

**Newsletter 04 Spring 2011**

*News and information for young people living with cardiac conditions*



**Rachael Marchant with her son Elliot who is 6**

**Rachael Marchant – undiagnosed**

At the age of 22 I noticed my heart seemed to 'jump' around and beat in an unusual way. I contacted my GP on a particularly bad day and was referred to a cardiologist. I spent 5 years under the cardiologists care and received every test possible but nothing major showed on the results. In 2009 I had my second child; after a few months passed my heart felt as though it was stopping for short periods of time and then beating fast to correct itself. This continued to get worse and I nearly crashed my car when I had a black out. I rang an ambulance who recorded my heart pausing for 9 seconds. I spent 3 weeks in hospital and was re-tested for everything. The conclusion was that I would have an ICD implanted; I was devastated to say the least but felt comfort in knowing that the ICD should be there for my protection. The operation was quick and straight forward and my recovery was speedy. I quickly returned to a normal life as a mother and student. I am starting University in September and feel very positive about the future. CRY has been an amazing support to me and just knowing that there are people who I can meet up with and chat to, that are in the same boat as me, is an amazing comfort.

**P2 What is an ICD?**

**P3 Living with an ICD**

**P4 About myheart**

**Moments going through security**

**Tony Eames**  
**Sears Tower, Chicago**



"As I made my way to the front of the security queue, I made it clear to the very large 6'6" security guard that I could not go through the metal detector due to my pacemaker; quite a simple request.

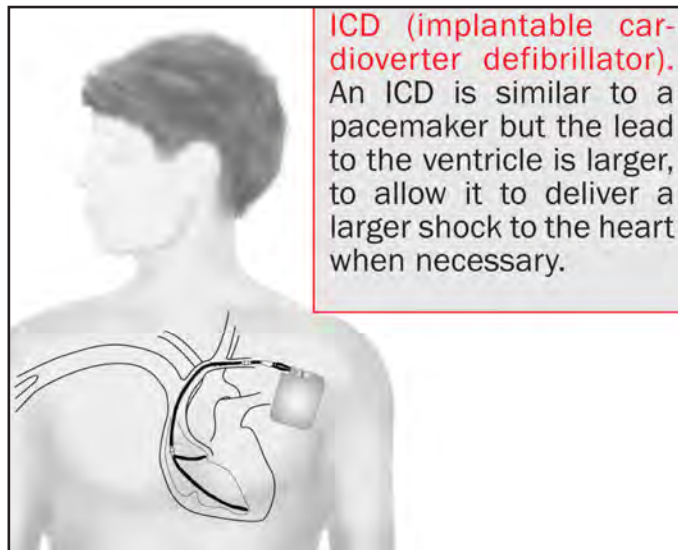
His first question 'do you have one of those...?' my response 'a pacemaker ID card?' 'No,' he responded asking again 'do you have one of those...?' my second response 'a medical bracelet?' Again, he responded no, and just looked at me.

My only logical response was 'I have a scar'. To my amazement, he responded 'yes that's it, can I see the scar.' Seconds later after revealing the scar I was through security heading to the viewing gallery 412 metres above the rather inquisitive security guard!!!"

# What is an ICD?

If the bottom chambers (ventricles) of your heart are prone to going into either a dangerously fast or a chaotic heart rhythm (called ventricular tachycardia and ventricular fibrillation respectively), or if you are thought to be at risk of your heart going into these dangerous rhythms, then an ICD can help you.

An ICD is a small device that is about the size of a matchbox. It is implanted under the skin below the collar bone, usually on the left hand side. One or more wires run from the ICD to the heart. The ICD is able to monitor your heart rhythm at all times; if it notices that your heart is going into an abnormal rhythm, it returns it to normal in one of three ways:



**ICD (implantable cardioverter defibrillator).** An ICD is similar to a pacemaker but the lead to the ventricle is larger, to allow it to deliver a larger shock to the heart when necessary.

1. Antitachycardia Pacing (ATP) – fast, low-voltage impulses try to override an abnormally fast heart rhythm (usually ventricular tachycardia), momentarily taking over control of the heart, with the aim of restoring it back into a normal rhythm.
2. Cardioversion – small electric shocks return the heart to its normal rhythm.
3. Defibrillation – bigger electric shocks put the heart back into a normal rhythm.

When you have your ICD fitted, you will usually be sedated. This means that you will feel very relaxed and sleepy, and as a result people often remember nothing or very little of the procedure. You will also have a local anaesthetic so that you do not feel any pain where the ICD is inserted. Most people stay in hospital the night after their ICD is fitted. Before you leave, some tests will be performed to check that it is working as it should be.

## Upcoming meetings

**This year there are meetings in:**

- Leeds
- London
- Birmingham

**If you are interested in attending a *myheart* meeting where you can socialise, share experiences, take part in group counselling and talk to an expert cardiologist in comfortable surroundings.**

**Please contact the *myheart* Coordinator on 01737 363222 or [myheart@c-r-y.org.uk](mailto:myheart@c-r-y.org.uk).  
[www.c-r-y.org.uk/myheart.htm](http://www.c-r-y.org.uk/myheart.htm)**

## My Box

My box,  
Protrudes from my beneath my skin,  
Intrusive in my mind,  
Vanity pays a heavy price.  
My heart thumps in my chest,  
Not to be seen in the flesh.  
I didn't choose for this intrusion,  
Unable to get over these insecurities.  
Described as a safety net,  
I carry this weight on my mind.  
I know I will be fine,  
In time my insecurities will fade,  
To have this aid,  
I'm truly blessed to have my box.



