



# Leukaemia Busters

The Children's Leukaemia Research Charity

Newsletter No. 16

AUTUMN '99

Reg Charity No.1010957

# LIGHTHOUSE CHALLENGE

## RAISES OVER £43,000

THE first ever Leukaemia Busters Lighthouse Challenge took place on Saturday 26 June 1999. Some 730 people of all ages signed up to take part and committed themselves to raising sponsors. With a choice of 6 different routes, the walkers donned their boots and trod the cliffs, coves and inlets of the Dorset coastline between the famous lighthouses of Portland Bill and Anvil Point. The weather was glorious. Walkers assembled in the beautiful grounds of Lulworth Castle and then were bussed to the starting points of their chosen walks. At the end of the day a barbecue was provided and exhausted participants could relax to the sound of Southampton salsa band Mambo Jambo. An additional highlight to



the evening was a winning display by the Coastguard Helicopter which delivered local celebrity, David Gower into the castle grounds much to the delight of the crowd.

Sponsor money is still pouring into the **Leukaemia Busters** Appeal Office and it is estimated that more than £43,000 will have been raised towards the **Leukaemia Busters** Millennium Appeal. The aim is to reach one million pounds by the end of the year 2000 to pay for the expansion of our laboratory facilities and enable us to run a paediatric trial in seven different cancer centres in Britain to test revolutionary new, safer treatments for childhood leukaemia.

### STOP PRESS CHILDHOOD LEUKAEMIA TRIAL RECEIVES OFFICIAL APPROVAL

Approval has just been given for the use of the Leukaemia Busters developed drug BU12-SAPORIN in a national trial in children with relapsed leukaemia. This will represent the first time that an antibody-based treatment has been used in children with leukaemia in this country. Trials will be conducted at seven children's cancer units around the UK. See page 5 for full story.



*"Fighting for Their Lives"*

Patrons: Gary & Michelle Lineker

Millennium Appeal Hotline: (01703) 796528/796270

Millennium Appeal Website <http://www.penlex.org.uk/lbindex.html>



# FUNDRAISING NEWS

To date the Millennium Appeal has raised a fantastic £640,000!



## Christmas Cards

Our lovely Christmas cards were designed by children on the cancer ward at Southampton General Hospital. They were the result of a competition judged by our patron, Gary Lineker. A mixed selection of 10 cards (5 designs) is available at £2.99.



## Stocking Fillas

Our **Leukaemia Busters** pin badges (£2.00 each) and baseball caps (£3.50) would make ideal stocking fillas. To order cards, badges or caps, send



a cheque made payable to **Leukaemia Busters** for the correct amount together with your name and address to Vickie Lush, **Leukaemia Busters**, Southampton General Hospital, Southampton S016 6YD and we will send them to you.

## Charity Flowers

Send a friend or relation some fresh flowers at Christmas and know that **Leukaemia Busters** will also benefit. Just ring 0990 300 600 (24 hours a day and 7 days a week), order the flowers you want and mention our special code LB or clearly state that **Leukaemia Busters** is your

## Just Wills

NEW THIS YEAR!

Where there is a will ...

Making a will is one of those jobs that most of us know is important but which always seems to get left until tomorrow.

So **Leukaemia Busters** has teamed up with Just Wills plc to ensure that writing your will is a cheap and easy service and will benefit **Leukaemia Busters** at the same time. You won't have to go to a solicitor's office. The whole process can be completed by post. For £35.00 plus VAT (a special discount for **Leukaemia Busters** supporters) you can have your will drawn up. For an extra £10.00 plus VAT per will, you can arrange a home visit. If you are planning to leave a legacy to **Leukaemia Busters**, Just Wills can advise you on the best way to do this.

In addition, for every will written under the scheme, Just Wills will donate £5.00 to **Leukaemia Busters**.

**So don't delay - write your will today!**

Read the Just Wills leaflet enclosed with this newsletter for instructions on how to do this.

## Events List

Friday, 12th November 1999, 7.30pm

### Music For Life Concert

Southampton Guildhall. A wonderful evening of light classical music. Tickets by phone, 01703 632601, for home postal delivery, or purchase from the Guildhall Box Office.

February 2000

### Barn Dance

June 2000

### The Millennium Lighthouse Challenge

July 2000

### Leukaemia Busters Summer Ball

Contact **Leukaemia Busters** for details

## Special People



Jean Seagrove, Jill Collins, Margaret Stubbs, Pauline Burnett, Marie Huntress and Merilyn Burke receiving a New Years Honours medal from Ian Murray, the Editor of the Southern Daily Echo for their services to Leukaemia Busters.

