

breath**easy**

BUCKINGHAMSHIRE

www.bebucks.co.uk



THIS ISSUE!
**We celebrate our
15th Birthday...**

**...we take to the
water once again...**



**...and just
who is that
woman in
red?**



NEWSLETTER
October 2010

breath**easy**
BRITISH LUNG FOUNDATION SUPPORT NETWORK



BREATHE EASY BUCKINGHAMSHIRE

WORLD COPD DAY

World Chronic Obstructive Pulmonary Disease (COPD) Day is held on the third Wednesday of November, so this year it is on 17 November.

The day is a global effort to expand understanding and awareness of chronic obstructive pulmonary disease and advocate for better care for patients.

Organised by the Global Initiative for Chronic Obstructive Lung Disease (GOLD), the Day is marked by activities implemented by health care professionals and patient groups throughout the world.



Breathe Easy Buckinghamshire will once again be in Wycombe General Hospital foyer with a table promoting awareness backed with British Lung Foundation leaflets along with the respiratory nurses and Smoking Cessation representatives.

We will also be running a tombola with excellent prizes to raise funds. Do come along and support us.

We look forward to seeing you on the day if you can make it.

breatheeasy
BUCKINGHAMSHIRE

COMMITTEE MEMBERS CONTACT DETAILS

Angie Lockwood	01494 527062
Mary Gillan	01494 874988
Charles Phillips	01494 812706
Elaine Smith	01494 443088
Paula Chamberlain	01628 485055
Eileen Peacock	01494 483841
Alethea Norris	01494 474381

NEWSLETTER
October 2010



FROZEN

I have been helping out with the BEB newsletter for a few years now, but I just wanted to let everyone know about another publication I am responsible for – my new book 'Frozen'.

The book is strictly non-fiction. It's the true-life story of how my wife and I struggled through years of fertility treatment and how our dream of a perfect family turned into a nightmare when things went horribly wrong.

My wife Lesley suffered a severe adverse reaction to the IVF treatment. Her body started to shut down and she put on a mind-boggling seven stones of weight in fluid in just 48 hours!!! She ended up in intensive care at Queen Charlotte's Hospital in London and it was touch and go for a while.

It may sound a bit grim and it was quite hard to write about, but when I think of what some of my friends in BEB have been through over the years... well, let's just say we all have our trials to face and, if someone like Angie can keep smiling, then so can we! In fact, my publisher describes the book as 'written with honesty and a wry sense of humour' and people who've read it tell me that it has made them laugh and cry in equal measure.

And of course 'Frozen' does have a happy, or at least a much warmer ending. I don't think it is giving too much away to say that, after everything that happened, Lesley and I finally decided to explore the possibility of adoption and towards the end of 2009 we became the very proud parents of a beautiful baby boy.

'Frozen', is available from all good bookshops and online bookstores as well as direct from the publisher at www.baaf.org.uk

Mike Butcher

Sign up for the British Lung Foundation's Patient and Carer Forum online at:

http://www.lunguk.org/BLF_COPD_Project/copd_project_forums/patientcarerform.htm



BREATHE EASY BUCKINGHAMSHIRE



ALL ABOARD!

We finally got the weather we had been waiting for this year for our Boat Trip. The day dawned bright and sunny and promised to hold for the day.

The walkers assembled in the park for a quick start in order to have plenty of time for a picnic and pub stop. It was wonderful to have Janet and Graham joining us as she had always said she hoped to always be part of our Boat Trip Day.

Salters had a new boat for us this year, I think the old one has gone to the boat yard in the sky!!! It was very smart with plenty of comfy seats.

However the sun deck was not big enough to take everyone and so the passengers who sat there on the way to Henley very graciously gave up their seats and sat in the bar area so that the joining walkers could enjoy the sun and the river for the return journey. There was a delicious selection of picnics this year, and to celebrate the sunshine everyone was welcomed back on the boat at Henley with a cool glass of Pimms!

The river was really beautiful this year, and being a sunny day the banks were full of people walking, picnicking and playing in the water. For the first time I saw a floating ice

cream man and he was doing a very brisk trade. Every year we say it – but we are very lucky to live so near to such beautiful countryside.

