunday 26th
March 2006

flower images courtesy of www.mackayphotography.co.uk

Think before you click!



We've all done it! You have the best intentions, you know how easy it is to raise some extra cash for Leukaemia CARE, but when you sit down at your computer, it goes clean out of your head!

So next time you go to buy anything online, please go to www.buy.at/leukaemiacare first. You can quickly see our shop, and which retailers you can access through this site.

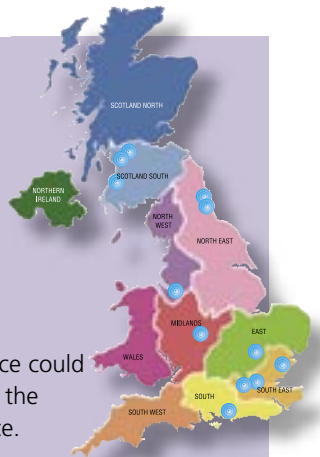
Simply follow these steps to supporting Leukaemia CARE:

- 1 Simply enter the website address **www.buy.at/leukaemiacare**
- 2 If you know the retailer you want, simply click the A-Z tab, then enter their store, or choose gift finder
- 3 Do your shopping as normal. The difference is that Leukaemia CARE will benefit from every purchase you make.

www.buy.at/leukaemiacare

Ever thought of Volunteering?

Can you spare some time every week? Are you over 25? Do you have proven experience of leukaemia, lymphoma or an allied blood disorder? If the answer is **YES**, we need you!



We really need people to train to become Volunteers across the country. You could give back some care and support to patients, their carers and families, over the telephone and in person.

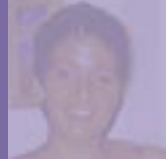
There are so many patients and families who are desperate for people to talk to. But most importantly, someone who understands what they are going through and who can answer their queries or help them find out the answer. Your

personal experience could make all the difference.

We will provide you with on-going training and support, including a full-time Volunteers Co-ordinator and Regional Co-ordinator both there to support you.

Give yourself the chance to bring comfort and reassurance to others and help them through a very difficult and uncertain time.

Please call Dawn Knott on 01905 755977 extn:230



Several Silly Santas racing 'round the racecourse

Sunday 4th December saw a mass gathering of Santas at Worcester's Pitchcroft racecourse, for the third annual Leukaemia CARE Christmas Fun Run.

Despite the last minute change of venue (due to an FA Cup match between Worcester City and Huddersfield Town)

spirits were running high among the 300 or so Father Christmases who took part. Luckily, the weather stayed fine (although rain earlier in the week had left parts of the course quite muddy) and a fun time was had by all.

The crowd were warmed up by Wyvern DJ Ed Nell and two fitness instructors. Ed Nell then compered as the neared the end and congratulated runners as crossed the finish line.

The race was won by 45 year-old Trevor McGuill in an impressive time of 18 minutes and 50 seconds, with chairman Clive Hatt bringing up the rear! The youngest participant was undoubtedly 17 month-old Jessica Gethins who completed the course strapped to the back of her grandmother, Lin Portlock.

With the BBC in town to cover the football match at St George's Lane, the outside broadcast crew arrived to film the Fun Run which was broadcast during half-time – fantastic coverage for Leukaemia CARE!

This was also the first year that the run was held at two sites, with around 60



Santas also running at Evesham.

All that is left to do now is to gather in the sponsorship money, the deadline for which was January 31st 2006. News will follow shortly about how much was raised in total on the day.

Congratulations must go to Louise Carlin and her team for arranging their first Christmas Fun

Run for Leukaemia CARE and for tackling every obstacle that was put in front of them to make the day a great success.



Louise said: "I think it's been a fantastic day and I'm so proud of everyone in Worcester for pulling together. It's been amazing to see everyone turn out and support such a worthwhile cause."



Flora London Marathon 2006

Date: 23rd April 2006

Ballot places for the Flora London Marathon were all allocated at the beginning of December 2005.

If you have been successful in the ballot, please join our London Marathon Team. You will receive a monthly magazine, training t-shirt, running vest, an invite to our free post race party for you and all your supporters, a free massage after the race to ease your aching limbs, plus a commemorative t-shirt.

To join the **Leukaemia CARE Marathon Team** please call **0870 7743667**



CASH from TRASH!



We all know that recycling makes sense and, even better, it's now possible to raise significant cash from your trash for Charity too. But how can you help?

You can recycle your unwanted mobile phones and Inkjet cartridges. It's that simple – request a recycling pack from Leukaemia CARE and you can find out exactly how you can help.