All organisations have their special people and **Leukaemia Busters** is no exception. Pictured here are a group of ladies without whom you would not have received this very newsletter that you are reading. Twice a year they give up their own time to pack our newsletters into plastic envelopes and attach address labels to them so that they can be dispatched to you. THANK YOU ladies!

## Fundraising hotline



(01703) 796528  
or (01703) 796270

## Literacy for Leukaemia

Bitterne C.E. Infant School was one of the many schools that took part in our Sponsored Literacy campaign. The children collected items to match adjectives such as 'broken', 'bendy' and 'hairy' and are seen here with their display. A brilliant £685.74 was raised.



## In memory of Gemma

Year 10 pupils at Oaklands R.C. School in Waterlooville raised £1,500.00 through a massive raffle and also a Concert of Talent which was staged in memory of Gemma Livingstone who lost her life to leukaemia in August 1998. Two of them are seen here presenting their cheque to Claire Coxwell from **Leukaemia Busters**.



Thank you to all schools who have supported Leukaemia Busters this year.



# CONGRATULATIONS



**Counting the cash for Leukaemia Busters** Musicians Sam Stewart and Vicky Manning raised an amazing **£4877.78** when they organised a Musical Extravaganza Concert in Southampton.



**Line Dancing Bonanza** Colleen Lyne (pictured here in line dancing gear) is a long time supporter of **Leukaemia Busters**. At the time of going to print, she and her husband Steve have raised **£1365.04** this year through their line dancing evenings and also through taking part in a variety of running marathons.



**Rockbourne Fair** This annual event raised an amazing **£7000.00** for **Leukaemia Busters** last year. Picture here (left to right) are Margaret Parsons and Anthea Farwell with fundraising bears donated by Mrs Jo Kay whose daughter, Helen, died from leukaemia in 1995.



**The Mayor** of Southampton Derek Burke has chosen Leukaemia Busters as the Mayors charity for 1999/2000. Councillor Burke commented "I'm privileged to be associated with the work of **Leukaemia Busters**. I hope the local community and businesses will support the events organised and help raise the funds required". Already a collection held alongside the Southampton Carnival organised by Southampton City Council's department of Community Culture in partnership with the local community raised over £800. *Picture by Southern Daily Echo*



**Weston Beach Race** Watched by huge crowds, Gaynor Nash, Jon Ashby and Matthew Bye all took part in the spectacular 16th annual Weston Beach race. Between them they raised **£552.70** for **Leukaemia Busters**.



**Coffee and Luncheon** This colourful display was just one part of a splendid coffee morning and luncheon organised by Mr & Mrs Burton. The event raised a welcome **£540.00** for **Leukaemia Busters** in memory of Sara Bevan.

## Walks & Challenges



**Flora London Marathon** This year we had at least 8 runners taking part in the London Marathon. So far they have together raised well over **£4000.00**. Pictured here is John Ioannou coming through the finish line and Colleen Lyne, Fiona Green and Ann Horton sporting their **Leukaemia Busters** t-shirts.



**Coast to Coast Walk** Pictured are Greg Dickinson, John Burgess, Lee Kenworthy and Shaun Smith who walked from the west to east coast starting at St Ben's Head in Cumbria and ending up at Robin Hood's Bay in North Yorkshire. A total of 192 miles was covered across the Lake District, Swaledale and the North Yorkshire Moors. A fantastic **£9000** was raised for **Leukaemia Busters** with a further **£9000** also donated to the Anthony Nolan Bone Marrow Trust.



**Swiss Challenge** Bruce Elkins, Tony Beck, Frank Stuttard and Jeremy Weavind collectively known as "The Mad Fellows" set out on their bikes last year from the Normandy Beaches near Caen for a 540 mile ride to the Swiss border high above Lake Geneva. They made it and raised a wonderful **£500** for **Leukaemia Busters**.

**Thank you to all our fundraisers who have supported us this year!**



# FOCUS ON BUSINESSES

Thank you to all businesses who support Leukaemia Busters and help us to 'fight for the lives' of children with leukaemia.

## Having a ball . . .



David Gower and Gary Lineker investigate the quad bike which was supplied for the Auction by Yamaha UK.