As always on the boat trip we take a moment to remember our 'Breathe Easy Angels'. Even the crew were remembering the legend of Diane Young and her adventure with the emergency services!!! Our thanks always go to the crew who are always helpful and flexible.

So... book early for next year!!!

Elaine Smith





BREATHE EASY BUCKINGHAMSHIRE

MYSTERY WOMAN

Even though this lady is residing in MY house, she may at some time appear in yours. Be alert!

A very weird thing has happened. A strange old lady has moved into my house. I have no idea who she is, where she came from, or how she got in. I certainly did not invite her. All I know is that one day she wasn't there, and the next day she was!

She is a clever old lady and manages to keep out of sight for the most part, but whenever I pass a mirror, I catch a glimpse of her. And whenever I look in the mirror to check my appearance, there she is hogging the whole thing, completely obliterating my gorgeous face and body. This is very rude!

I have tried screaming at her, but she just screams back. The least she could do is offer to pay part of the rent, but no. Every once in a while, I find a fiver stuck in a coat pocket, or some loose change under a sofa cushion, but it is not nearly enough.

I don't want to jump to conclusions, but I think she is stealing money from me. I go to the ATM and withdraw £100, and a few days later, it's all gone! I certainly don't spend money THAT fast, so I can only conclude the old lady is pilfering from me. You'd think she would spend some of that money to buy wrinkle cream.

And money isn't the only thing I think she is stealing. Food seems to disappear at an alarming rate - especially the good stuff like ice cream, biscuits, and chocolate. She must have a real sweet tooth, but she'd better watch it, because she is really packing on the pounds. I suspect she realises this, and to make herself feel better, she is tampering with my scales to make me think I am putting on weight, too.

For an old lady, she is quite childish. She likes to play nasty games, like going into my wardrobes when I'm not home and altering my clothes so they don't fit. And she messes with my files and papers so I can't find anything. This is particularly annoying since I am extremely neat and organised.



She has found other imaginative ways to annoy me. She gets into my mail, newspapers, and magazines before I do and blurs the print so I can't read it. And she has done something really sinister to the volume controls on my TV, radio, and telephone. Now, all I hear are mumbles and whispers.

She has done other things - like make my stairs steeper, my vacuum cleaner heavier and all my knobs and taps harder to turn. She even made my bed higher so that getting into and out of it is a real challenge.

Lately, she has been messing with my groceries before I put them away, applying glue to the lids, making it almost impossible for me to open the jars. She has taken the fun out of shopping for clothes. When I try something on, she stands in front of the dressing room mirror and monopolises it. She looks totally ridiculous in some of those outfits, plus, she keeps me from seeing how great they look on me.

Just when I thought she couldn't get any meaner, she proved me wrong. She came along when I went to get my picture taken for my driving license, and just as the camera shutter clicked, she jumped in front of me!

I hope she never finds out where YOU live!

EASTER LUNCH

Usually looking for our Easter lunch venue starts with either myself and Elaine, or myself and Eileen testing the venue that is decided on. This would be in the line of duty of course!

Unfortunately this year Eileen was in hospital, I had my operation and then Alan was taken ill so nothing was chosen through personal sampling.

Because I knew of another club that held their monthly lunch in the conference room at the Papermill, Loudwater, I thought it would be a good idea for us to try too. It is very central to all, especially for our Chalfont members, plus it has plenty of car parking available and easy access.



We had a good attendance as usual. 24 of us sat down to enjoy our chosen meal to celebrate our Easter lunch. We had a great time despite it being a little cramped. Food and service were excellent too.

We were pleased that Lin, a respiratory nurse, joined us.

If anyone has any ideas for next year's venue perhaps you could let me know.

Angie



MY LIFE AS A BROWN OWL

I started running 1st Terriers Brownies in April 1994. The current leader was retiring and although I had no experience of Girl Guiding I stepped into the role.

My life is always busy and has at times been immensely stressful and traumatic. In those times going to Brownies gave me a total break from life, you really do leave all your woes outside and for two hours it's just about the girls. Then you are revived and ready to face the world again. Some of my young leaders have also felt the same as a relief from school or exam pressure.



