

♥ BACKUP BACKUP BACKUP ♥

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

**Next BackUp Meeting**

**Tuesday 7<sup>th</sup> December**

**6 pm**

**in the Restaurant**

**downstairs in**

**the Atkinson Morley**

**Building**

HELLO FROM THE CHAIR

I would like to apologise that we had to cancel the AGM on 9 October at such short notice. Our key speaker, Professor Camm, was unwell and unable to attend and as you can imagine, it was just too late to find someone else to step in. We hope to reschedule his talk on Understanding Arrhythmias for another meeting. The AGM will be held in the early part of next year – we promise to give you plenty of notice once the date has been confirmed.

I'm delighted to say that we *will* be having a Christmas Get-Together on 7<sup>th</sup> December. We look forward to seeing you then and meeting the new patients among you who will be able to come along. As at similar meetings, it will be a chance to chat to old friends and meet new ones.

I guess it must seem that BackUp has been rather quiet this year and that not many newsletters have gone out. Well, rest assured, BackUp is still going strong and is always there to help you in whatever ways we can. New patients are now contacted after their implant but the committee members' phone numbers are always available for any one who wants a chat or some (non-medical) advice.

Just to remind you who the committee is:

**Sue Jones** – Sue needs no introduction of course. Without her BackUp would never have got going. She is also very involved with starting up the National ICD Patient Support Group. Not all hospitals are as lucky as we are having a support group, so this means that every ICD patient in the country will have access to help, advice and support.

**Stephanie Cruickshank.** Many of you will know Stephanie, who is a Cardiomyopathy Nurse Specialist now based at the Heart Hospital and is an ICD patient too. I am glad to say, Stephanie still wants to be involved with BackUp, although she is on maternity leave just now. Please join me in

BACKUP FUNDS & DONATIONS

**Don't forget. You can give donations to BackUp at any time. And please keep on letting us have your annual donations.**

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

STILL WANTED – COMMITTEE MEMBERS

We're still keen to recruit new committee members.

The committee meets with Sue Jones at St.George's about once every two months and otherwise makes contact on the phone or by email. It's a rewarding activity and not too onerous.

**If you'd like to know more, please get in touch with Sue at the Pacing Clinic on 020 8725 1372.**

congratulating her on the birth of her lovely baby son, William, born in August! [and have a coo at the picture on the next page –ed]

**Simon Noble.** Without our Editor Simon, we wouldn't have such a wonderful newsletter. In fact, without him we probably wouldn't have one at all. But he has many work commitments and so if any of you feel the urge to take up journalism, please contact me or Simon to see where your enthusiasm and talent can be put to good use.

**Gill Noble.** Gill runs our Partner's Support Group after identifying important issues that sometimes crop up for partners and family of ICD patients. The group meets once a year at the AGM, but Gill can be contacted throughout the year

**Tina Amiss.** Those of you who received the last Newsletter will have read about Tina's experiences having an ICD and also those of her husband. Tina is a Physiotherapist working in a hospital in North London and is an enthusiastic supporter of BackUp.

**John Pohorely.** John works as a Specialist Nurse at a hospital in Surrey and brings his experience and enthusiasm to the BackUp committee.

**Derek Jones.** Derek is Treasurer and keeps our financial records impeccably. As you know, we ask for a voluntary contribution of £10.00 per year. If any one wants to contribute, please send a cheque payable to BackUp to Derek, c/o the Pacing Clinic.

**Martin Byne.** Martin lives in Devon now, so many of you will not have met him as he cannot make many of the meetings. But I am pleased to say he is still in phone contact with us.

Finally, there is me, **Louise Power** – your current Chair. I have the dubious honour of having had my first ICD implanted in 1988. Support Groups were unheard of then, so when Sue invited me to be involved with starting BackUp, I was delighted to accept. I believe the Support Group is there for us all to use how and when we need it. But I would like to take this opportunity to emphasise that BackUp is YOUR group and we on the committee welcome comments and suggestions about how we could improve it. If you want to get more involved – in any capacity – or just want to comment about it, please do phone me or any of the other members.

I look forward to seeing those of you who can make the Christmas Get-Together very soon and hope to hear from any of you who can't make our meetings at any time.

Best wishes  
Louise

## THE ISRAELI PATIENT

Zvi Har'El had his first implant on the 27th of February, 1995. He's created his own website, <http://www.math.technion.ac.il/~rl/whaticd.html> in memory of his son, which we're honoured to quote here.

"The little (80cc) gadget had a seat of honor in my chest, close to my heart. Since that day, it ... saved my life three times by detecting a fatal irregular heart beat and generating a series of electrical shocks to treat it. On the 15th of September, 1999, after its battery had been depleted, it was replaced by a new, improved, and much smaller (49cc), model. Finally (so far...), on the 16 of July, 2003, it was replaced by a smaller (36cc) device. It also functions as a full-fledged pacemaker, and helps me in my daily activity.

My beloved son, [Gilead](#), was not so fortunate. He inherited my Hypertrophic Cardiomyopathy, and his first arrhythmia, on the 27th of June, 1996, was fatal, since the Mobile Cardiac Intensive Care Unit with its external defibrillator was too late to arrive... The cardiologists just didn't think he too needed an **implantable defibrillator**...

After Gilead's passing away, blood tests have shown that my other two children suffer from the same genetic disease. Now they are both owners of their own **implantable defibrillators**. May they never need to use it..."



**Tina Amiss, 0208 900 0684**

**Martin Byne, at work on 0117 973 1019 and email [byne2001@yahoo.com](mailto:byne2001@yahoo.com)**

**Stephanie Cruickshank, on 020 8668 6673 (home) and email [sruickshank@hotmail.com](mailto:sruickshank@hotmail.com)**

**Sue Jones, 020 8725 1372 and [sue.jones@stgeorges.nhs.uk](mailto:sue.jones@stgeorges.nhs.uk)**

**Simon Noble, 07766-237312 and [simon@sinclair-noble.co.uk](mailto:simon@sinclair-noble.co.uk)**

**John Pohorely, 01483 898436**

**Louise Power, 020 8889 0789**

