

# ♥ **BACKUP BACKUP BACKUP**

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

### GREETINGS FROM YOUR EDITOR

Welcome to all new members of Backup - that includes all of you who have had new ICD's implanted and of course all of you old members – no offence intended!!

Backup is there if you need support but if you don't then that's your choice. We will always help if needed.

We try to keep you in touch with what is happening in the ICD world but haven't been very good at it lately with the last Newsletter back in November - so apologies for that.

Anyway here we are now and still thinking about you all. We had a really successful meeting on May 8<sup>th</sup> which was attended by nearly 100 people. More about that from our trusty chair person Louise.

Feedback from the meeting was excellent and we have taken your comments on board for next time.

Technology continues to improve and change and more and more of you will find you are being offered home monitors when you come to clinic. All new ICD's now have them available but unfortunately some of the older ones do not so for those of you with older devices be patient!

Sue - Ed

### Backup Autumn Meeting

**Cardiac Drugs**  
**Tuesday November 23<sup>rd</sup> 2010**  
**6.00 pm**  
**John Parker Theatre-AMW**

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

### MESSAGE FROM THE CHAIR AND AGM 2010 REPORT

**Louise Power**

It was great to see all of you who joined us for our BackUp AGM this year. It was on Saturday 8 May at St Bede's Hospital Conference Centre. We all thought it was a brilliant place for our Saturday meetings and we hope to book it again for our 2011 AGM.

There was excellent turn out and we were delighted to meet all the new patients who came as well as seeing many familiar faces again. Our AGM business was brief but nonetheless important. Sue Jones gave a brief resume of our finances and introduced the committee members - old timers (!) Stephanie Cruikshank, Tina Amiss and me, Louise Power plus our newer members Alan Butler and Patty Hemingway. If anyone would like to see a copy of our financial report, please contact Sue at the clinic and she will send or email you a copy.

The programme for the day slightly changed from our original plan as Dr Elijah Behr couldn't make it, so Dr Rachel Bastianen stepped in and gave us a very interesting talk about Inherited Cardiac Diseases. Then Dr Lisa Anderson spoke about Heart Failure and ICDs and finally Suzanne Armstrong who is a Rehab Nurse Specialist talked to us about rehab for ICD patients. Each speaker took questions and this was useful and interesting for us all. **By the way, this was the first meeting where we had only women speakers and they were all brilliant – sorry, guys!**

After a delicious lunch, the meeting split into two groups, one for the partners only and the other for the patients. Over the years, we have found that this works well as it gives our partners a chance to talk about the issues that particularly concern them. The patients also had a useful discussion. We asked for feedback at the meeting and it transpired that you would like the time for the separate groups to include small subgroups so that everyone – even those who find it difficult to speak out in a large group – have a chance to make a comment or ask a question.

(Continued on next page)

Other ICD Groups around the country  
Milton Keynes: [sam.shunmoogum@googlemail.com](mailto:sam.shunmoogum@googlemail.com)

Brighton - [Catherine.Shannon@bsuh.nhs.uk](mailto:Catherine.Shannon@bsuh.nhs.uk)

Sutton –  
Bill Pontin [bill@thecastle39.freemove.co.uk](mailto:bill@thecastle39.freemove.co.uk)

Thanet & Canterbury - Alan ward 01483 587793

Ashford, Maidstone, Sevenoaks, Tonbridge &  
Medway  
John Padwick 01233620532

Swansea - [-restart.group@btinternet.com](mailto:-restart.group@btinternet.com)

Poole - [-fiona.keene@poole.nhs.uk](mailto:-fiona.keene@poole.nhs.uk)

Oxford - [-geoff@icf.org.uk](mailto:-geoff@icf.org.uk)

High Wycombe - [bryan.longson@btinternet.com](mailto:bryan.longson@btinternet.com)

Co. Antrim - [-errol@hiddenloop.com](mailto:-errol@hiddenloop.com)

Bournemouth - [-arrhythmia.nurses@rbch.nhs.uk](mailto:-arrhythmia.nurses@rbch.nhs.uk)

Gloucester - [-info@icd-gloucestershire.org.uk](mailto:-info@icd-gloucestershire.org.uk)

**See Arrhythmia Alliance website for  
associated groups and further details**

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## HEART RHYTHM CONGRESS 2010