Just pop your unwanted mobile phones and used inkjet cartridges (not Epsom) into the bag, complete your details in the space provided and then post it for free! It's really that easy to turn your trash into cash! And it won't cost you a penny. You could set up a Leukaemia CARE recycling box at work and raise vital funds for us by simply sending away your rubbish!

Return two or more inkjet cartridges or mobiles and be automatically entered into our free monthly draw for a luxury Hilton Hotel break for two!

Stamps

We are very grateful to all those who collect stamps on our behalf, but please don't send them direct to the us. Please remember to send them to: Leukaemia CARE, PO Box 6198, Leighton Buzzard, Bedfordshire, LU7 9XT. Please note that to save us extra costs, this is NOT a freepost address.

Reasons to recycle:

- ✓ The Recycling Appeal allows charities to raise significant cash sums for your waste
- ✓ We should all be playing our part to protect the environment
- ✓ There are millions of mobile phones and print cartridges discarded every year
- ✓ Binned mobile phones and cartridges end up in landfill sites destroying our countryside
- ✓ Recycling appeal has raised over £600,000 for good causes
- ✓ This service is simple, free and benefits everyone



2nd July 2006 During its brief five year history, the annual **British 10k London Run** has quickly grown to become the third most significant mass participation road race in the UK. It is staged on the world's greatest route, which no other road race can match, passing many of London's most famous historic landmarks, and is run on some of the most famous street names in the world!

The race has played host to some of the finest athletes from the world of middle and long distance running, and many celebrities have run the race to raise money for their chosen charities. Alongside these famous faces, many

thousands of runners from all over the UK and overseas compete, including teams from hundreds of UK charities.



!!! CHARITY PLACES AVAILABLE !!!

11th June 2006 The **Edinburgh Marathon** is not only the biggest marathon in Scotland, it is now the 2nd fastest marathon in the UK. Over 15,000 people are expected to enter the 2006 event and, in order to accommodate this growth, there will be some changes to the course. It will be much flatter than in previous years and therefore many runners may be able to clock a PB, so don't miss your chance!

Dates to remember...

If you don't like running, how about one of our other activities - overseas expeditions, skydiving and whitewater rafting. See www.runleukaemia.org.uk for more details.

- | | |
|---------------|--------------------------------|
| 14 Jan | Great Winter Run |
| 12 Feb | Tough Ten Challenge |
| 13-21 | Sahara Trek |
| 9 April | Great Ireland Run |
| 23 April | Flora London Marathon |
| 21 May | Great Manchester Run |
| 11 June | Edinburgh Marathon |
| 2 July | British 10k London Run |
| 18-26 Aug | Iceland Trek |
| 4 Sept | Hydro Active Women's Challenge |
| 14-23 | Sept Peru Trek |
| 1 Oct | Great North Run |
| 29 Oct-10 Nov | Vietnam Trek |



If you'd like further information about
Leukaemia CARE, please complete
 the Contact Form below,
 post it to us and we will send you
 an information pack.

Contact Form

Leukaemia CARE - caring for people affected by
 the leukaemias • Hodgkin's and other lymphomas • myeloma •
 myelodysplasia • myeloproliferative disorders • aplastic anaemia

please tick

I would like information about the following condition:

I would like to receive Focus regularly.

Please send a copy of Focus to my friend:

I would like details of ways in which I can help
 as a Volunteer, and can offer the following skills:

I would like to help with fundraising.

I would like information on regular giving or to leave a
 legacy. Please send me further details.



Leukaemia CARE
supporting a quality of life

Please complete and return this form to

Leukaemia CARE
One Birch Court
Blackpole East
Worcester WR3 8SG

All information that you provide is protected by the Data Protection Act, and will not be shared
 with any other organisation. You have the right to advise us at any time if you do not wish to
 receive future mailings from Leukaemia CARE.

Please complete your details below:
 (PLEASE USE BLOCK CAPITALS)

Full Name _____

Mr/Mrs/Ms/Miss/Dr _____

Address _____

Postcode _____

Telephone No _____

Email _____

Membership No _____

Occupation _____

Are you a Patient Carer Professional ?

Other please tick

If other, please state _____

Relationship to you _____

Patient's date of birth _____

Type of leukaemia/allied blood disorder _____

Date of diagnosis _____

Hospital where treated _____

How did you hear about Leukaemia CARE?

JOINING LEUKAEMIA CARE IS FREE. However, you may wish
 to enclose a donation of £ _____ towards the work of the Charity.
 (Please make cheques or postal orders payable to "Leukaemia CARE")

please tick

giftaid it

Declaration:

I would like Leukaemia CARE to claim the tax back on all donations I make
 until further notice. I am a UK taxpayer and understand that I must pay an
 amount of income tax/capital gains tax equal to the amount Leukaemia CARE
 reclaims on my donations in the tax year (currently 28p for every £1 donated).

