

♥ **BACKUP BACKUP BACKUP**

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

GREETINGS FROM YOUR EDITOR

Sorry we have not produced something for you all this year but time just gallops away and before you know it, it's Christmas again. However we have been busy and have not shut down in case you were wondering. Welcome to all our new ICD patients.

The committee has been re-energised and we have two new members to help out with getting things organised and keeping an eye on things so a really big welcome to Patty Hemingway and Alan Butler. Patty is a newish ICD patient and Alan is the partner of Liz who has had her ICD for a while. Alan has agreed to be our Partner Contact Co-ordinator. (See details at end of Newsletter)

Lots of plans afoot - a poster giving all details of the Group and contact numbers for members. Another meeting in the pipe-line for after Christmas, contacts for new ICD recipients and a fresh look for our website which is hosted by the Arrhythmia Alliance as we are affiliated to them.

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

More and more groups are forming around the country and Alan as our contact liaison is going to check them out and provide a list of other groups. Some of these are included later in the letter. Contact the above website and go to the ICD affiliate groups link. He is also tasked with looking at DVLA issues so fingers crossed there.

**Backup Christmas Meeting
Q's and A's
Dr. Gallagher**

**John Parker Theatre-AMW
10th December 6.00**

**Cardiac Investigations for a
chat and a nibble**

Hello from the Chair

It has been a while since our last meeting but we are glad to announce that we will be having a Christmas meeting and get-together on Thursday December 10th starting at 6.00. It will be in the John Parker room and we are delighted that Dr Mark Gallagher will be joining us to answer your questions about ICDs.

After the meeting there will be refreshments and time to catch up with old friends and perhaps make new ones. Personally, I really value this time at our meetings when we can chat informally and I know my patient committee member colleagues do too. Unlike Sue and the Pacing Team we don't get the chance to get to know you so this is a great time to talk about things that may concern us or share common experiences or just enjoy the opportunity to meet other patients.

We understand that not everyone can make it to the meetings but if you feel you would like to come along I just wanted to say that we do our very best to welcome every new BackUp member, including partners and members of your family. So please do join us on December 10th if you possibly can.

If you have any questions or wish to make any suggestions about BackUp or the Newsletter please let me know. You can reach me on 0208 889 0789 or email:
louise.power@blueyonder.co.uk

I look forward to seeing you at the next meeting.
Best wishes
Louise

St. George's Support Group for ICD patients

The 'Backup' ICD Support Group
Established since 1997

What is the backup?

- It provides a forum for ICD patients and their families to discuss their concerns and problems.
- It provides advice on how to live with an ICD and how to deal with the implications of living with one.
- It provides information on what to do if you have a problem with your ICD.
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For more information visit our website www.backup-icd.org.uk or contact Alan on 0203 755 1572 or Errol on 01927 65 0000

Committee Members:

Alan Keene Tel: 0203 755 1572	Alan Keene Tel: 0203 755 1572	Linda Pinner Tel: 0203 755 1572	Thea Dale Tel: 0203 755 1572	Polly Hensington Tel: 0203 755 1572

- Other ICD Groups around the country
Milton Keynes: sam.shunmoogum@googlemail.com
- Brighton - Catherine.Shannon@bsuh.nhs.uk
- Sutton - Bill Pontin
bill@thecastle39.freeserve.co.uk
- Thanet & Canterbury - Alan ward 01483 587793
- Ashford, Maidstone, Sevenoaks, Tonbridge & Medway
John Padwick 01233620532
- Swansea - -restart.group@btinternet.com
- Poole - -fiona.keene@poole.nhs.uk
- Oxford - -geoff@icf.org.uk
- High Wycombe - bryan.longson@btinternet.com
- Co. Antrim - -errol@hiddenloop.com
- Bournemouth - -arrhythmia.nurses@rbch.nhs.uk
- Gloucester - [info@icd-gloucestershire.org.uk](mailto:-info@icd-gloucestershire.org.uk)
- Thanks to Alan for getting these contacts.