**Birmingham Hilton Metropole**

**ICD Patients Day  
Sunday 3rd October**

**For agenda and registration see  
Arrhythmia Alliance Website**

### MESSAGE FROM THE CHAIR (cont.)

We ended the day with a raffle, kindly organised by Alan and Liz Butler who also sold Liz's beautiful hand made cards and they raised over £180.00. I'd just like to add that it's worth coming to our meetings just for the chance to buy these lovely cards so thank you Liz and Alan! And on behalf of everyone who came, the committee would like to thank all our speakers very much for their excellent and helpful contributions to what was an informative, useful and really enjoyable day.

I'm looking forward to seeing those of you who can make it to our next meeting but don't forget that all the committee members are available by telephone or email so if you can't manage the meetings but have a question or concern, please don't hesitate to give one of us a call.

Louise

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### Questionnaires and Feedback

Most of you who attended returned our questionnaire which was fantastically helpful.

98% of you thought that the presentations were Excellent and rated them between 4 and 5 (Good and Excellent)

The venue was really rated highly and many of you have asked us to use it again which we are planning to do for next year's meeting.

### AGM Provisional date 4<sup>th</sup> June 2011

Most of you wanted smaller groups for both the patients and partners and more time so we will organise this next time.

If anyone out there has a burning request for topics for discussion please let us know. **This group is for you.**

**Contact me at the clinic Sue**

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### NEWSFLASH

**The new Airport security X-ray  
body scanners will not affect your  
ICD's.**

**Old rules apply to conventional  
scanners.**

## DRIVING AND ARRHYTHMIAS

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 an 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.

**Alan Butler**

**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.**

## HELPING YOURSELF TO EMOTIONAL REHAB

At the recent Backup meeting (8<sup>th</sup> May2010) Suzanne Armstrong spoke about the benefit of a comprehensive programme of rehabilitation, which included counselling, exercise and goal setting for ICD patients, and I felt that it was certainly something I would have liked after receiving my ICD.

I had excellent support from individuals at the pacing clinic and on the ward, but once I left hospital, I was very much on my own and coping with a range of emotions including fear, anxiety and sometimes panic. So, I set about putting in place my own supports, and trying out techniques for relaxation and ways to stay positive, because I had seen enough research which showed that this would speed up the healing process, and I longed to return to "normal" life.

In the patient forum before Suzanne's inspiring talk we had touched on how it feels when you get an ICD, and people began talking about how to cope when they felt anxious or even depressed, but we ran out of time, so I would like to offer some ideas of my own to keep the discussion going, and I hope that other ICD patients will find this useful and feel able to share their own ideas in future newsletters.

### Things that helped

JIGSAWS were a pleasant distraction, which helped to focus my mind and I soon found myself concentrating on the puzzle rather than my worries.

MEDITATION doesn't have to be complicated. It can be as simple as watching a flickering flame and allowing your mind to empty. I got a book and a CD to help me, and loved how I felt after doing a guided meditation.

COLOURING IN MANDALAS is therapeutic and healing for people of all ages. Healing mandalas are simply patterns which make us feel good. The simplest example is the smiley face icon. There are plenty of examples in colouring books or on the internet.

FRIENDS WERE ON CALL when I hit rock bottom, and just needed someone to talk to or come for a walk with me when I was afraid to be alone. I was respectful of the fact that other people have their own busy lives, so I called on different people for different needs. Most people will tell you that helping others makes them feel good too, so don't be afraid to ask for help.

FILLING THE SILENCE when I had to be on my own, with the radio playing cheerful chatter, or relaxing music, kept me calm and distracted. The right music will actually change how you feel. In ancient Rome you might have called for a musician to make you feel better. Nowadays Mozart is a good place to start if you want to relax.

KEEPING IN TOUCH WITH SPECIALISTS AT THE PACING CLINIC was very reassuring when I did not feel right, and on at least one occasion I went along to be checked and left feeling better for knowing what was what. We all need reassurance, and in my experience the team looking after me were always there to answer my questions.

Let us know what worked for you.

