

♥ BACKUP BACKUP BACKUP ♥

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

GREETINGS FROM YOUR EDITOR

Not quite so long in coming, here at last is the second 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. Our next evening meeting is coming up very soon.

Simon

HELLO FROM THE CHAIR OF
BACKUP

First, some good news! Please join us on the BackUp committee in sending our love and congratulations to Stephanie Cruickshank and her partner, Ian, on the birth of their second baby, George.

For those of you who are new to our group, Stephanie is a founder member of BackUp and works with the Cardiomyopathy Association (CMA) too. She works as Cardiomyopathy Nurse Specialist based at the Heart Hospital in Central London and is an ICD patient too. I am very glad to say, Stephanie is still committed to BackUp, despite her busy life with her job, her work with the CMA and, of course, her growing family.

For those of you who are able to come to our meetings, I'm delighted to say that our next one will be the Christmas Get-Together. It will be on **19th December**, details attached. We look forward to seeing you then and meeting the new patients among you who will be able to join us. As ever, it will be a chance to chat to old friends and meet new ones, especially for those of you who have only just joined BackUp.

Some of you may be aware of this year's Arrhythmia Awareness Week, 12-19 September. The week ended with a major conference – the first UK Heart Rhythm Congress which combined for the first time the professional medical groups concerned with Cardiac Arrhythmias and the Arrhythmia Alliance patient groups. Two major charities, SADS UK and STARS held separate meetings where Cardiologists and other experts presented to both patients and interested medical practitioners, such as GPs and nurses. Tina Amiss and I went along to the SADS day and we had a very interesting and informative time. If anyone is interested in finding out more about the Arrhythmia Alliance, here is the phone number and website address:

ARRHYTHMIA ALLIANCE
www.arrythmiaalliance.org.uk
01789 450787

**The date of the next
BackUp meeting is**

Monday,

18th December

Outpatients Clinic

**Atkinson Morley
Wing**

If you would like to contribute to the BackUp newsletter or want to make any suggestions or get involved in any way, please let me know. You can reach me on 0208 889 0789 or email tp015f4579@blueyonder.co.uk

I look forward to seeing you at the next meeting.

Best wishes
Louise

DOING NICELY

Our funds during the year have grown to an amazing level.

An enormous amount of our income comes from professional report fees for the DVLA generously waived by the medics at St.George's.

We spend probably less than 5% of it on photocopying and stationery for the newsletter and almost none of it on catering for our meetings – the ICD manufacturers, CPI Guidant and Medtronic have always been very generous in supporting these.

Please do continue to give your annual donations.

These are traditionally around £10 each. Send them to Sue Jones at the Pacing Clinic.

MAKING CONTACT WITH NEW ICD PATIENTS

When you first become an ICD patient, as we all know, it's a blurr, and although some people get the chance to plan for it, it usually happens pretty unexpectedly. To help in the early stages after a new patient goes home, BackUp Volunteers (fellow patients) call every new patient at home within a month of them having their implant. Contact details are kept confidential, so the patient doesn't have to be concerned about further contact from the volunteer if he or she doesn't want it. The idea is to offer a bit of mutual support during a new experience, as well as to explain what BackUp is there for. Our volunteers are selected with care and are trained to make the contacts sensitively and discreetly.

You don't have to be new to make contact with fellow patients, or partners – you can call committee members any time....

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_cardiovascular.htm

This is the current position

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 in the ICD clinic or give Sue Jones a call

TRAVEL INSURANCE

As with all medical conditions, travel insurance can be a bit of a challenge for us patients with ICDs. We know many of you are travelling the world and we'd like to hear from you about your experiences.

It doesn't follow that your insurance will cost more, or worse, that you'll be turned down but recent experience reported by some patients suggests that insurance companies are getting more demanding about the conditions on which they allow any of us to be fully insured and prices are rising. Sometimes they 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! We know it pays to shop around. We'd like to hear how you've got on with it. Contact Simon – his details are at the bottom.....

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

Tina Amiss: 0208 900 0684; Martin Byne, at work, 0117 973 1019 & email byne2001@yahoo.com; Stephanie Cruickshank, on 07905 981945 & email scruickshank@hotmail.com; Sue Jones, on 020 8725 1372 & Sue.jones@stgeorges.nhs.uk; Simon Noble, on 07766-237312 & email simon@sinclair-noble.co.uk; Louise Power, on 020 8889 0789

