

♥ 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 the first edition of BackUp in 2006. 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.

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 meetings during the year. Last year's AGM really was the best yet and our next evening meeting is coming up very soon.

*Simon*

**The date of the next BackUp meeting was still to be fixed when this went to print, but full details should be enclosed in your envelope. If not, call Pacing for details**

**HELLO FROM THE CHAIR OF BACKUP**

Firstly, on behalf of my colleagues on the committee, I would like to apologise for the long delay in contacting you with a newsletter and information and dates about meetings. We haven't forgotten you and I promise we haven't lost interest in BackUp! But we have all had pressing commitments that inevitably mean writing newsletters and organising meetings get temporarily put aside. Excuses done, here is some good news! We are organising our next BackUp meeting for Tuesday 30 May. It will be at 6.00pm at St George's and we'll be inviting one of our Consultants to answer your questions. This style of meeting is always very popular but we appreciate not all of you can make it to the meetings. So if you have a question which you think would be of general interest, please let me know as we can answer these questions in the next newsletter.

There have been many changes in the past year and many more patients are receiving ICDs since the NICE decision to authorise more ICD implants has come into effect. Sue has written a few words about this as you can see.

On the home front, the Pacing Clinic has seen a major change with the retirement in January of Dorothy, the clinic receptionist. We will miss her and BackUp will be buying her a small gift as a token of our gratitude for her wonderful kindness, thoughtfulness and efficiency in helping us all when we phoned or visited the clinic.

We look forward to seeing you at the meeting in May and welcoming any new members who we haven't met yet. For those of you who can't make the meetings, please feel free to contact me or any of the committee members. We are keen to hear your questions and thoughts about the Group and what we do. And if you feel you might want to get more involved in any way please let me know. You can contact me on 0208 889 0789, email [tp015f4579@blueyonder.co.uk](mailto:tp015f4579@blueyonder.co.uk) or write to me via the Clinic.

Best wishes

## HELLO EVERYBODY

As Louise says you've been really patient! with us and I also want to say sorry for the delay in setting up another meeting for you all.

The main reason is lack of help and the fact that our numbers have increased quite significantly in the last year so we are struggling to keep up. With new indications for implanting ICD's the demand is getting greater.

However we now have a date and welcome you all to come if you can.

What's happening in the world of arrhythmias?

Well, the new publication from NICE has recommended that ICD's should be implanted in more patients - so your cardiologists are identifying more people who will benefit from having one. One of the really important issues that was tackled last year when the NSF(National Service Framework) on arrhythmias was published was the need for patient support in all areas but particularly for patients with ICD's implanted. This has led to a nationwide push to set up support groups around the country. Unfortunately there was no money provided to do so and this has resulted in problems. We are however getting there with the help of company support and goodwill of the professionals involved.

The Arrhythmia Alliance which is a charity that has done an important job in bringing this problem into the public domain has been working hard to try and help the situation and has done an enormous amount to raise the profile of all our problems in this area. Check out their website if you can on [www.rrhythmia.alliance](http://www.rrhythmia.alliance) for loads of information about the current status.

HRUK(Heart rhythm UK) is working closely with the AA to provide as many facilities as possible for professionals and patients who have arrhythmias and are having a big conference in September to bring it all together. There will be a day when patients can attend and voice their concerns or just get to know more about what is happening in this field. Information about this for anyone interested is also available on the website.

Well, hoping to see as many of you as can make it at our meeting. If any of you want more information talk to us when you come to clinic.

## ABOUT PARTNERS

I was sitting chewing the fat, wondering what to write for this newsletter, when my train of thought (more minibus really) was interrupted by my wife – “You're late again”.

To cut out the usual protestations of innocence, she **was** actually right. In fact she's always right, even when I'm not late. Truth is, I'm always the last one to saunter out the door, the one who arrives just on time. Not always exactly late, but generally pushing it a bit – and this is like a red rag to a bull. No, no! She's damn attractive. I mean, because she approaches everything in a different way (actually, as if powered by rocket fuel) and is never late (unless she's waiting for me to pick her up), my being late, or just in time, or sometimes just being me, drives her up the wall.

Now I can already hear mutterings from the audience. And not just that one at the back about being “not surprised the way he goes on”. “What's this got to do with having arrhythmia and an ICD” I hear you ask? Well, bear with me.

I've had an ICD for nearly 9 years. I've had two shocks and two changes of device. Compared to many, I've considered this pretty straightforward, even if I've moaned about losing my licence twice (and the golf course I was on for both shocks). Outside the immediate aftermath of each episode and each little op to replace the battery, I've lived a normal life – work and play in reasonable balance, when I'm on time. Most of the time I'm free of any kind of symptom and, after the first 18 months or so, I'm much less prone to panics and imagined symptoms.

However, this isn't what her indoors thinks. Just as she knows I'm always late, she knows I'm having symptoms, a turn, a shock – all that's needed is for me to be late, forget to call when I promised I would, leave my mobile on the desk when she tries to call me, cough when I don't have a cold (I've tried it as a way of kicking my heart out of arrhythmia), moan out loud (usually because I'm late or I've forgotten something). **I'm** having a normal day, **she's** calming herself in the face of a crisis.

There's nothing neurotic in all this. Partners out there will recognise the signs. The patient carries on oblivious, leading life the way they've always done. Meantime their partner (or other family) remembers what happened last time they got a call from his/her work/felt sick/overdid it in the garden.

So you see – I **am** always late, that's how I am - and it generally winds my wife up. I **am** an ICD patient leading a normal life and my wife is a patient's partner and it does sometimes drive her to distraction. Small wonder.

**For more information on BackUp here's details on how to contact members of the committee:**

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