I think Girl Guiding is an opportunity and you can make as much or as little of it as you like. We meet every week in term time. Every year we take the girls away on Pack Holiday, which is a weekend in some form of hostel. They cook, clean, make things, hike and just play.

We usually have a theme around which everything is based. This year was Cowgirls, my best one ever was 'Winnie the Pooh and the Windy day', we were at Ellesborough and we climbed up Coombe Hill to fly kites that we had made.

My most amazing moment was when I met the Queen in Marlow for her Golden Jubilee, if I wasn't a Brown Owl I probably wouldn't have gone and if I hadn't had the Brownies with me she probably wouldn't have spoken to me!



I have been canoeing on the Thames, Climbing, abseiling, made doughnuts at Tesco, and I slid down a Fireman's Pole on a visit to the Fire Station.

This year is the Girl Guiding Centenary, celebrating 100 years of the Girls movement. I went with the Guides and camped overnight in Warwick Castle, we also had a weekend on Brownsea Island, which is where the first ever Scout camp was held. This was adults only, and I was amazed to learn how to make a fire hearth, a shelter and a flag pole with only a few bits of rope, a hammer and naturally found objects in the surrounding woods.

Recently we attended a Brownie Party for the Centenary. Over 2000 people, most of those under 10, came and in the sunshine made things, took part in activities and learned some Circus skills.

The most amazing thing about Guiding and also Scouting is that it is totally voluntary, from unit helpers, to the amazing teams who put on the huge Centenary Events. I think like everyone else, we find the time because we can and we do it because we believe in it.

Elaine Smith

ODE TO THE SPELLCHECKER

Eye halve a spelling checker
It came with my pea sea.
It plainly marks four my revue
Miss steaks eye can knot sea.

Eye strike a key and type a word
And weight four it two say
Weather eye am wrong oar write,
It shows me strait a weigh.



As soon as a mist ache is maid
It nose bee fore two long;
And eye can put the error rite,
It's rare lea ever wrong.

Eye have run this poem threw it
And I'm shore your pleased two no.
Its letter perfect awl the weigh,
My chequer tolled me sew.



EXACERBATION - MY STORY

Like most of you reading this newsletter, I have COPD and have had many exacerbations, but none like the one I had in January 2010.

I did the usual self medication and started taking antibiotics and steroids which I hold in stock for such occasions. They kicked in and started to work and I began to feel better. Unfortunately I seemed to re-infect myself and, as you do, started a fresh course of antibiotics and steroids. This time though I didn't get any relief.

I know, I thought, if I can use a nebuliser that will make the difference. So ring the doctor I did and she rang back after her morning surgery. After putting the question to her she said yes, if I could get up there I could use the nebuliser.

What on earth made me think I could get up there mystified me to this day, seeing as I found it hard to walk just across my lounge without puffing and panting. Anyway as they say where there is a will, or sheer desperation, there is a way.

If you cast your mind back to January 2010, then you will remember we were in the 'big freeze'! Snow and ice compacted on the ground. I shuffled along our path, hanging onto my husband's jacket tails for support, a few steps at a time, stopping and starting until I made it to our car. Brian, my husband, slipped and slid out of our close and up to our local surgery. He borrowed a wheelchair and was able to push me into the surgery and eventually in to the doctor's room.

The readings from the Oximeter showed my oxygen levels were down to 82 - so quite low. I had my session on the nebuliser, inhaling two drugs. This seemed to work and I felt a lot better than when I started the journey to the surgery. Great, I thought I am now on the right road and oxygen levels were on the increase and up to 87 as I left.

I was given the nebuliser to use at home as and when I thought was necessary, with the warning not to over use it, as there isn't anything else that will work. This worked for a few days but then I went back nearly to square one, so booked another appointment to see my doctor. She said that the best place for me was hospital as she couldn't do any more for me. She arranged for me to go to High Wycombe hospital while I was in the surgery. Once she had confirmed the booking Brian took me to the hospital.

I was put on oxygen and assessed before being put on the Medical Assessment Unit (MAU) where I remained for two days before being moved up to 6B, which was next to the pulmonary ward then where I spent another two days before being released and sent home.