Picture by Southern Daily Echo

The five star De Vere Grand Harbour Hotel in Southampton was the venue for the 1999 **Leukaemia Busters** Summer Ball. Sponsored by Barclays Bank plc it attracted over 200 guests who mingled with celebrities at a champagne reception and then enjoyed a five course dinner in the banqueting room. A charity auction supervised by auctioneer Roger Townsend from Edward Symmons & Partners and aided by Capital Radio DJ Mike Osman and TV personality, David Gower, raised further funds and the evening ended with dancing to excellent music provided by the band 'Eternal Flame'.

So far the total sum raised from the Ball is in excess of **£30,000**. A huge thank you to all businesses and individuals who supported this event.



'Eternal Flame' provided music into the early hours of the morning.



**Looking Rosy** The Bargate Shopping Centre have chosen to support **Leukaemia Busters** this year. Approaching St Valentines Day, roses were sold in the centre with all proceeds going to the **Leukaemia Busters Millennium Appeal**. Nearly **£300.00** was raised. Pictured here are Sarah Creighton and Sarah Adams in the Centre.

Picture by Southern Daily Echo



### Leisure World

The Odeon cinema at Leisure World, Southampton is supporting **Leukaemia Busters** this year. The film premier of 'Don't Go Breaking My Heart', in February, raised a fantastic **£9,236.00** including a very

generous donation from Bill Kenwright, the producer of the film. Since then, the Odeon staff have held a gruelling 24 hour basketball marathon which they hope will bring in thousands of pounds for **The Millennium Appeal**.

Picture by Southern Daily Echo



**Mambo Jambo** This lively 14 piece Latin American band have supported **Leukaemia Busters** this year by playing free of charge at the evening barbecue after our gruelling Lighthouse Challenge sponsored walk.

Picture by Southern Daily Echo

**AXA FA Cup** The AXA FA Cup Sponsorship team have supported **Leukaemia Busters** on two separate occasions this year. The famous trophy returned to The Dell in Southampton for a Saints family fun day where it was reunited with David Peach, one of the stars of the 1976 Wembley win. It also visited the **Leukaemia Busters Summer Ball**. Photo sessions at this event raised over a thousand pounds. Here Harry Redknapp also a keen and generous **Leukaemia Busters** supporter and West Ham Manager is seen holding the cup with his wife, Sandra.



Picture by Southern Daily Echo

**STOP PRESS:** The Portman Building Society have adopted Leukaemia Busters as one of their charity's for the Portman 2000 Calendar charity appeal. Branches of the Portman BS will be advertising this in 12 of their branches throughout the area and inviting customers to make a donation.



# FINAL APPROVAL GIVEN FOR USE OF A REVOLUTIONARY NEW DRUG IN CHILDHOOD LEUKAEMIA

The antibody-based drug BU12-SAPORIN developed by **Leukaemia Busters** scientists working at Southampton General Hospital has been given final approval for use in a **national** clinical trial for children with relapsed leukaemia. This revolutionary new drug unlike conventional chemotherapy currently used in the treatment of childhood and adult leukaemia's, selectively targets the leukaemia cell through the use of a monoclonal antibody that recognises and binds only to the leukaemia cell. This will hopefully eliminate any damage to normal tissues in the patients body that so often occurs with conventional drugs. BU12-SAPORIN has already successfully been through safety evaluation in adult patients with lymphoma and is now set to become the first biological-type therapy to be used in children with leukaemia in the United Kingdom. Developed entirely with **Leukaemia Busters** funding in the Simon Flavell Leukaemia Research Unit at Southampton General Hospital, BU12-SAPORIN shows great promise and it is hoped this new drug will eventually supplement current treatments improving the overall cure rates for patients with aggressive forms of leukaemia.

***"This will be the first time that an antibody-based treatment has been used in children with leukaemia in this country. We're all very excited and we believe this new drug holds great promise for those patients who are currently incurable"***