Joseph Tanner

# Living with an ICD

## Rob Jackson – arrhythmogenic right ventricular cardiomyopathy (ARVC)



When I first had my device fitted I was very worried about the way it would affect my life, as I had always been really active in the Army and thought I was pretty robust. I was now unsure about walking through the alarm barriers in shop doorways or whether my ICD might give me a shock if I used my mobile phone too close to it, and

then there is the worries about having sex! There were so many things that I was unsure of and I found myself making a conscious effort to be careful not to knock it or dislodge the leads from my heart. I had a really good chat to my cardiologist about my worries and he was really understanding, he knew my background and put me at ease about activities I can or can't do. I now pretty much manage my condition by the way that I feel, and as long as I don't push myself too hard I've been ok. I have had a couple of shocks over 4 years and in some ways I'm glad that I know how it feels, as now I don't worry about it as it's not that bad, and ultimately it's saved my life a couple of times.

I would advise anyone with an ICD to try to live as normal a life as you can, and most importantly stop worrying, as this can have a bigger effect on your health. Obviously don't put yourself at risk but with careful planning or just letting someone know you can overcome most of life's challenges: I have been skiing, I help out with junior rugby and am currently renovating our house I often forget I've got the device fitted.

## Adam Payne – hypertrophic cardiomyopathy (HCM)

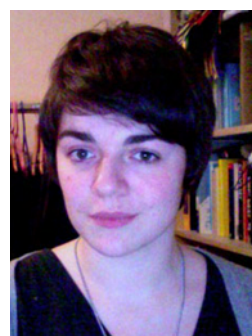
When I found out I had HCM I was so scared that my life was over and that nothing could be done. However, the doctors then offered me the



operation to have an ICD fitted. Like most young people the thought of having this done scared me but I realised that maybe this was the best thing for me and my family. My uncle had died at 30 and I did not want to go the same way. I was so scared about having the operation and how my life would change after, but it changed for the better. Now I'm happier than ever and the ICD has meant I can carry on with things that I enjoy instead of being told to quit them!! I am so glad I had the operation done and would say to all young people facing this daunting choice, go for it as you will live a better and happier life afterwards.

## Emma Jackson – hypertrophic cardiomyopathy (HCM)

When I was 13 it was discovered I had a heart murmur, after lots of testing I was diagnosed with hypertrophic cardiomyopathy. At 14 I had an internal cardiac defibrillator fitted as a precautionary measure. Six years later, I had my first



shock, after walking up the stairs I sat down and woke up on the floor! Over the next two months whilst trying various beta blockers I had six more shocks and blackouts due to VF. I haven't had a shock since starting on Amiodarone and I will be on it as long as it is safe. Originally I was annoyed at having a defib, but obviously now it has been completely worth it, I barely even think about it. Recently I had my defib changed and I got to keep the first one, I'll treasure it forever.

# About *my*heart



## What we can do for you

It is estimated that 1 in 300 young people aged 35 and under who undergo cardiac screening are found to have a potentially life-threatening cardiac condition that will require treatment. With an increasing number of young people now being screened every year through CRY clinics and mobile units, even more people are likely to need emotional support and information to help them cope with their diagnoses.



**"I was diagnosed with long QT and given a pacemaker which has now become my best friend. I thought I'd never get used to it, but now I wouldn't ever consider not having it. It's a good conversation starter!"**

**Rebekah Goddard**

myheart (previously the Surgery Supporters Network) was created to offer support to young people (and their families) who have been diagnosed with a heart condition, who are recovering from cardiac surgery or perhaps living with a pacemaker or ICD.

Members email each other regularly to share experiences and help each other cope with important issues such as:

- starting new schools, university or work
- managing sports and social activity
- living with an implant and being able to tell friends about their condition.

Members meet up to socialise, take part in group counselling and talk to an expert cardiologist in comfortable surroundings.

**We need your stories and news for future editions of the myheart Newsletter, please email to the newsletter editor, Mair Shepherd, at [mair@c-r-y.org.uk](mailto:mair@c-r-y.org.uk)**

## How to get involved

This is your newsletter. We need you to let us know about the issues that matter to you and what you want to see covered in these pages.

We could, for example, have a Questions and Answers section to deal with important issues such as travelling advice, getting back to sport, recovering from surgery, living with a pacemaker or ICD etc. Tell us what you think.

And, of course, we would like to include your own stories and photos. Please send these to us, along with your comments and feedback.

## Get in touch

myheart members can be contacted through the CRY office. They are happy to help any young person who has had or may be undergoing implantation or ablation surgery, or those diagnosed with a cardiac condition who would just like to link up with others with a similar experience to share.

If you would like to join myheart or contact members, you can email the myheart Coordinator at [myheart@c-r-y.org.uk](mailto:myheart@c-r-y.org.uk)

Or check out the myheart facebook page.

## Useful links...

[www.c-r-y.org.uk/living\\_with\\_condition.htm](http://www.c-r-y.org.uk/living_with_condition.htm)

Personal stories from young people living with rare heart conditions


[www.c-r-y.org.uk/Implantable\\_Cardioverter\\_Defibrillators.htm](http://www.c-r-y.org.uk/Implantable_Cardioverter_Defibrillators.htm)

Useful information about implantable cardioverter defibrillators (ICDs)

**The Surgery Supporters Network is now called myheart. This change of name reflects that support is available to any previously fit and healthy young person (35 and under) who has suddenly been diagnosed with a heart condition and was inspired by the CRY Philips testmyheart tour.**

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 **Cardiac Risk in the Young (CRY) Head office:** Unit 7, Epsom Downs Metro Centre, Waterfield, Tadworth, Surrey KT20 5LR **Tel: 01737 363222** Fax: 01737 363444 E-mail: [cry@c-r-y.org.uk](mailto:cry@c-r-y.org.uk) web: [www.c-r-y.org.uk](http://www.c-r-y.org.uk)