NEXT MEETING TO BE HELD AS AGM AND WILL BE AN ALL DAY SATURDAY MEETING IN WIMBLEDON WHICH WE ARE HOPING WILL BE IN FEBRUARY.

TOPICS WILL INCLUDE: Rehabilitation, Inherited conditions, Heart Failure and a partners' group.

Driving and Arrhythmia

The Medical profession have access to guidance on medical standards for drivers. If you suffer from an arrhythmia problem, your consultant can advise whether you should stop driving and when - possibly even before any ICD implantation. That advice must be followed for safety reasons but also for legal and insurance liability reasons.

By being pro-active in addressing the question of giving up driving for a period, you will retain control of the process. There is a procedure that you can follow which prevents you becoming frustrated by delays and snarl ups either at DVLA or Medical Administration.

As soon as your medical adviser recommends that you should cease driving, you should ring the DVLA Drivers Medical Group and ask for a "Declaration of Voluntary Surrender" Form. They are very approachable and friendly and can be contacted on 01792 799080 (This is a local rate call number -don't ring the advertised number of 0870 600 0301 it is very expensive). Record the details of your licence then send both the paper and plastic licences along with the completed form to DVLA. They will then suspend your licence.

When your medical adviser decides that you meet the health requirements to resume driving, get an "Application for a Driving Licence" Form D1 from the Post Office and write a covering letter quoting details of your licence and say you are seeking restoration of that licence. Send the completed form and letter to DVLA using a postal method which gives proof of delivery. Medical enquiries will be made by DVLA but whilst these are ongoing, the law provides cover for you to commence driving immediately, under Section 88 of The Road Traffic Act 1988 .

This means that as soon as your application is received at DVLA and you are medically fit to drive (provided you are not prevented from driving for any other reason), you can resume driving even though you do not have your licence physically back yet. If you are required to produce your licence at any point, DVLA will confirm your licence is valid.

Additional note from Ed. If you give the ICD clinic as your main point of contact for the DVLA it will speed up the process as I can access your records as soon as we get the request from them. Otherwise the forms tend to sit on the Consultant's secretary's shelf for ever and nothing happens.

SUCCESSFUL SPRING MEETING

BackUp's Spring meeting this April was a great success. We had a fantastic turn out, the largest for an evening meeting for a long time. Thanks to all of you who came to hear Dr Elijah Behr speak about Inherited Cardiac Conditions, such as HCM, (Hypertrophic Obstructive Cardiomyopathy), SADS (Sudden Adult Death Syndrome) and Ion Channel Disease. It was a fascinating and very informative talk outlining how these genetic diseases can affect all ages although one of the big issues is the number of young people who are affected.

The most common cardiac genetic disease is HCM. This condition is when the muscular walls of the heart become thickened preventing the heart from filling up with blood properly and stops it being pumped from the heart. The Ion Channel Diseases are caused by 'electrical fault' in an otherwise apparently normal heart. These include Long QT Syndrome and Wolff Parkinson White syndrome.

Sudden unexplained deaths, especially in young apparently very healthy people are being researched more and more and it appears that SADS is often the cause. Competitive athletes (including professionals such as footballers and cricketers) can be at high risk of sudden cardiac death. You may recall Marc-Viven Foe, the Cameroonian International footballer who collapsed and died during an international match in France in 2003. It was later suggested that he had one of the Ion Channel Diseases.

The families of anyone suffering SADS are now screened and treated. The most effective treatment is an ICD sometimes with anti-arrhythmic drugs as well. If you would like more information about any of these conditions, the British Heart Foundation produce helpful booklets or you could go on their website

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

British Heart Foundation main telephone number: 020 7554 0000

The following websites and phone numbers are support organisations

<http://www.cardiomyopathy.org/>

call 0800 018 1024 or email

info@cardiomyopathy.org

social gathe<http://www.c-r-y.org.uk>

call 01737 363 222 or email cry@c-r-y.org.uk

<http://www.sadsuk.org/>

call Anne Jolly BACP Accr. 01277 230642

Cont.

