

# KATIE'S LYMPHOEDEMA FUND NEWSLETTER NOVEMBER 2009



## AN EVENTFUL LUNCH IN FEBRUARY!



Beautiful orchids from the Tropical Plant Company

**Raising an amazing total of just over £8,000, not only was our lunch this year our most successful yet, it was, without doubt, our most eventful!**

On arrival at Fortnum & Mason we were informed that there had been a massive power cut from Leicester Square to Jermyn Street. We were running on emergency generators which would last for 4 hours and, therefore, through our lunch. Phew! Guests arrived, champagne in hand – the fire alarm went off! Evacuation! On to the street for us all, where we milled around, thankfully with no rain, for about half an hour!

Finally back upstairs for a delicious lunch. We owe a big thank you to the kitchen staff at Fortnum & Mason who prepared the lunch by candlelight! We subsequently discovered that we were on emergency power in the dining room but that had not extended to the kitchens! Thanks to them all for the professional way they dealt with the 'crisis' – we had no idea until the lunch was over.

The raffle was luxurious as always with some extraordinarily generous prizes, including tickets to the Masters tennis at the Albert Hall with lunch in the players' area and a £300 voucher for Maria Grachvogel's spring and summer collection. As always Anya Hindmarch donated one of her beautiful handbags (The Perry) and we had a number of prizes from Denmark courtesy of Katie's old friend Becca Shaw Frandsen.

For the first time we ran a silent auction, due to a number of unique and non-raffleable prizes. These included a week's internship with top fashion designer Maria Grachvogel, either as a PR or a Design Assistant; a photographic portrait including makeover at top UK fashion photographer

Tony McGee's studio; tickets to a Madness concert including backstage passes and signed Austin Healey dancing shoes! One of our great supporters, Will Greenwood, took up the challenge of raising funds for the auction.



For the Austin Healey dancing shoes, he decided to use a reverse bid procedure whereby we all stood up at the beginning and as he increased the bid, we could opt out at any point by sitting down. What a fabulous ruse! The Auction raised almost

£4,000 which was incredible!

Then came the speeches. **Our guest speaker, Shelley Dolan, Chief Nurse of The Royal Marsden** took to the middle of the room to make a heartfelt and very well received speech.

**Pat, Katie's Mum, presented Shelley with a £15,000 cheque** for The Royal Marsden. Marcus, Katie's brother, then told us all about his life with Katie and what had prompted him to set out to climb to Mount Everest Base Camp as our sporting fundraiser for 2009. In the midst of his very funny and very touching speech, the batteries ran out in the hand-held microphone but he carried on regardless, to a great round of applause. Read more about his exploits later in the newsletter.



We were also **delighted to welcome award winning journalist Sarah Stacey from YOU magazine** to the lunch - see back page for information. All in all a wonderful event!

**Diary Date: Monday, 22<sup>nd</sup> February, 2010 – same time, same place, same price (£45)!**

**For new supporters:**

Noon for 12.30 p.m., St. James's Restaurant, 4<sup>th</sup> floor, Fortnum & Mason, 181 Piccadilly, London W1. Carriages at 2.15 p.m.

**To request tickets:**

Email [info@katieslymphoedemafund.co.uk](mailto:info@katieslymphoedemafund.co.uk) or write to: 58 Halliford Street, N1 3EQ. Please do not send money until your place

**Special thanks go to:**



The Tropical Plant Company  
Columbia Rd



## 2009 MAIN FUNDRAISING INITIATIVES

Since our last newsletter we have had another very successful year of fundraising.

Thanks to everyone who has contributed!

Luncheon	£14,113 (gross)	£8,041 (net)
Christmas Cards/Notelets		£1,268
Himalayan Challenge		£4,285
Pat's Roman Coffee Morning		£800
Jenny's Christmas Card Lunch		£984
Thorndon Park Golf Club (see back page for info)		£986
Other donations		£709
<b>TOTAL</b>		<b>£17,073</b>

## WHAT TYPES OF PROJECTS HAVE WE BEEN SUPPORTING?

Development of an **Online learning module on lymphoedema**. This forms part of the blended learning **Lymphoedema in Cancer Practice module** which has run twice since 2007 with an updated version planned to run for the third time at the end of the academic year 2009-2010.

