

♥ BACKUP BACKUP BACKUP ♥

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

GREETINGS FROM YOUR EDITOR

Here is 2008's first edition of BackUp. To all of 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.

There's an update on driving, a report on the AGM held at the end of September, a briefing on lead problems, and news from around the country.

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 2-3 meetings a year. The AGM was a cracker and our next evening meeting is just around the corner.

I am substituting for Simon at the moment but we are hoping to have a new news editor(sic) very soon.

The date of the next backup meeting is Wednesday March 5th in Cardiac Outpatients at 6.00 pm

RSVP Sue Jones

SPRINT FIDELIS LEADS and OTHER RECALLS

Many of you will have now been notified if you have one of these leads implanted. These leads are at risk of possible early breakdown and we are keeping a very close eye on them. We have ways and means of following them up to ensure that they are functioning so we are trying to minimise the risk and worry to all of you who have one of them.

We will keep you updated of any further developments with this problem.

I would like to re-assure you all that we keep a very close watch for any potential problems and that if we see any sign of something out of the ordinary we report it to both the manufacturer and to the MHRA which is the UK regulatory affairs body. They monitor all failures/problems with devices and leads very closely and liaise with the NHS and the manufacturers to make sure that all patients are as safe as they can be.

Because of the nature of implantable devices and leads, there will unfortunately always be some failures and every manufacturer has had some over the years. This is despite the most stringent quality control and checking of all new devices coming to the market. Some faults are time dependent and are not picked up until time has elapsed.

This is however a very rare event and most devices and leads will happily last their allotted time with no problems at all.

The overall failure rate for most systems is <0.1% which is tiny if you think of the total numbers implanted.

If you have any queries contact the clinic.

Sue Jones

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

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 WEEK ONLY driving ban NOW applies after:

- Routine Box change only

And a ONE MONTH ban applies after:

- A lead change or
- Change in anti-arrhythmic drug therapy
- Or if we have had to induce an arrhythmia at the procedure

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

THIS YEAR'S AGM

The BackUp AGM for 2007 was held on Saturday 29 September at Epsom Hospital. We had an excellent turn out and we were delighted to meet many new patients as well as see lots of familiar faces again. Our AGM business was brief but nonetheless important. Sue Jones introduced the committee members who were there – Louise Power, Paula Jones and Stephanie Cruikshank. Many of you will know Paula who, of course works with Sue in the clinic and Stephanie as she works as an Arrhythmia Nurse Specialist at St George's. Stephanie is also an ICD patient herself. Our other current committee member is Tina Amiss who was on holiday. Louise and Tina are both ICD patients.

Louise gave details of BackUp's accounts, which our Treasurer, Derek Jones, kindly prepares for us. (Thank you, Derek!). At present we have about £7,000 in the bank so as the account is healthy, we are not seeking contributions from members at present. Our funds mainly come from donations from the ICD Manufacturers (Guidant and Medtronic) and from the DVLA fees which the staff at St George's generously donate.

Louise also put out a plea for new committee members as, sadly for us - but lovely for them – Simon and Gill who have been involved with Backup from the very beginning have moved to Scotland. For those of you who have only recently joined, Simon was the editor of our newsletter and Gill ran the Partners Support Group.

We had a very full agenda with five speakers. Each speaker covered a very different topic but they were all equally informative and enjoyable. Trudie Lobban from the Arrhythmia Alliance gave a very interesting talk about the AA and how it got started – literally from her garage! Trudie's daughter has syncope and Trudie described how she had been approached by her daughter's consultant to speak to another patient. From that conversation she realised the importance of sharing information and help so she started a support charity called STARS. Gradually, Trudie realised that if STARS joined forces with other similar organisations they could make a greater impact creating awareness in both the medical profession and the general public. STARS, therefore, joined with the CMA, SADS and what was then called National ICD Patients Support Group, of which our group (BackUp) was a part. These charities then teamed up with HRUK, who represent medical professionals working with Arrhythmias and the whole organisation snowballed from there. One of the AA's greatest achievements was to help get a new chapter on Arrhythmia added to the National Service Framework (NSF) for Cardiology. You may already know that there is now an Arrhythmia Awareness week each year. This year it is from 9th - 15th June and you can find more about everything to do with the AA by going on the website:

<http://www.hearhythmcharity.org.uk>

AGM REPORT (CONT.)

