

# ♥ BACKUP BACKUP BACKUP ♥

## THE NEWSLETTER OF ST.GEORGE'S ICD PATIENT SUPPORT GROUP

### GREETINGS FROM YOUR EDITOR

It's been a long time coming, but here at last is 2005's first edition of BackUp. To all you for whom this is a new experience – WELCOME – you're one of a fast-growing band of patients from across the south of England (and beyond) who automatically become members of BackUp, the support group for ICD patients operated from St. George's Hospital, Tooting. The group's run by a committee of patients and staff and provides this newsletter, a range of leaflets, regular meetings at St.Georges and telephone support for new members and their partners. BackUp is for partners as well as patients.

To make up for the inordinate wait we have a fact-filled four page newsletter and as little frippery as I can contain myself to... There's an update on driving, a report on the AGM held at the end of February, stories from two patients, and news from around the country. We've also got a piece on insurance with an interesting tale of persistence and derring-do from Michael Solomon, one of our members.

Don't forget, there's always a chance to catch up on old stories by getting back numbers of the newsletter or joining us at one of our 3 meetings a year. The AGM was a cracker and our next evening meeting is just around the corner.

*Simon*

**The date of the next backup meeting is yet to be fixed, but we'll send you details soon**

### NEWS FOR DRIVERS

**The rules on driving for ICD patients change quite often. To get the most up-to-date information you should either contact Sue Jones at the Pacing Clinic or phone DVLA on 0870 600 0301 or go to the official website:**

[http://www.dvla.gov.uk/at\\_a\\_glance/ch2\\_cardio\\_vascular.htm](http://www.dvla.gov.uk/at_a_glance/ch2_cardio_vascular.htm)

Another change has been made to the processing of licences for ICD drivers.

#### Bottom line is this:

1. If you have had an ICD implanted because of a previous sustained, serious cardiac arrhythmia eg VT, VF or Cardiac arrest then you must not drive for 6 months after implant and MUST notify the DVLA.

You still have to fill in forms - as will your implanting centre - BUT you will now get a regular licence re-issued provided that you sign one of the forms "DECLARATION OF TRUST" that you will notify the DVLA if you ever have a dangerous rhythm and treatment from your ICD that causes loss of consciousness, dizziness or any incapacity.

A one month driving ban still applies after:

- Box change
- Change in anti-arrhythmic drug therapy

2. If you have had an ICD implanted for prophylactic reasons e.g. you have never had a life threatening rhythm but you may be at high risk because of a genetic/family connection then you DO NOT NEED TO NOTIFY THE DVLA on implant and you are only stopped from driving for 1 month.

You will however be required to notify them if at any time you DO have a dangerous rhythm.

3. You should be aware that if you do have frequent shocks which cause dizziness or incapacity or loss of consciousness and the rhythm that is causing these cannot be satisfactorily controlled by drugs then the DVLA may issue a longer or permanent ban. This does not happen very often but can in some circumstances.

If you have any queries about this ask me in the ICD clinic or give us a call.

Sue Jones

## MY STRUGGLE FOR CORRECT DIAGNOSIS - SIMONE BROWN'S STORY PUBLISHED BY KIND PERMISSION OF SADS UK .

It's 16 months since I was diagnosed with LQT (a type of arrhythmia) and being fitted with what I call 'my equipment'! Prior to this I had spent the last two years becoming increasingly disabled by stronger and more frequent episodes of weakness, panic, breathlessness and unconsciousness. I would be speaking to people on the telephone and would frequently arrest and come round whilst they were still on the other end of the line! I couldn't stand up for fear of falling down, I was reluctant to answer the front door, hear a telephone ring and lived in fear of a siren making me gasp for breath and fall in the street. I remember saying to one friend that the 'episodes' I was having made me feel like I was dying! Little did I know that that is exactly what was going on and I had been living with this since the age of 14 - and I'm 45 now.

I was diagnosed with epilepsy when I was 19 and had taken medication for this for approximately 10 years. I went back to have some tests when I was 38 to see if I could come off this medication and was told after a series of tests that it seemed unlikely that I had epilepsy. It was established that I had a very low heart rate but despite seeing a cardiologist who had my ECG results in front of her, she missed my diagnosis. What was curious is that my sister (who didn't have a history of blackouts throughout her life) arrested at home in August 2002, was revived by her husband and ended up in hospital being diagnosed with epilepsy by the same Doctor! It turned out that she had LQT and was taken to St. Thomas' where she was fitted with an ICD. My sister had had a 'stroke' when she was 21 but this had been put down to taking the pill and she had spoken to her doctor about fainting and breathlessness after her 3 children were born but she was told she was hyperventilating.