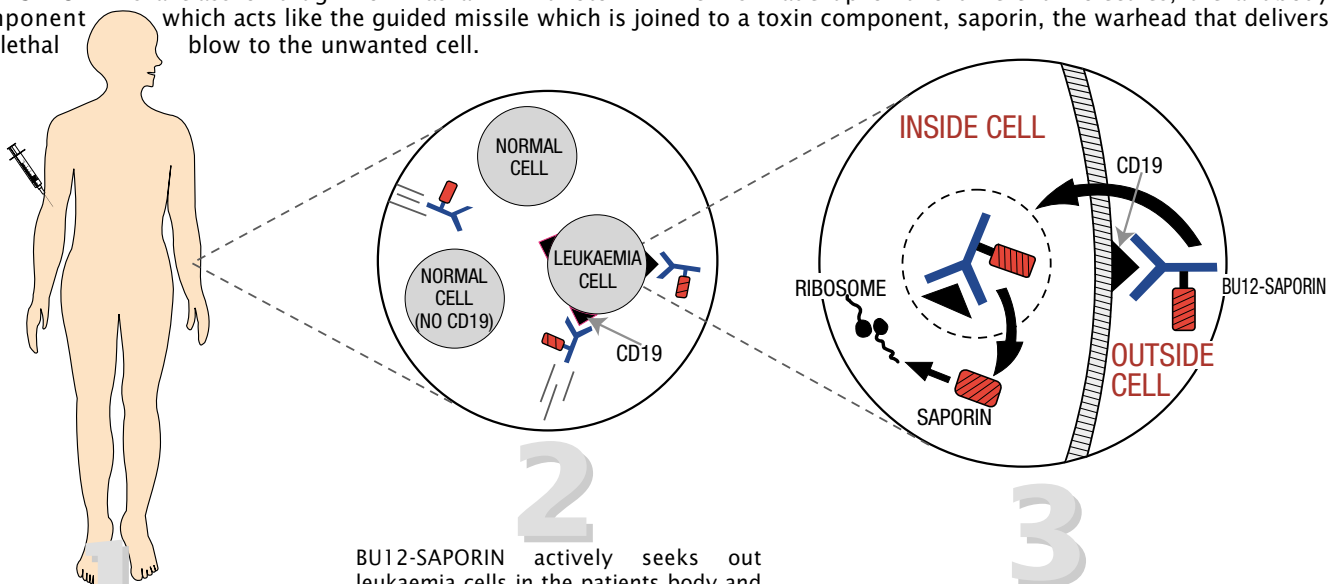


Drs. David and Bee Flavell with the antibody used in the manufacture of BU12-SAPORIN

The initial trials will be conducted at seven major children cancer centres around Britain (Southampton, Leeds, Birmingham, Manchester, Bristol, Newcastle and London) and will capture around eighty percent of the cases of relapsed childhood leukaemia that occur each year in Britain. "This is a major step forward for our work" commented Dr David Flavell, Scientific Director of **Leukaemia Busters** "it will require the co-ordinated efforts of many individuals at the seven different centres to ensure that the trial is conducted effectively". BU12-SAPORIN for the trial will be supplied through **Leukaemia Busters** funding and the trial itself will be co-ordinated by the United Kingdom Childhood Cancer Study Group (UKCCSG), the official body comprised of expert children's cancer specialists that is responsible for the design and implementation of all trials for childhood cancer in Britain. Also involved are the London based charity the Cancer Research Campaign who will provide expert input in helping organise and monitor the trial. "Because so many centres are involved and because this is the first time a drug of this nature has been used here it is of paramount importance that everybody involved work together to establish if this drug will be of benefit" added Dr. Flavell.

## How the New Treatment Works

The new treatment developed by Leukaemia Busters funded scientists selectively targets only the leukaemia cells in the patients body leaving normal cells and tissues largely unharmed. This is radically different from conventional chemotherapy drugs where normal as well as malignant cells are damaged and destroyed. The new treatment achieves its selectivity by utilising a monoclonal antibody that recognises and attaches to the leukaemia cells but not to the majority of normal cells. BU12-SAPORIN is a class of drug known as an immunotoxin which is made up of two different molecules, the antibody component which acts like the guided missile which is joined to a toxin component, saporin, the warhead that delivers the lethal blow to the unwanted cell.



1 The drug BU12-SAPORIN is injected into the bloodstream of the patient.

2 BU12-SAPORIN actively seeks out leukaemia cells in the patients body and firmly attaches to them via the antigen CD19 which is on the surface of these cells. The majority of normal cells do not have the antigen CD19 on their surface and are therefore not recognised by BU12-SAPORIN and are left unharmed.

3 The entire BU12-SAPORIN molecule is taken inside the leukaemia cell whereupon the toxin and antibody components separate. Saporin, the toxin part of BU12-SAPORIN then enters the cytoplasm of the cell and inactivates protein synthesis thus killing it.