Dr. Behr then took questions from the audience and we then went on for refreshments and a social gathering which was also extremely successful.

Alan and Liz Butler sold Liz's wonderful hand-made cards and raised £95 for the Cardiac fund which will go towards buying equipment for the department.

Thanks to all of you who donated and we hope you enjoyed the evening.

We will be holding another meeting later in the year.

NEW MUM

Many of you will remember Paula Jones who defected back to her homeland in New Zealand at the beginning of the year. Well she is now the mother of a baby daughter, Freya, who is a bonny wee thing and looks just like her Mother. All best wishes from us all Paula. We'd love to see you and Freya.



HAVE YOU HAD PROBLEMS? WHAT ARE THEY?

One of the aspirations of your new committee is to provide help, through information and advice, about any current practical living problems caused by your having an ICD fitted.

In order to do that, the committee need to understand what the main problems are, when and how they occur and who (if you know) is causing the problem.

As a starter, I am particularly interested in current problems with driving restrictions and driving licences. I would like to hear from any patient (or supporter) who has had or is currently having, any problems with any Govt bodies or others regarding driving.

I can be contacted by e mail alan241@tiscali.co.uk or by letter sent to the clinic.

Phillipa's Story - a word of encouragement to all ICD patients



I am a real outdoors type enjoying running, and cycling and all things to do with horse riding (including all the mucky work). Before I had the ICD implanted I had begun to stop enjoying these activities, and had become slightly worried about doing them, which meant I would then try to convince myself that nothing was really wrong and go out and push myself really hard.

Now I have the ICD the biggest thing it has done for me is allow me to get back on with my life and the things I enjoy without feeling anxious about the consequences. I now do everything I previously did, and in fact even more (I have taken up Skill At Arms competition – drill games to test your skill with the pistol, sword and lance from horse back).

“I didn't think it appropriate to say that I now set the alarms off at most Sainsbury stores and will probably soon be on their most wanted list!” I thought I'd include this – Ed.!

NEWS IN BRIEF

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

WWW.ARRHYTHMIAALLIANCE.ORG.UK/AFFILIATES

TRAVELLING ABROAD

IF YOU ARE TRAVELLING ABROAD AND WOULD LIKE CONTACT DETAILS FOR LOCAL HOSPITALS OR DOCTORS WHO LOOK AFTER ICD PATIENTS EITHER CONTACT THE ICD CLINIC OR LOOK ON THE MANUFACTURERS' WEBSITES.

WWW.MEDTRONIC.COM/TRAVELLING

WE ALSO KEEP A LIST OF TRAVEL INSURANCE COMPANIES WHO ARE ICD FRIENDLY AND IF YOU WOULD LIKE A COPY OF THIS CONTACT THE ICD CLINIC. IF YOU KNOW OF A PARTICULARLY GOOD INSURANCE COMPANY ALSO PLEASE LET US KNOW AND WE WILL ADD IT TO THE LIST.

PLEASE NOTE WE CANNOT GUARANTEE ANY NAME THAT IS ON THE LIST AS THE TERMS AND CONDITIONS WILL VARY DEPENDING ON

Committee Who's Who

Tina Amiss, Physiotherapist, whose qualifications for membership are well-documented in her story described by her husband in an earlier newsletter 0208 900 0684 tinafizzyo@btinternet.com

Alan Butler our new Partner Co-ordinator can be contacted on alan241@tiscali.co.uk

Stephanie Cruickshank, Arrhythmia Nurse Specialist and ICD patient can be contacted on 0208 296 2000

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

Patty Hemingway Who is an experienced Homeopathic practitioner is at pattyhemingwayhomeopath@inbox.com 0208 333 0413

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

Sue Jones, ICD Services Manager, is on 020 8725 1372 and email sue.jones@stgeorges.nhs.uk

Louise Power, chair and committee secretary, tireless and ever-patient supporter and counsellor lives in N North London and can be contacted on 0208 889 0789 or email louise.power@blueyonder.co.uk