At the same time that my sister was in hospital I was on holiday in Spain (determined to give my children a holiday abroad and trying to stay upright and avoid being taken to hospital in a foreign country). When I returned home I remember my mum telling me that she had good and bad news. My sister was in hospital but it looked as though there was an answer to what was wrong with me. I went to see my sister and was diagnosed on the ward by her doctor who read my ECG there and then. I collapsed on the way home from visiting my sister and was admitted to Hospital. They finally took readings of what my heart was doing and my situation was so critical that they allocated me a doctor to travel with me by ambulance to St. Thomas. I had to be shocked several times in the intervening week and was finally given a temporary pacemaker before being fitted with my ICD.

I am feeling physically well these days after a lot of re-tuning at the outpatient's clinic. I have been affected by pacemaker mediated tachycardia which sometimes knocks me out for a day at a time. I am trying to stay positive but do feel angry about the mis-diagnosis not only 20 years ago but, as I've described, in cardiology departments in the last few years. The lack of a proper diagnosis has been hugely detrimental to my personal life and especially disruptive in terms of work and career. I can't blame others for questioning the substance of my symptoms and there were a lot of times when I felt as if

*Simone Brown, contd*

it was 'all in my head'. Some of the symptoms I would only have been able to describe to an alternative practitioner because they sounded so bizarre. For instance, when I heard a siren or fire bell, when I woke up suddenly, when I was stressed, tired or panicked. But I have the diagnosis now and my two children, who have escaped a diagnosis of LQT thus far, will, if they are affected at some stage in their lives, have the information they need to 'remedy' the

## THIS YEAR'S AGM

We had our AGM for 2004/2005 in February. For those of you who are new to BackUp or cannot attend meetings, the AGM is always an all-day event held on a Saturday. We have speakers, patients' forum questions and answers, a separate meeting for partners and a delicious lunch and even a raffle!

This year our guest speaker was Professor John Camm. Many of you will already know Prof Camm not just a leading light in St George's Medical School but a leading national cardiologist. He's a great supporter of our group. He spoke about ICDs and how important they are and explained what is currently going on with regard to offering ICDs to more patients. It seems the UK is implanting fewer than many other European countries and far fewer than the USA. He gave us a fascinating insight into the cost of treating arrhythmias and the politics of prioritizing health treatment. At the moment government advisors are saying it's too expensive to make big increases in the number of patients to get ICDs each year.

As it is the AGM we had a short 'business' meeting at the beginning of the day. This included a brief resume of what the group has been up to during the year and an outline of our funds. As you know, we usually ask for a voluntary donation of £10.00 per patient. However, our funds are quite healthy this year so we decided not to request it this time. We do not actively fund raise - although our raffles contribute and we are very grateful for Don and Rene Walker and their daughter who organise this so splendidly each year. We have a bit more money in the coffers this year thanks to the generosity of the St. George's staff who donate the professional report fees they receive from DVLA. The money is used for expenses - such as the newsletter, printing leaflets and so on - and we are buying the Pacing Clinic a colour printer so they can print the leaflets themselves. If any of you would like to see the Treasurer's Report, please contact Sue Jones who will arrange to send a copy to you.

Simon made a plea for volunteers to tell their story for the newsletter - 12 people offered to help. He'll be in touch with them in due course and their stories will start to appear in subsequent newsletters.

Our second speaker was unable to attend the meeting at the last minute, so Sue stepped in and did a presentation about the psychological issues that arise from having an ICD. I think we all found this very useful and informative.

The partners had their meeting conveniently near where the tea is served(!) while us patients stayed in the main meeting room and had an open discussion about whatever had come up for people - particularly from Sue's presentation.

It was a very successful day and a brilliant turnout and we hope all of you who were able to come found it helpful and - more importantly - enjoyed it.

*Louise (Chair)*

## THE ENGLISH PATIENT

Martin's story, first published way back in our very first issue, May 1998. Don't believe it? Ask him at our next meeting!

"I was born on the 27th April 1944 with a hole in the heart. I remember having to go to the Bristol Royal Infirmary every year to be examined. It was a pain because we would be kept waiting all day. Still, when they gave you an x-ray in those days they gave you something they called ice cream. and then watched it go down inside you. I liked the ice cream.