The module is open to registered nurses, physiotherapists, occupational therapists and manual lymphatic drainage therapists who are currently caring for people with cancer related lymphoedema, but need to develop their theoretical knowledge and skills in lymphoedema practice. The module is also open to NHS and hospice employees. **KLF is providing 5 sponsored places per module in addition to funding the module development.**

We have also **donated funds to buy lymphoedema related study books** for The Royal Marsden School of Cancer Nursing and Rehabilitation.

## WHO HAVE WE HELPED?

Practitioners we have funded in furthering their knowledge of lymphoedema this year include:

- Community Matron Lymphoedema Staff Nurse x 3
- Community Cancer Care Specialist
- Community Staff Nurse
- Physiotherapist
- Lymphoedema Nurse

## JANUARY LYMPHOEDEMA UPDATE DAY

Some of this year's funds have gone towards **sponsoring a 'Lymphoedema Update Day: Focus on Manual Lymphatic Drainage'**. This is being held on 26 January 2010 and is offered to all health care professionals and MLD therapists who treat patients with cancer related lymphoedema. The day is designed to explore and challenge the different approaches to MLD (Vodder, CasleySmith, Leduc and Foldi). It will also consider the challenges an independent MLD therapist faces in practice. Either Pat or Jenny will be attending the event as a guest speaker.

## SUPPORTING THE TRAINING OF A LYMPHOEDEMA SPECIALIST

**Mary Woods is Clinical Nurse Specialist and Head of Lymphoedema Services at The Royal Marsden Hospital.** Her role is to lead and manage the clinical service provided for patients with all kinds of cancer related lymphoedema.

She also plays a key role in teaching and training others on lymphoedema both within The Royal Marsden School of Cancer Nursing and Rehabilitation and outside the School.

Katie's Lymphoedema Fund (KLF) has **sponsored Mary in furthering her knowledge and she has recently completed the 'Lymphoedema Management: Medical Lymphatic Drainage' course** based in Wolverhampton and run by Jane Wigg and Professor Leduc.

Before the course Mary had gained a lot of knowledge about MLD through her clinical practice and also through clinical and research based papers. She had completed her MSc dissertation on the patient's experience of MLD, so she felt she had a sound knowledge base for this aspect of treatment.

Mary chose the course due to its very practical nature, underpinned by theory and research studies and also because the Leduc approach is based on two main hand movements which are then adapted and used in a variety of ways depending on the patient's lymphoedema. She is now



Katie's Lymphoedema Fund have helped us to develop a longer term plan to offer MLD training to a wider group. To be a part of that plan and for me to help shape the MLD training that we want to offer in conjunction with KLF, I felt I needed the practical skills in MLD and a more rounded approach to this aspect of treatment.

able to help patients manage their swelling using the specialised movements required for MLD and is able to apply them to a wide variety of clinical conditions.

The UK-based course also meant Mary could manage this around her work and family commitments.

Since completing the course and with more resources, Mary and her team are now able to offer 'maintenance' to MLD patients who have completed a full course of 3 weeks' daily MLD and she runs an MLD clinic for patients one afternoon each week. **In this way she can provide better care for patients, work closer with and support the MLD therapist within her team and use the skills she has gained.**

Mary has also been part of discussions and planning for the School's own MLD course which they hope to run in early 2010 and which we hope will be funded by KLF.

We are delighted to have supported Mary on this course and hope to support other practitioners in a similar way.

## HIMALAYAN CHALLENGE

Marcus, Katie's brother, has **climbed the Himalayas to Everest Base Camp** - our major sporting fundraiser this year!

**He has raised over £4,250!!** Thank you to all of those who have supported his endeavours with pledges and donations. The trek took 14 days, reaching a maximum altitude of 5,545m. It was physically and mentally challenging, but Marcus feels that Katie was sitting on his shoulder urging him on when the going got tough!



