

Upcoming meetings

The next meeting will be held on **11th December** at **Reigate Manor Hotel** (just outside London). In **2012**, we hope to also have meetings in **Leeds** and **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 **Karla Griffith**, the **myheart** Coordinator, on **01737 363222** or **myheart@c-r-y.org.uk**.

Abi – right ventricular outflow tract ventricular tachycardia (RVOT-VT)

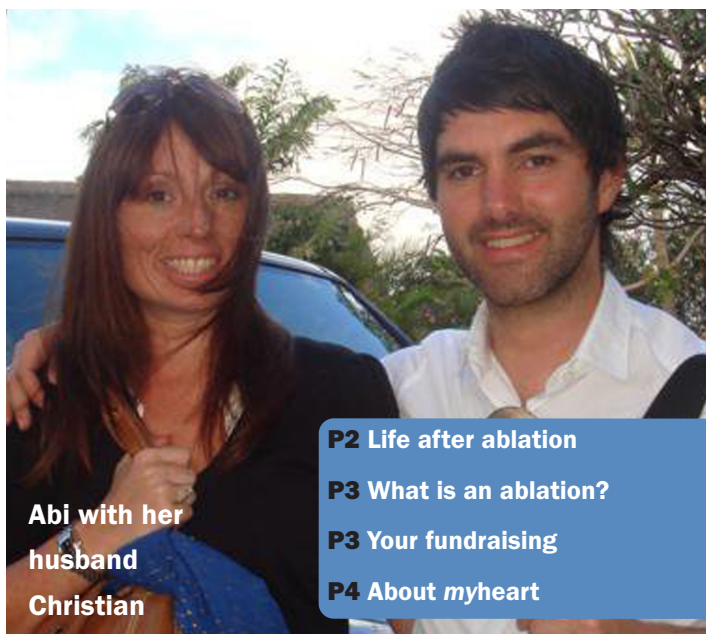
My condition came to light at the end of 2008 when I was 34. I'd been to the doctors to discuss these strange palpitations and dizzy spells I'd been experiencing but was sent away and told it was due to "stress". This seems to be the usual response from a GP the first time you report these symptoms. I remember thinking, I didn't even know I was stressed but perhaps I was and this was how my body was coping.

Fitness wise, I was reasonably active. I swam and ran every week and generally felt well, so wasn't worried that this was anything more serious than stress related palpitations.

After a routine trip into hospital to have four wisdom teeth removed under a general anaesthetic, the nurses told me they had trouble stabilising my heart rhythm when I was in recovery. Once back in my hospital room, I was advised to see a cardiologist to ensure that everything was fine.

Again I wasn't too concerned but thought I would mention it to my doctor when I was fully recovered. The next evening I was home, in bed recuperating when my heart started to behave very strangely. It began flipping, jumping, and felt like it was falling over itself. A strange way to describe it but it's how it felt. It would flip and felt like it was stalling. I felt dizzy, sick, scared, as if I was going to fall unconscious. I rang the emergency medical line and they told me to call for an ambulance who took me straight into hospital. From there they referred me to a cardiologist who over a period of weeks carried out a series of tests; a stress test, echocardiogram, an MRI of my heart and I had to wear a 24 hour Holter monitor etc.

The results were in – the good news was that structurally my heart was fine, but the Holter Monitor found something. It was a run of tachycardia around 250bpm – it was then that I received the diagnosis of RVOT-VT, a benign heart arrhythmia, although



Abi with her
husband
Christian

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sometimes frightening for the sufferer. I was sent home and told to see how things go and to try beta-blockers.

For some people beta-blockers are great and work wonders, but they made me feel dreadful, tired and depressed so I came off them. As time progressed the symptoms got worse and having felt like I'd exhausted all routes of medical help in my local area I went online and came across the London Bridge Hospital website and from there contacted an Electrophysiologist who felt confident that they could help me.

After my consultation and more tests, my first ablation was booked. I'd read up a little about what was involved but I can still remember shaking when I was getting ready in the hospital room. All kinds of things were running through my head; will it be painful, will I survive, what if it doesn't work, how long will it take?

I was given a huge gown to wear, one that has loads of pockets that can be pumped full of warm air to keep you comfortable when you're in theatre. I looked pretty funny and my husband and I were joking about it, he even took a picture of my theatre outfit!

Life after ablation

As I walked down to theatre I remember thinking I hope this is the end of all the problems and that my life will return to normal. I couldn't believe that my quality of life had changed so much in such a short space of time. RVOT VT had meant I was no longer able to run or exercise without feeling utterly drained and ill afterwards. My arrhythmia was daily and left me feeling weak, ill and unable to concentrate on anything. I had chest pains and sleeping had become a problem too. I couldn't sleep on my left side and would suddenly wake gasping for air. So, despite my fears of going into theatre I focused on my future, one that would allow me to go on to start a family without being plagued with these symptoms.

Everyone involved in the procedure were amazing. They helped me onto the theatre bed and began attaching the leads, which they use to monitor your heart throughout the procedure. I was warm and comfortable. They gave me a sedative to relax me and I actually fell asleep a few times during the procedure. I also had an oxygen mask.

They made an incision in my right groin into the femoral artery which is how they get the wires up into the heart chamber. I didn't feel any pain. They would stimulate the heart with electrical current so they could see the problematic areas on the monitor and know where to ablate. I could feel some pressure in my chest when they were stimulating the heart but after some more sedative I drifted off to sleep. Two and half hours later I was back in the hospital room and was elated that it was all over.

After about eight months it became apparent that my particular RVOT-VT would require a second ablation. So I was back in hospital again and this time the procedure took over four hours. I don't remember this one as I was blissfully sleeping throughout, but was told afterwards that there were multiple sites that needed treatment. Recovery from ablation is very quick. I stayed in hospital overnight to ensure that my heart was happy and that the incision in the femoral artery had closed. The next day you're home and on your way to feeling better. I took a few weeks off work to rest.