I suppose I was a sickly child and caused my mother a lot of concern, especially when I burnt my hands at the age of 5. I put my hands on one of the old electric fires when it was off and my sister switched it on. I was unable to get my hands off and was severely burned. That started off years of visits to a plastic surgeon. I wasn't allowed to do games at school and could not go swimming since I would go blue. Fortunately we live near Bath where there are hot springs and warm water baths and as a child we used to go there. Fortunately, as well, I did not take any time off school and so had a normal education.

I remember the doctors used to listen with their stethoscopes and used to say "can you hear the split second sound". To this day I have often wondered what this meant. It was what they called an ASD. They were able to operate in about 1963 and close the hole and so I thought my troubles were over.

When I was about 40 I suffered ventricular tachycardia (VT) on a weekend trip to Paris. Obviously, I did not know what VT was at that time. We were fooling around and having races around the Place de la Concorde and my heart started to go into overdrive. It stayed that way for at least 48 hours until we got back to Bristol and I went into the Royal Infirmary and was given a drip to put it right. That started my 10 year acquaintance with amioderone. The drug makes you look very well and gives you a sun tan even in the winter, which, though stylish, may not impress the bank manager when you're after a loan. Still, I'm off that one now.

I kept having VT and kept going into the Royal Infirmary where I would be given a 24 hour drip and, latterly, cardioverted. I became very well known in the local Coronary Care Unit and was called the "bed and breakfast" patient because I would normally come in during the evening and go home again at tea-time the next day. On one occasion I went in three times in one week.

They never really knew what was wrong with me in Bristol. They only got an EP (Electro Physiological) lab in 1996. They would simply treat me and send me home. I was referred to Professor Camm in 1993 and he diagnosed me straight away as having ARVC.

I am now on my second ICD. It has fired off a few times but not for over two years now. Once it went off in a police station where I was sitting in on a police interview - I wasn't the criminal! It was a bit of a shock to all the other people in the room and when I got over it I went outside and they gave me a cup of tea. It also went off just after we had a meal in a pub in Devon. One of the girls nearly dropped the tray of all our plates. It's gone off in the middle of crossing the Atlantic (twice) and in a Mexican hospital (if you could call it that) where it went off about five times. Without it I would have been finished. You're really carrying your own hospital with you.

I have been taken ill in various parts of the world and have had some unforgettable experiences but do not worry about traveling now since one shock normally restores my heart to a normal rhythm. At one time I was afraid to go very far away from Bristol since at that time I had no ICD and if I went into the Bristol Royal Infirmary a whole lot of explaining didn't have to be done and they knew what the treatment was. On one trip I even carried liquid amioderone.

Now I can go virtually anywhere."

## TRAVEL INSURANCE

Given the choices **and** the tiny print insurers use for the terms and conditions, it's hardly surprising that many tremble at the thought of arranging travel insurance. There's a fair few who duck the issue altogether. But it's well worth having and, usually, not as expensive as you might fear – certainly when compared to the costs and trauma which could be involved if things go wrong.

As with all medical conditions, travel insurance can be a bit of a challenge for us patients with ICDs. It's **vital** to declare that you have one (insurers often talk about declaring "your condition"), but it doesn't follow that your insurance will cost more, or worse, that you'll be turned down. Some insurers are less familiar with ICDs, and may not want to be bothered and might turn one of us down.

Recent experience reported by fellow patients suggests that insurance companies are getting more demanding about the conditions on which they allow any of us to be fully insured. Often they will seek to exclude your declared condition – exactly the thing you want to know you can get help on.

What to do? Don't give up! As with many good deals it pays to shop around. Your very own editor found his usual insurer, British Airways – having previously offered cover at no extra cost - now insisted on excluding heart related problems, even though he hadn't even had an episode over the past year. Shopping around found a sympathetic insurer prepared to provide full cover for a modest increase in fee.

Fellow BackUp member, Michael Solomon had exactly the same experience. Michael's had general medical insurance with BUPA for many years, and has routinely taken out Annual Travel Insurance with them. Last year they changed their rules and excluded heart conditions from his policy. They advised him to contact a company called All Clear who do cover such excluded conditions, but Michael found they were a lot more expensive. Michael reckoned it was his age (he's 77) and his triple heart bypass as much as his ICD that was affecting his rating with the insurers. He approached Saga, Norwich Union and several others without a better result.

However, he persisted. Age Concern was just right. He now has an annual policy worldwide with them at about the same price as he had with BUPA. For each trip he makes he has to go through a medical screening questionnaire and is told how much excess he might have to pay in relation to his heart – for China in 2004 it would have been £500.