I did think of Katie a lot on this trip - the first thing that came to mind was that she would say to me "I'm glad you're doing this rather than me!" Katie was one for comfort and style and this was anything but. I had lots of chats with her along the way about all sorts of things from the trivial to the more serious, such as what I should do with my kids school wise, are they happy, etc. I really felt her presence a lot egging me on, especially up the really steep and horrid bits. Walking through the snow on the higher points did remind me of our skiing holidays we had in the Alps trudging to or from some bar!

On the way down I met an American chap who was recovering from cancer and he asked me why I did base camp and I told him all about KLF - the connection and relevance to him really hit home and made me realise how worthwhile my trip had been both personally and for the Fund.



During his trip Marcus wrote a funny and touching journal which you can read in full at [www.katieslymphoedemafund.co.uk/himalayan\\_challenge.php](http://www.katieslymphoedemafund.co.uk/himalayan_challenge.php). **Here are just a few extracts:**

**17 March, Tuesday:** Finally we start trekking. I meet Dorge (my guide) and we set off at a fairly blistering pace. This is definitely not for the faint hearted. The wind is picking up as we start to climb. My right knee is starting to grind a little. I hope it holds out. I love this place. It's like Switzerland but full of Tibetan-looking people. There is a very fast flowing glacial river below us with turquoise coloured water.



**18 March, Wednesday:** Walking much more slowly today and feeling less dizzy and headachy. Legs are good and strong as are those of the porters carrying stuff up to Namche. One guy, who has now shot ahead, must himself have weighed 55 kgs and was carrying 50 kgs of rice. Total respect for these people - my backpack comes in at about 2kgs.....Stopped for a rest. The sun's out and it's a stunning day. Got my first glimpse of Everest. God she's beautiful. Cloud was swirling around her quite rounded top.



**20 March, Friday:** .....Dorge brought me my lunch and then disappeared to eat his. It's so sweet, he knows I like to have a little time to write my journal etc. He kept calling me Mike so I called him Dodgy and that's how it remained for the whole trip!.....My fingers and toes have started to tingle like mad - just the tips. Extraordinary feeling, bit like a soft electric shock. Apparently it's altitude sickness again but otherwise no headache or nausea.

**21 March, Saturday:** The room was freezing and my water had a thin layer of ice on it. I slept in all my clothes except the hiking trousers. I had 2 sleeping bags and the 'bed' was like stone..... It's snowing like mad and a yak is feeding just outside my window.

**22 March, Sunday:** Finally got to Kumku, 4730m. Highest I've ever been. Feel quite tired and a bit giddy because of lack of oxygen. ....Tomorrow we head for Lobuche 5018m. Good job we did 4730m. today. Only 3 more days till Base Camp. I am enjoying the challenge but it's very, very hard and anyone who says it's easy is lying. It's not the walking, that's the nice bit, it's not even the altitude sickness. It's the bloody cold. Unreal.

**24 March, Tuesday:** Woken at an ungodly hour, 5.30 but actually felt OK. Dressing was laborious and painful it was so cold. I could hardly believe it. Next holiday must be somewhere warm. I'm hating this cold big time. How they did it in the old days I have no idea.....The views were stunning on the way, looking down on huge glaciers with rocks in them and some tunnel type structures. Finally got to Gorake Shep. Quick tea and biscuits and off to Base Camp.

**“ MADE IT !!! THIS IS BY FAR THE HARDEST THING I HAVE EVER DONE! ”**

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## NATIONAL PRESS COVERAGE

Sarah Stacey is an award-winning journalist and TV producer. She is currently Health Editor of the Mail on Sunday YOU Magazine. She has also written for other leading newspapers and magazines and is co-author of the bestselling The Beauty Bible series. Her website is [www.beautybible.com](http://www.beautybible.com).



On 26 April we were delighted to see an article on the Fund, helping to raise awareness nationally of lymphoedema, its treatment via Manual Lymphatic Drainage massage and of course our Fund.