# In loving memory of . . .

## Catherine Remnant 1985 - 1999

Catherine was fourteen when she died from Leukaemia in January this year. She had been bravely fighting cancer since her diagnosis in 1996.

She was a genuinely caring, loving and generous girl.

Catherine's generosity was only matched by her ability to talk for England. She packed as many words of conversation into her short life as many people could speak in three score years and ten.

A passion for horses and ponies characterised Catherine's life, and she was fortunate enough to own a horse called Amber, which she doted on.

Catherine's death left a huge hole in the lives of those who were lucky enough to know and love her and she will always hold a special place in our hearts.



### A Poem by Catherine Remnant

To: Mum and Dad

I feel upset and angry  
at the illness I've acquired,  
It leaves me mad and frustrated  
and feeling rather tired.

I am jelly in the middle  
but I put on a brave face.  
They say it's OK to cry  
so I have no disgrace.

But sometimes it all fades away  
you can forget just for a bit,  
like when I'm riding Amber  
or when I'm feeling fit.

There are grey skies at the moment  
But they shall soon be blue  
because whatever happens  
I will always love you.

## "Lauren Katy Hunter"

whose carefree loving character will never be forgotten  
15.06.95 - 10.06.99.

Lauren was diagnosed with A.L.L. on the 13th August 1998. Lauren had never been ill before. She was always dashing around enjoying and making the most of life. It was a big shock for us all, especially for Lauren. At 3 years old, she could not understand what was going on or why she was in hospital. Her words were, "But I'm not poorly". She fought the nurses with all her might. She eventually got used to "Mr Wiggly" (Hickman Line). She then seemed to grow up and take everything in her stride.



Lauren sailed into remission. However, our joy was short lived when, in the New Year, it was discovered she had relapsed. She had a very aggressive type of A.L.L. and needed a bone marrow transplant. Lauren had more chemotherapy but her leukaemia would not be beaten.

After picking up an infection in May, Lauren was admitted to hospital. The infection seemed to come under control but her leukaemia had taken over.

Lauren passed away in the early hours of 10th June - only five days before her 4th birthday. I am proud to say she fought to the end. Our darling courageous little girl.

There are no words to express the pain we felt when Lauren died. A big part of us died too. The support and care we received from all the kind, brave nurses on Piam Brown Ward was absolutely fantastic. I hope and pray that some day very soon there will be a cure for children like Lauren who do not respond to the chemotherapy available today.

The paper used in printing Leukaemia Busters newsletter has been kindly donated by

**Lunnons, Chichester**  
**(01243) 779966**

The Simon Flavell Leukaemia Research Unit is a living memorial to all those children who have lost their lives to leukaemia.

The laboratories are dedicated to these children so that the work carried out in them will provide a better chance for those children who come after.



The design & production of the Leukaemia Busters newsletter was donated by Romsey Communications Group (01703) 255255

## Ways in which you can help...

1. Joining an existing or setting up a new fundraising group.
2. Organising a local fundraising event such as coffee mornings, jumble sales, craft fairs and so on.
3. Entering a sponsored event for Leukaemia Busters such as swimming, running, walking and so on.
4. Persuading the company you work for to adopt Leukaemia Busters as their charity.
5. Introducing Leukaemia Busters to a group or association which you may be involved with at work or socially.
6. Making a direct contribution, possibly by gift aid or a deed of covenant.
7. Making a bequest to Leukaemia Busters in your will.

**For more information please contact Leukaemia Busters at:**  
Southampton General Hospital  
SOUTHAMPTON. SO16 6YD

A Donation in support of Leukaemia Busters' work is always very welcome. Please use this form if you feel that you are able to help:

(Mr/Mrs/Miss/Ms) Initials \_\_\_\_\_ Name \_\_\_\_\_

Address \_\_\_\_\_

I would like to make a donation of £\_\_\_\_\_ in support of Leukaemia Busters. (Cheques payable to Leukaemia Busters), or I wish to make a credit card donation by  
 Visa - MasterCard - Delta. (delete as applicable)

Name of cardholder: \_\_\_\_\_ Card Expiry date: \_\_\_\_\_

Card No.

Usual Signature: \_\_\_\_\_  
 If you are making a donation of £250 or more, please consider **Gift Aid**, which enables us to recover an extra third in Tax relief - a tax form will be sent to you for signature. Or if you would like to make a regular gift, please consider **Deed of Covenant**, please ring us for further information.

Please send to address to the left or phone: (01703) 796528/796270