I was pleased to be home and back to normal. This didn't last long, just a few days and I started coughing again, which is always a sign for me that I have another or the same infection starting. I started yet another set of antibiotics and steroids but found they were once again not improving my exacerbation. I called the doctor out this time to my home. The doctor arrived mid afternoon and after going through the preliminaries prescribed more medicines for the nebuliser and doubled up the quantities on both the steroids and antibiotics. My poor husband had to go to five chemists to get the nebuliser medication, but get it he did, bless him. I dutifully took the prescribed medicines but to no avail.

I do remember sitting up in bed and dialling 999 and then waking my husband and just saying 'ambulance'. He took over the phone as I just didn't have the puff to say anything coherently. I was able to give him one word answers to convey to the operator. I remember the 'quick response' team arriving, putting me on oxygen, asking questions. They told me they were going to take me to hospital and that was the last I remember until three weeks later! I had to be told it was three weeks later after I had come round.

Whatever the infection I had, it caused all my major organs to fail requiring me to be ventilated via a tracheotomy. I don't remember having this done to me just the end results. I spent from the beginning of February 2010 to St George's day in High Wycombe ITU. I had my ups and downs and shingles too. As if I hadn't had enough, my kidneys packed up at one point for five weeks and they were on about sending me to the Churchill in Oxford but couldn't until they had weaned me off the ventilator machine. I was coming on nicely with this but picked up another infection which set me back to square one nearly again.

Because I wasn't progressing with my weaning off the machine one of the doctors referred me to Lane Fox Unit at St. Thomas hospital, London. He had worked there and knew that if anyone was to succeed in weaning me off the

ventilator then they would as they are the pulmonary specialist for the whole of the country. A few days later, much shorter than the two weeks predicted, off I went to my new board and lodgings! The ambulance transfer was not the most comfortable, but we did the journey in a record 40 minutes using the blues and twos where necessary. The nurse accompanying the doctor with me said she felt sick but fortunately she wasn't. I am sure that would have started a chain reaction and that would not have been good.

The Lane Fox ward had been newly refurbished and looked good. They had different ventilators to help the process of weaning and this worked for me. One of the side effects, as some of you will know, is that with such a long hospital stay your muscles deteriorate. I had no dexterity in my hands.

I remember my husband bringing in some soft stress balls to squeeze while still in High Wycombe hospital. He used to get quite frustrated as I would hold these balls and squeeze to no effect. He would just say I wasn't trying. One thing that worked for me eventually was to pretend I was typing. Good job it was pretend as I would have hated to see what I would have produced should it have been on a real keyboard!

At Lane Fox unit they had their own physiotherapists who worked on the ward all day with the patients; whereas Wycombe had them but they were shared on other wards and you had a 15, 20 or sometimes 30 minute slot. Although Wycombe's physios were very good I soon learnt that I could wriggle out of doing too much but at Lane Fox they had the time to persist and encourage. Must admit I didn't have very nice thoughts of them on occasions.

I needed so much therapy as I couldn't lift my feet off the bed or even sit up let alone walk. It was such hard work to do what they knew I needed to do. I used to come out in really bad hot flushes and sweats that were so uncomfortable plus extreme shortness of breath on the simplest of movements.

I would cry for the silliest of reasons, which I found very hard to understand and cope with as it was so out of character for me. Five weeks two days later I eventually was discharged from the Lane Fox unit at St Thomas and sent home.



I was elated. Home at last but I soon realised that being home was not going to be without its problems. My mobility was more or less nil – being home didn't suddenly make me mobile again as I think I thought at the time it would. You know how it goes 'if only I was home...' etc. It doesn't work that way I can assure you.

Having to use a ventilator at night carried its own encumbrances. I had been used to a nurse fitting the mask and adjusting it if not on correctly and of course being monitored via machines as well as nurses. Now I had to rely on my husband.

No disrespect meant but Brian and medical things do not go together, though I have to say this last six months has turned him around somewhat. The thing that worried me most was sleeping downstairs with him upstairs and I just worried about being able to let him know that I needed his assistance in one way or another... as he is a little deaf to say the least!

I need not have worried, as when he realised this he rigged up a door bell system for me. I had the bell pusher beside me and he had plugged the unit in upstairs so that he could hear this when I activated it. I did try not to abuse it – honest. As time went by I became more confident in using the ventilator and eventually managed to sleep too.