We had a great response to the article with a lot of traffic to our newly launched website (as you can see below) and some new joiners to our database of supporters. We directed any clinical questions to our friends at The Royal Marsden.

We invited Sarah to the lunch in the hope that she would write about the Fund in one of her weekly articles in YOU magazine. She accepted immediately as she has personal experience of lymphoedema in her family and was interested in finding out more about our activities.

To read the article, go to: <http://www.mailonsunday.co.uk/home/you/article-1172354/Health-notes.html>.

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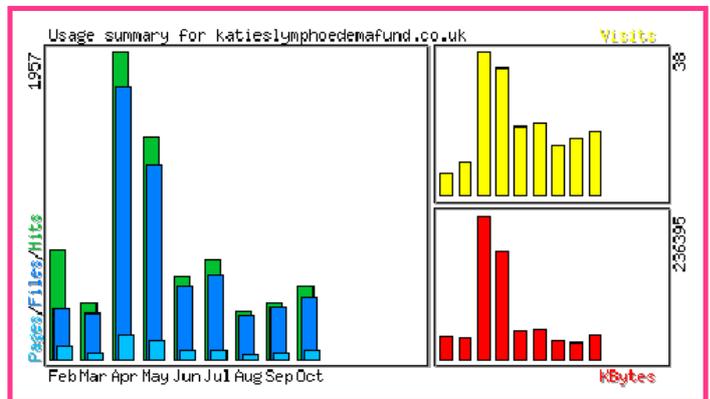
## WWW.KATIESLYMPHOEDEMAFUND.CO.UK WENT LIVE ON 23 FEBRUARY 2009

An enormous thank you goes to Mike Fish of Shoal Computer Solutions who dedicated a significant amount of time and thought (for free!) to designing and delivering our wonderful website which went live on 23 February this year. Take a look at the site:

[www.katieslymphoedemafund.co.uk](http://www.katieslymphoedemafund.co.uk)

You can see from the usage summary what an impact the YOU magazine article had in April!

For more information on Mike's work go to : [www.shoalcomputers.com](http://www.shoalcomputers.com).



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## WESTMINSTER CONNECTIONS

In April this year, leader of the Liberal Democrat party, Nick Clegg MP, gave his support to the British Lymphology Society as they held their first ever national awareness campaign for the condition, Lymphoedema. We also have some parliamentary interest in the form of Frank Field MP.

Mr Field used to live in the same block of flats as Pat and after a chance meeting on a London bus, he graciously agreed to meet her to find out more about the Fund. We hope that this connection will at some point enable us to raise awareness of the Fund within the Houses of Parliament.

He has kindly agreed to look into ways we might publicise the Fund in the House. Also to explore any synergies with the British Lymphology Society via Nick Clegg to see whether there are any opportunities for our Fund to link up with them in some way.

Thank you for all his efforts on our behalf!

## CHRISTMAS CARDS

You will see Pat's latest Christmas card designs on the enclosed sheet and her lovely 'herbal' notelets. Please place your orders early so that we can dispatch them in good time for the festive season.

If you want to join our database or amend existing details, please email [info@katieslymphoedemafund.co.uk](mailto:info@katieslymphoedemafund.co.uk) or call Emma on 07831 213205. Also, in today's environmentally conscious world, if you would prefer to receive this newsletter by email in future, please email [info@katieslymphoedemafund.co.uk](mailto:info@katieslymphoedemafund.co.uk) to let us know.

Pat, Emma and Jenny wish you all the very best and hope to see you on 22nd February 2010!

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## SPECIAL MENTION

A big thanks to a new fundraiser this year — Carole Bradford, Lady Captain, of Thorndon Park Golf Club, Essex. She and her ladies have raised £986 at three events: the Ladies' Spring Meeting, Open Meeting and a bridge and tea afternoon.

Thanks also to all of you who have made donations outside of the mainstream fundraising events. If you wish to make a donation, an easy route is via our Just Giving page on the website.

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## VATICAN CONNECTIONS!

On 15th December last year, Pat, Katie's Mum, was interviewed on Vatican Radio about the Fund. You can listen to the interview on the website.