It's been over a year now since my last ablation and I'm very pleased with the results. My heart is so much better. It's been a long emotional journey, not just for me but for my entire family. I'm due to have a check-up in the next two weeks but I feel confident about the future and know that I shouldn't be frightened of this condition. I'm looking forward to starting a family and living a healthy happy life.

Chris Smith – Wolff-Parkinson-White syndrome (WPW)



I underwent a catheter ablation procedure in November 2009 after being diagnosed with Wolff-Parkinson-White (WPW) syndrome in May 2009 following a CRY screening at Myerscough College in March 2009. I was a fit and healthy swimmer in my final year at school, I trained at my club 5 times a week and up until 2 weeks before the screening I had not experienced any symptoms at all. My first inkling that anything could be wrong with me happened during a training session where I experienced a rapid heart rate and chest pain, this was a frightening experience. I didn't experience any other symptoms until after the screening. I went along to the screening not expecting to be told anything untoward. I was surprised to be called in with my Mum to see the cardiologist Dr Michael Papadakis and told there was an abnormality with my ECG, I was told it would be sent to London for Professor Sanjay Sharma to look at. I was then invited down to London for further tests and following these tests I was diagnosed with WPW. By the time I went to London in May for the tests I was experiencing more and more symptoms. These increased in frequency and severity that they were affecting my everyday life. I was having symptoms more and more often up to four or five times a week and not only when exercising I was having episodes when sitting at my desk at school. When Professor Sharma told me the diagnosis he discussed treatment options with me and my parents and recommended catheter ablation as he felt drug treatment would not be very suitable for me as the drugs would affect my swimming. I decided that the catheter ablation would hopefully offer me a permanent cure.

I was referred to Dr. Murgatroyd at King's College Hospital London where he agreed to perform the ablation, I went in for the procedure on the 5th November 2009. It felt strange to be the youngest person on the ward knowing that there was something

wrong with my heart; I would be lying if I said I wasn't scared at the thought of what was going to happen to me. The doctors and nurses were very kind at putting my mind to rest. The procedure felt very strange and a little uncomfortable. It didn't feel right being awake but less than 2 hours later I was on the ward. I was told to rest in the hospital bed for a couple of hours then I was brought something to eat and drink. I was then given an ECG which looked to be normal and was told he was 90% positive on a cure. I was then discharged from the hospital and allowed to go back to our hotel for an overnight stay. I was told to take things easy for a few days and apart from some bruising in my groin I felt fine

and relieved it was all over.

I have now been discharged from the hospital and my WPW is completely cured. I have been symptom free for almost two years now. I am now back into swimming and have started open water swimming which I now use to raise money and awareness for CRY through sponsorship. I will be forever grateful to CRY for all the help and support they have given me and for saving my life. I am a very lucky young man, thanks to CRY.

If anyone is told they need an ablation, I would say to them don't be afraid and have it done. It will change your life, it did for me.

What is an ablation?

An ablation (sometimes called a catheter ablation) is a procedure that is used to correct a faulty electrical pathway within the heart, which is causing or could potentially cause an abnormally fast heartbeat (called a tachycardia or tachyarrhythmia, in medical terms). This can therefore be the treatment if you have one of the following conditions, all of which have the potential to produce a very fast heartbeat:

- Supraventricular tachycardia (SVT) • Wolff-Parkinson-White syndrome • Unifocal atrial tachycardia • Atrial flutter or atrial fibrillation • Ventricular tachycardia.

During the procedure, you may be sedated so that you feel relaxed and sleepy, although this is not always possible because the medications used for sedation can sometimes suppress the faulty electrical pathway, therefore making it difficult for the doctors to find and fix it. You will, however, have a local anaesthetic at the point where one or more femoral sheaths (thin hollow plastic tubes) are placed. After everything has gone numb, a small cut will be made in your groin to put these sheaths in, usually into your femoral vein but sometimes also into the artery. Long tubes called catheters will then be fed through these sheaths towards your heart. These catheters are attached to a device that can either produce radiofrequency energy at their tips (called radiofrequency ablation), or cause the tips to become very cold (cryoablation). The tips of the catheters can then be used to destroy the faulty electrical pathway that is causing your arrhythmia.

You will probably have to stay in hospital overnight after your ablation procedure, and may feel sleepy if sedation has been given. The area in your groin where the catheters were inserted may feel sore for a few days afterwards, but usually gets better within 1 week.

Your fundraising

- Pezo Benjamin, with her family and friends, took part in the CRY Heart of London Bridges Walk 2011 and raised £1,756.
- Danielle John sent in a donation of £202.63 in respect of her *myheart* day.
- Lisa King (Chairman) and Wix Young Farmers Club raised £2,000.
- Rachael Marchant raised nearly £250 from a sponsored microlight flight.
- Dan Reeves, with family and friends, held a fun day in their village and raised £1,350. There were lots of stalls including a Raffle, Tombolas, cakes, bouncy castle, Gladiators



challenge, Penalty shoot out, Tug of war and lots more. We had a lot of community support for a small village which is Wragby in Lincolnshire. The photograph shows Daniel with his sister Charlotte (red CRY shirts) at the fun day.



- Chris Smith took part in the open water swim at Ullswater and raised £400.
- Charlotte Torr, Current Vice Chairman of South Axholme Young Farmers Club held a race night at the Reindeer Inn, Sandtoft, and raised £250.



Please send us your photos.

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

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, Karla Griffith, at myheart@c-r-y.org.uk

Or check out the *myheart* facebook page.


Useful links...

www.myheart.org.uk

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 test*myheart* tour.

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