I now have a stair lift which has helped me to get back some of my independence and normality - like going to the toilet and not using the commode, and sleeping back upstairs in my own bed with my husband.

Oxygen has eventually been sorted as, since being hospitalised, I have needed oxygen 24/7. Things are improving too oxygen wise as I was on 4 litre and now on 2 litres. I also now have conserved oxygen at long last which enables me to be away from home for longer. Who knows, my husband and I might get away yet for a few days holiday, fingers crossed!

All the way through my illness I did have fantastic support from my friends and family which I am sure went a long way to aid my recovery. All I can say is a big thank you to them all.

Eileen Peacock

JUST THINK, ELVIS WOULD BE 75 THIS YEAR!



If Elvis had lived longer, he possibly would have re-written, 'Are You Lonesome Tonight'

Here's how it might have turned out. We have no idea who wrote this, it came as e-mail "spam" but we thought it was worth sharing.

You all know the tune, so sing along:

ARE YOU LONESOME TONIGHT? (Senior Citizen Version)

Are you lonesome tonight?
Does your tummy feel tight?
Did you bring your mylanta and tums?

Does your memory stray,
To that bright sunny day,
When you had all your teeth and your gums?

Is your hairline receding?
Your eyes growing dim?
Hysterectomy for her,
And its prostate for him.

Does your back give you pain?
Do your knees predict rain?
Tell me dear, are you lonesome tonight?

Is your blood pressure up?
Good cholesterol down?
Are you eating your low fat cuisine?

All that oat bran and fruit,
Metamucil to boot.
Helps you run like
A well oiled machine.

If it's football or baseball,
He sure knows the score.
Yes, he knows where it's at
But forgets what it's for.

So your gallbladder's gone,
But your gout lingers on,
Tell me dear, are you lonesome tonight?

When you're hungry, he's not,
When you're cold, he is hot,
Then you start that old thermostat war.

When you turn out the light,
He goes left and you go right,
Then you get his great symphonic snore.

He was once so romantic,
So witty and smart;
How did he turn out to be such
A cranky old fart?

So don't take any bets,
It's as good as it gets,
Tell me dear, are you lonesome tonight?

Ladies and gentlemen, Elvis has left the building!!!



BREATHE EASY BUCKINGHAMSHIRE

BREATHE EASY BUCKS 15TH BIRTHDAY PARTY!

Breathe Easy Buckinghamshire's 15th Birthday Party was held on Monday 12th July at the Papermill in Loudwater.

We booked the Function Room well in advance, but on the day they rang to say it was double booked, so we had to hold it in the Restaurant itself. They partitioned the restaurant and supplied us with a table to put the Raffle on as well as the cake.

We pre-booked our Sandwiches in advance to save time on the day and it worked really well except some of us forgot what we ordered! Luckily the list was to hand and Elaine oversaw the sorting out of the sandwiches, thank you Elaine. The Sandwiches, tea and coffee went down a treat, with plenty of refills of coffee and tea for all those who wanted it.

I made the iced fruit Birthday Cake and it too was enjoyed by all.

We had a lovely selection of gifts donated for the Raffle, thank you to everyone who donated them. I think nearly everyone went home with a prize. Thanks Angie for overseeing the Raffle.

It was a lovely day and was made even more special by having Eileen back after her extremely long stay in Hospital. I think she enjoyed her outing as much as we enjoyed seeing her again. Welcome back Eileen!



Ashley came from the BLF and managed to get round to speak to most of us, as well as winning a prize from the Raffle - we hope his girlfriend enjoyed the perfume. Thanks to him for attending.

Alethea Norris

INDEPENDENT LIVING CONSULTANTS

Your local mobility dealer
YOU TALK WE LISTEN



NOW AVAILABLE
The Ultimate Hill Climber
HERCULES 85

The most powerful electric scooter,
ideal for High Wycombe Hills



TRY BEFORE YOU BUY AT OUR DOWNLEY SHOWROOM!

FREEPHONE: 0800 389 2554

A COMPREHENSIVE, CONFIDENTIAL, COMMUNITY CARE CONSULTANCY
10 Cross Court, Plomer Green Avenue, Downley, High Wycombe, Bucks HP13 5UW
Ample Free Parking