Because everything's so individual, we can't give you any recommendations, but on the next page are a few companies tried in the past with some success by patients before or highlighted by Which? Magazine in a 2002 survey as good for covering pre-existing medical conditions. If you'd like more info or more numbers, contact Sue at the Pacing Clinic.

♥ Age Concern Insurance Services	0845 603 4526	
♥ Club Direct	0800 074 4558,	<a href="http://www.clubdirect.com">www.clubdirect.com</a>
♥ Go Travel	0870 243 6006,	<a href="http://www.gotravelinsurance.co.uk">www.gotravelinsurance.co.uk</a>
♥ Norwich & Peterborough Insurance	01394 605100,	<a href="http://www.npib.co.uk">www.npib.co.uk</a>
♥ Primary Direct	0870 444 3772,	<a href="http://www.primarydirect.co.uk">www.primarydirect.co.uk</a>
♥ Free Spirit	01483 255888	
♥ Medi Cover	0870 735 3600,	<a href="http://www.medi-cover.co.uk">www.medi-cover.co.uk</a>
♥ Perry, Gamble & Co	020 8542 1122	

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## NEWS IN BRIEF

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### FEEDBACK FROM PARTNERS OF BACKUP MEMBERS

In our survey of partners last year we discovered that 80% of members read this newsletter. 60% want to see more information published, especially about driving rules, travel, other people's experiences and the drugs we take. Although more than half have not attended BackUp meetings, the vast majority of those who have, enjoyed the event.

We're pleased with the response we've had from partners – we're working on ways of providing more information direct to partners and we hope the articles on driving and insurance are just what you want.

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### ARRHYTHMIA AWARENESS WEEK

This took place 2 months earlier this year, between 2<sup>nd</sup> and 9<sup>th</sup> March. This is a campaign which aims to improve awareness, diagnosis and treatments leading to better quality of life for those with cardiac arrhythmias. The campaign is aimed at professionals – like GPs nurses and so on just as much as at the public. As you'll see from the next story, people of any age can be affected.

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### PREMIERSHIP FOOTBALLER SAYS "EVERYTHING IS PERFECT"

Bolton Wanderers and Senegal winger Khalilou Fadiga says "everything is perfect" as he prepares to sign a new contract. Fadiga's career was on hold for 18 months after the 29-year-old midfield footballer was diagnosed with an irregular heartbeat. He had an ICD implanted in Belgium and made his English debut in October last year.

Italian side Inter Milan terminated his contract after his arrhythmia came to light in the summer. Fadiga left Inter without a single first-team start to his name after joining them from French club Auxerre at the start of last season.

Now with Bolton his future in the Premiership looks assured.

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### ICD MUM BACK TO WORK!

Steph Cruickshank, cardiomyopathy nurse and BackUp Committee member is back to work after giving birth to baby William last year (pictured in our last newsletter). Steph is not only a nurse and a mum, she's also a fellow patient. As with any of the BackUp committee members you can contact her any time, but cardiomyopathy sufferers will find her specialist training and role particularly helpful. You can contact her during office hours on 0207 573 8888 or via the Cardiomyopathy Association on 0800 0181 024.

## Committee Who's Who

**Tina Amiss**, fitness instructor, whose qualifications for membership are well-documented in her story described by her husband in an earlier newsletter 0208 900 0684

**Martin Byne**, a solicitor living near Bath, long-standing ICD pioneer and our most intrepid traveller. His story is re-told here. He can be contacted at work on 0117 973 1019 and email [byne2001@yahoo.com](mailto:byne2001@yahoo.com)

**Stephanie Cruickshank**, leading light in sister group for Hypertrophic Cardiomyopathy (the CMA), is on 020 7573 8888 (work) , 07905 981 945 mobile and email [scruickshank@hotmail.com](mailto:scruickshank@hotmail.com)

**Derek Jones**, our new treasurer, lives in Surrey and has a wealth of experience in managing financial affairs.

**Sue Jones**, favourite ICD Co-ordinator, is on 020 8725 1372 and [sue.jones@stgeorges.nhs.uk](mailto:sue.jones@stgeorges.nhs.uk)

**Simon Noble**, your editor, can be contacted on 01932 349727 or almost anytime on 07766-237312 and email [simon@sinclair-noble.co.uk](mailto:simon@sinclair-noble.co.uk)

**Louise Power**, chair and committee secretary, tireless and ever-patient supporter lives in North London and can be contacted on 020 8889 0789