Sign & date _____

Please detach this page and post or fax to us on 01905 755166

24 hour CARE Line 0800 1696680



The CARE Line is the only dedicated freephone telephone service for people affected by leukaemia, lymphoma and the other allied blood disorders. Having the opportunity to talk with someone any hour of the day, 365 days a year, can be of great benefit and comfort for patients and their families, particularly those who are feeling lonely and isolated.

Patient Advocacy



Our involvement in various patient forums and consultation groups means we can use our influence to affect government opinion, particularly with regard to patient wellbeing,

NHS funding and availability of drugs and new drug licensing.

Regional CARE Teams



Regional CARE teams are operated by Volunteers across the UK and, working closely with local hospitals, they are able to reach and help patients at an earlier stage of diagnosis.

Our support is substantial and provides the personal, friendly contact which so many patients, their families and carers need. The knowledge that there is a friend who understands, is compassionate and can empathise, brings great reassurance to a patient. Our Volunteers provide over 30,000 CARE hours per year to patients, their families and carers.

Support Groups



There are many Support Groups across the country that provide help and advice to patients on a local basis. Many of these groups are located within hospitals,

and enable patients to talk with others in a similar situation. We are increasing the number of groups across the country, and want to hear from you if you think there is a need for a Group in your hospital. For more information on a Support Group near you, please call the CARE Line on 0800 1696680.

Information and booklets



Although the Charity does not provide actual medical support, we do supply a wide range of information on leukaemia, lymphoma or any of the allied blood disorders. We also have many authoritative booklets and information sheets on a range of

issues that can affect patients. In addition, our website www.leukaemiacare.org.uk acts as a gateway to more specific information.

Financial assistance



In certain circumstances, Leukaemia CARE can provide limited financial assistance to needy patients and their carers.

This can include travel costs to and from hospital for other family members, payment of utility bills, food vouchers, or help with the purchase of essential household items. We also provide a signposting service in respect of welfare rights, other charities and organisations who may be able to offer additional assistance.

Holiday programme



For many patients a holiday break provides a real boost, bringing a refreshing change from hospital visits. Leukaemia CARE is building on its current programme by developing a wider range of

breaks, to enable the patient to create more individual and varied holidays required by their treatment.

If you or a member of your family or friends have any questions or further needs, please contact Leukaemia CARE on 0800 1696680 where someone will be happy to assist you.

A Night to Remember...

For our 10 lucky patients, and their carers, comes the chance to experience a truly memorable evening of champagne, fine food and music as they attend A Night Under the Stars with Elton John on 11th June 2006.

For the first time Leukaemia CARE has put together a fantastic, fun programme, which we hope will bring back memories for years to come.

As a patient with a life threatening blood disorder, you are so involved with trips to hospital, and sometimes painful treatment, it can be difficult to find the time, and money, to treat yourself. This is also often the case for your carer or members of your family, as their lives are taken over with caring for you.

So we wanted to give you the chance to do just that and bring a bit of sparkle into your lives! You don't have to be a member of Leukaemia CARE to enter this amazing competition. If you would like to take part in this Night to Remember, simply complete the entry form and send it back to Leukaemia CARE as soon as you can. The closing date is 28th April 2006 and the draw will take place on 2nd May 2006. The first 10 lucky names to be drawn will each win two places on our Night to Remember, and

will be able to bring along a carer of their choice.

The Programme

Everyone will meet at our national office in Worcester at the allotted time, where you can leave your car in safety. To whet your appetite we will have welcome drinks and, if you don't know us yet, a quick introduction to what we do.

You will then be taken by mini bus to a fine Worcester restaurant and then whisked onwards after the meal to the Elton John open air concert. It is being staged at the well known New Road home of Worcester County Cricket Club, with the impressive backdrop of Worcester Cathedral.

Then it's 'take your seats' for a night of music under the stars (umbrellas will be provided if the weather isn't kind to us!). Afterwards, we return by minibus to our offices once more to collect your vehicles.



Don't forget to fill out your form NOW!

Closing date: 28th April 2006

ELTON JOHN

A NIGHT UNDER THE STARS

10 pairs of tickets to be won!

If you are a leukaemia, lymphoma patient, or have an allied blood disorder, we would love you to enter our competition to win a place for you and your carer on our Night to Remember on 11th June 2006.

See inside the back cover for full details of the fantastic programme we have lined up for you, entry form and closing dates.



Leukaemia CARE
supporting a quality of life

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Fundraising Team: **0870 7743667**
CARE Line: **0800 1696680**
Website: www.leukaemicare.org.uk

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