

♥ 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.

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 late summer, contacts for new ICD recipients and a fresh look at our website which is hosted by the Arrhythmia Alliance as we are affiliated to them.

<http://www.rrhythmiaalliance.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. We will include it in the next Newsletter. 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.

**ARRHYTHMIA
AWARENESS WEEK**

WORLD HEART RHYTHM WEEK
8TH-14TH JUNE 2009

**Theme of this week is
"Know Your Pulse"**

If you are interested in this see the AA website.

**ST GEORGE'S IMPLANTS 500,000TH UK
PACEMAKER**

We hit the news this month and could be seen on News at One on BBC1 on Wednesday 23rd April with a report on St. Georges implanting the 500,000th UK pacemaker. This was a big landmark and the patient who received the implant was given a Biventricular ICD which represents the highest level of technology available.

It is possible to be exact about the numbers as all implanted devices are registered with the National Data Base. CCAD

St. Georges was chosen as the site of this implant as we did the first implant in the UK back in the dark ages of 1958.

Times and technology have changed considerably since then.

Despite 500,000 people now having received pacemakers and ICD's, cardiac arrhythmias are estimated to affect more than one million people in the United Kingdom, and is consistently in the top ten reasons for hospital admission.

We are still under-implanting as a country compared with Europe and the USA and more awareness needs to be raised about arrhythmias and their treatment.

**SUPPORT ARRHYTHMIA AWARENESS
WEEK – TAKE A LEAFLET TO YOUR
GP**

A BIT OF A SHOCK!!!!

I was at NAiDEX the exhibition for services and equipment for the disabled. It's one of my annual chores to go round the exhibition and report to everyone back at the office on interesting developments.

The day involves an early start to get the train to Birmingham Exhibition centre. Then traipsing up and down the rows to make sure I see everything. Its fairly exhausting day chatting to old friends and making new contacts. By the end of the day I am pretty well running on auto pilot. Well that's my excuse for what happened at almost the last stand I came to.

The young lady on the stand gave me some patter about how this device invigorated and improved the circulation etc. etc. She led me to a machine with two, rubber, foot shaped marks on the sloping top. "Just put your hands on the foot marks". Like a lamb I complied. The machine started and gave a tingling feeling in my hands. If I thought at all I suppose I thought it was mechanical vibration. Then the tingling started to work up my forearms. I began to worry. "It's giving tiny electrical pulses." said the young lady. My brain clicked in and I started to pull away but too late. THUMP my ICD fired and I fell backwards into the wall of the next stand.

I shook myself but I was all right just a bit shocked by what had happened. The machine had been moved back on the table top to reveal the warning "Not to be used with an implant".

Examining my thoughts afterwards I am not sure I would have understood the warning and of course the surface appeared to be rubber so there was no indication of direct electrical action. I thought that sort of thing went out with the Edwardians.

So don't trust quack remedies even when they are offered by a pretty young lady. Now I wonder if that's another excuse!

There is one thing at least I know what it feels like when the ICD fires.

[I popped into the hospital for a quick check the following day. They were very kind and told me that I had not damaged my ICD.]

The Circulation Enhancer! Don't let anyone buy you one for Xmas

Roger Holmes ICD person



A salutary lesson – as everyone knows most electrical kit does not inter-act with ICD's but always check the instructions and advice with anything new and if not sure check with us at the ICD clinic. Ed!

HEALING - WITH A LITTLE HELP FROM MY FRIENDS

I had been resuscitated, my VT (Ventricular Tachycardia) had been successfully ablated, and I had been fitted with an ICD during my three and a half weeks in hospital. Yes, I had recovered from a terrible trauma, but as I headed home a few months ago, I knew that the healing had only just begun.