**Patty Hemingway**

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## AGM QUESTIONS

**Stephanie took some notes at the AGM of questions that our two speakers Lisa Anderson and Rachel Bastianen were asked. Below is some of them with the answers. If anyone has questions, we would be pleased to address them or point you in the right direction for an answer.**

### Q & A's from meeting

**Q Italy have a higher rate of CRT implants, why is this?**

A Italy is the only European country with a database for HF. In the UK the rates of implant appear patchy, this may be due to the distribution of implanting centres. In the USA the rates appear higher, we need to be in the middle.

**Q SWLCN area have only one HF Consultant, why is this?**

A Ideally we do need more than one HF Consultant. There are plans to recruit another Consultant in the near future.

**Q Implant rates for CRT rose from 20 implants to 150, has the pacing clinic got more resources accordingly?**

A The increase in implants does stretch resources. We are doing 2 extra optimisation clinics and already have an extra member of staff to cover this but more resources will be required.

**Q If CRT is the one of the best options for HF, why doesn't everyone with HF and an ICD have a CRT device?**

A CRT is a relatively new technology only starting in 2004/5. If you are newly diagnosed and require CRT and an ICD you would be offered one. All older implants will be considered for an upgrade if required.

**Q I have an ICD. My son is 16, why hasn't he been tested?**

A Different conditions require different schedule of tests, ask your Cardiologist if your son should be screened.

**Q What gene tests should be done?**

A It depends on the condition, if we know the condition and it is inherited then we advocate screening. We don't commonly do genetic screening for Coronary Heart Disease. More often screening is carried out for Ion Channel conditions such as LQT.

**Q How long does it take to get the results of a Gene test?**

A If we know the gene we are looking for, then it may take up to 3 weeks to get a predictive gene test result. If it's a new gene, then it may take up to a year.

**Q Do you predict great strides forward in the field of Cardiac Genetics?**

A Much more emphasis is put on genetic testing now, we have learnt a great deal over the last 5 years.

These are just a few of the ones that came up.

## STOP PRESS

### Email address

We are hoping to set up an email mailing list for all of you who have email addresses.

Could you email me with your address at  
sue.jones@stgeorges.nhs.uk

This will enable us to send you the newsletter by email and save some of the mailing expenses. It will also save us having to stuff 600 envelopes!

## Tina's story



My story began in 1994, having suffered a respiratory arrest out of the blue. Several weeks and many tests later I was given the diagnosis of dilated cardiomyopathy (DCM). Although it is well known that this condition can be hereditary, and the cause of mine was unknown, I was not offered genetic testing at this stage. The treatment was medication and lifestyle modification. As I gradually improved and became asymptomatic I was able to come off of the medication. When I began to experience symptoms again, several years later, my original diagnosis of DCM came into question. It was decided that further investigation was required and this included giving bloods for genetic testing.

I was informed by the cardiologist, who proposed genetic testing, that some of my blood would be tested in the UK and some sent abroad. Also that testing can be a very lengthy process, and that it might draw a blank. I was not offered or given genetic counselling (I don't think that the hospital even had a genetic counsellor then). By agreeing to give blood and be tested I would also be participating in a research programme. For me it was a win-win situation as I'd be helping to advance medical knowledge and also hopefully get an answer for myself. Since diagnosis and genetic testing I'd had a couple of children and was aware that if my condition was hereditary that I may have passed it on to them. My parents and brother and sister had been tested (ECG, echo and chest x-ray) and given the all-clear.

Approximately 2 years passed and nothing conclusive had come from the tests. I went for my routine cardiology appointment one day and a genetics counsellor, who I'd never heard of before, asked if she could have a word with me. I remember her opening words very clearly. They were "as you are aware you have arrhythmogenic right ventricular cardiomyopathy (ARVC) A gene mutation had been identified. I was so taken aback and unprepared for this news. However I was grateful and relieved that I finally had an answer.

I broke the news to my parents and asked if they'd mind undergoing genetic testing. They were only too happy to oblige. As there was no family history I was hoping that my parents would be clear and that the genetic mutation had begun with me. They got their results far quicker as there was only the one definitive gene (identified in me) that was being looked for. My Dad came back negative and my Mum positive. This meant that no further testing was required in my Dad's family but that it would be pertinent if my Mum's 2 sisters were to get tested. Both my Mum's parents had died many years earlier, when I was a young child, so it was impossible to delve back further. Of my Mum's sisters one came back positive and one negative. My cousins and their children have been gene tested and some have come back positive and some negative.