Our second speaker was Dr Elijah Behr, Consultant Cardiologist at St George's who some of you will know. He described the NICE Guidelines for ICDs and explained in terms we could all understand what these mean for us and why some patients get an ICD while others might not. Dr Behr also chaired a lively Question & Answer session – always one of the most popular parts of our meetings.

After a delicious lunch we divided into groups so that the partners of ICD patients could have an informal discussion about their thoughts and experiences. The rest of the group went to a workshop about Cardiac Resuscitation with Jon Sions. This was great fun and well done to Jon for making such a serious topic both educational and fun.

Louise Power, our Chair, then spoke about ICD patients and the need for psychological support and counselling. Louise will write a little more about this important and relevant subject for another newsletter. Last, but by no means least, Stephanie Cruikshank described her role as Arrhythmia Nurse Specialist and explained how she can help ICD patients.

On behalf of everyone who came, the committee would like to thank Trudie Lobban, Dr Behr and Jon Sions very much for their excellent and helpful contributions to what was an informative, useful and really enjoyable day.

We would also give a big thank you to Medtronic, Guidant and St. Jude Medical who helped to sponsor the day.

I would like to reinforce my plea for new committee or working members. If you feel you could contribute something even if it's your own experiences please contact Sue or myself.

Louise Power
Chairperson

USE OF FUNDS

As you know from our treasurer's report (mentioned by Louise) we have had quite a healthy bank balance for some time thanks to contributions from our members and sponsors and we have been looking to spend some of it on helping to buy something needed for patients at St. George's.

We have now used some of the funds to buy a new colour printer for the ICD clinic so we can run off our leaflets and we are also helping to fund a new form of patient event recorder that some of you may benefit from and that will help us in the diagnosis of abnormal heart rhythms.

Thanks to all of you who have contributed.

Sue

**DON'T FORGET THE NEXT
MEETING**

MARCH 5TH

6.00

**CARDIAC OUTPATIENTS
ST. GEORGES**

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.

ARRHYTHMIA ALLIANCE NEWS

ICD SUPPORT GROUPS NATIONWIDE. NEW GROUPS ARE SETTING UP ALMOST MONTHLY. FOR A LOOK AT WHAT'S HAPPENING NATIONWIDE CHECK OUT THE ARRHYTHMIA ALLIANCE WEBSITE

ARRHYTHMIA AWARENESS WEEK 9-15TH JUNE 2008

WWW.ARRHYTHMIAALLIANCE.ORG.UK

ARRHYTHMIA NURSES FOR THE SOUTH WEST NETWORK THE SOUTH WEST LONDON CARDIAC NETWORK HAVE SECURED FUNDING FROM THE BHF FOR **SIX ARRHYTHMIA NURSES** TO WORK AS A TEAM ACROSS THE SECTOR. THIS MEANS THAT ALL THE AREAS ARE COVERED. THE NURSES AND THEIR AREAS ARE LISTED BELOW

Stephanie Cruickshank & Raj Mungur	Epsom & St Helier
Evaun Teoh	St Georges
Michael Sampson	Mayday NHS Trust
Emma Hegarty & Edward Caijolg	Kingston, Richmond & Twickenham

Arrhythmia Nurses provide a seamless pathway of care for patients with arrhythmias (cardiac rhythm disorders). There are many different types of arrhythmia and the nurses will be taking on various projects within the network. The role of the BHF arrhythmia nurse includes:

- developing specific care pathways for patients
- providing nurse-led clinics including pre-assessment for cardioversion and permanent pacemaker implants
- helping with the management of patients with ICDs (implantable cardioverter defibrillators)

Committee Who's Who

Tina Amiss, fitness instructor, whose qualifications for membership are well-documented in her story

Martin Byne, a solicitor living near Bath, long-standing ICD pioneer and our most intrepid traveller. He can be contacted at work on 0117 973 1019 and email byne2001@yahoo.com

Stephanie Cruickshank, Arrhythmia Nurse Specialist and ICD patient can be contacted on 0208 2962000

Bleep 125 (work), 07905 981 945 mobile and email scruickshank@hotmail.com

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

Paula Jones, (no relation!) Kiwi committee member- one of the team at the Pacing Clinic on 0208 725 1372.

Sue Jones, favourite ICD Co-ordinator, is on 020 8725 1372/3597 and email sue.jones@stgeorges.nhs.uk

Louise Power, chair and committee secretary, tireless and ever-patient supporter and counsellor lives in North London and can be contacted on 020 8889 0789 and email louise.power@blueyonder.co.uk