No one expects to have a cardiac arrest, and I certainly knew very little about what was happening to me at the time, but I was lucky to have people around me who knew what to do. Although my heart was pumping again I had no recollection of the CPR (cardio pulmonary resuscitation) or defibrillation that had been given, as I came into consciousness in a haze of pain relief feeling very grateful to be alive. How much more scary the episode must have been for my son who witnessed my collapse, and called the ambulance, and for my partner who saved my life by beginning CPR. I was revived and cared for by the wonderful paramedics who arrived quickly, and the expert nurses and cardiologists who attended me in hospital, but that was just the beginning of my journey back to health.

My body had initially shut down to protect me, but as sensation and feeling returned I was aware of the bruising to my ribs and spine from the CPR, and the lacerations on my swollen tongue, which I had probably bitten into as I fell. I needed to do something about these injuries if I was going to be able to lie still for the catheterisation and ablation; that first week, my ribs went into spasm if I tried to lie down and I slept sitting upright.

I am a homeopath, but I learned that you cannot always help yourself when you are in shock, and I gratefully accepted the help of my colleagues, friends and family who brought me in remedies to support me at every stage of my treatment; and when I arrived on the cardiac ward it was another patient who reminded me that Arnica cream helps to relieve the bruising which can result from the daily blood thinning injections.

I am now extremely grateful to be rid of the VT which had gone undiagnosed for so many years, and to be cured of the palpitations which had made life difficult and scary. However, I was extremely nervous before the procedure because I would be conscious throughout, and I had no idea how I was going to manage to lie flat on the operating table.

My wonderful cranial osteopath, Naval Mair, treated me on the ward, and I instantly felt more relaxed, slept better and experienced fewer episodes of spasm. We both knew however that I would need to continue this treatment once I left hospital, and indeed it was essential for recovering full movement in my left shoulder and arm, and improving my breathing after I had been fitted with an ICD.

I had to come to terms with having an ICD and I wondered, what my life would be like afterwards; how I would cope; whether you can feel it; and what happens when/if it goes off? Well, luckily for me, I was about to meet two fantastic people who answered all my questions and made themselves available whenever I had a wobble of confidence. Sue Jones, the director of the pacing clinic at St Georges, made several trips to my bedside bringing reassurance and information, and I learned that I did not have to face this alone, as she has built a network of patients who are there for each other. One very special member of Backup, the patient support group, is Louise Power, who also came to visit, and calmed and consoled me as I poured out my woes and worries. My thanks to both of you.

My wound healed well, although it became red, puffy and sore on a couple of occasions, but there was no local or systemic infection, and the most likely explanation was that I was having a mild allergic reaction to the internal stitching. It is apparently not unusual for some people to be sensitive to vicryl sutures. Once I knew what was happening I treated the discomfort with a homeopathic remedy, and made sure I wore only natural fibres as artificial fabrics seemed to make my wound feel even more prickly. Back home I was still experiencing episodes of anxiety, and even panic, if I felt an irregular heartbeat, even though I knew that ectopic beats were harmless, and normal for many people. It has taken me a few months to let go of this nervous habit, and dare to venture out into the wider world with confidence once more. I discovered, there are plenty of things that we can do to support the healing process and help our minds and bodies to recover from trauma and surgery, and if anyone would like further information then they are welcome to contact me.

Patty Hemingway (see end of Newsletter for contact details)

SUCCESSFUL SPRING MEETING FROM LOUISE POWER (CHAIR)

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 in the summer.

FUNDRAISING

St. George's like all NHS hospitals has never enough money for what it really needs. Like all others we have a list of equipment that we cannot get funded by normal means as the priority list is always being squabbled over and there is never enough to go round.

We have therefore started a program of fund-raising for some of the equipment needed for the Cardiac Unit and would welcome any ideas or suggestions for this.

If you would like to raise funds for us then please let us know.

Contact Sue Jones or Amy Lovegrove

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.

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

ARRHYTHMIA AWARENESS WEEK 9-15TH JUNE 2009

WWW.ARRHYTHMIAALLIANCE.ORG.UK

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 YOUR UNDERLYING CONDITION AND WHETHER THE COMPANY

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 North London and can be contacted on 0208 889 0789 or email louise.power@blueyonder.co.uk