I'd had both my children checked (ECG and echo) at a very young age - even though I'd been advised that it wouldn't be necessary until they were much older (cardiomyopathy typically presents during teens but can in fact present at any age). They had come back clear. Now that I knew that I carried a defective gene, responsible for ARVC, I was very aware that I may have passed this on to my children. For my husband and myself there was absolutely no question as to whether or not we should get them tested. We were 100% in agreement that we wanted to know. We were told that we'd have to undergo genetic counselling before we'd be allowed to go ahead. During the session with the genetic counsellor we were informed that we'd need to prepare ourselves for the fact that one or both of our

children could come back as positive. Also that the fact that they'd undergone genetic testing may have to be declared at some stage eg if applying for a mortgage later in life.

I received the call, approximately 2 weeks later. I was driving, alone, when the call came. I pulled over to the side of the road with a pounding heart and dry mouth. I needed to know but was also desperately scared of what I might hear. My daughter's result was negative whilst my son's was positive. I called my husband, who was working abroad at the time, in tears.

I would rather know than not know that he may be at risk as a result of being gene positive; as to my mind forewarned is forearmed. The last thing I would want would be for him to be at unnecessary risk. There was a certain amount of anger and resentment that this has happened. I also thought how unfair life could be. I know that some parents experience guilt – this is not something that I have experienced (after all I have no control over my genes!). I did wonder though whether or not genetic counselling may have been pertinent prior to making the decision whether or not to go ahead and have a family. However I don't think it would have affected our decision as both my husband and myself wanted to have a family.

Finally there was acceptance that this is the hand that fate has dealt us, and we just have to get on with it. If he is unlucky enough to develop ARVC then we will cross that bridge when we come to it; there is no point in worrying about something that may never happen.

As they are both very young still (13 and 10) we have not told them yet. But we will one day - when we feel the time is right. The good news, as a result of having had them tested, is that my daughter no longer needs to be tested (whereas prior to a negative genetic test she would have needed to be tested annually). However I am aware that new genes are being discovered with time and maybe she could be positive for another ARVC cause that hasn't yet been identified (it is possible to have more than one

defective gene). My son continues to be tested annually.

**Tina Amis**

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## USEFUL WEBSITES

The following websites and phone numbers are support organisations

### ARRHYTHMIA ALLIANCE

[www.heartrhythmcharity.org.uk](http://www.heartrhythmcharity.org.uk)

Tel: 01789 450787

### BRITISH HEART FOUNDATION

[www.bhf.org.uk](http://www.bhf.org.uk)

Tel: 020 7554 0000

### CARDIOMYOPATHY ASSOCIATION

<http://www.cardiomyopathy.org>

Tel: 0800 018 1024 or email  
[info@cardiomyopathy.org](mailto:info@cardiomyopathy.org)

### CARDIAC RISK IN THE YOUNG (CRY)

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

Tel: 01737 363 222  
or email  
[cry@c-r-y.org.uk](mailto:cry@c-r-y.org.uk)

### SADS UK

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

Tel: Anne Jolly BACP Accr. 01277 230642

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## NEWSFLASH 2

Young St. George's ICD patient to swim the Hudson River for Charity. Watch this space.

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## NEWS IN BRIEF

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### 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](http://WWW.ARRHYTHMIAALLIANCE.ORG.UK/AFFILIATES)

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### 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](http://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 POLICY IS STILL THE SAME!

## 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](mailto:tinafizzyo@btinternet.com)

**Alan Butler** our new Partner Co-ordinator can be contacted on [alan241@tiscali.co.uk](mailto:alan241@tiscali.co.uk)

**Stephanie Cruickshank**, Arrhythmia Nurse Specialist and ICD patient can be contacted on 0208 296 3175 07905 981 945 mobile and email [scruickshank@hotmail.com](mailto:scruickshank@hotmail.com)

**Patty Hemingway** Who is an experienced Homeopathic practitioner is on 0208 333 0413 or email [pattyhemingwayhomeopath@inbox.com](mailto:pattyhemingwayhomeopath@inbox.com)

**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](mailto: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](mailto:louise.power@blueyonder.co.uk)