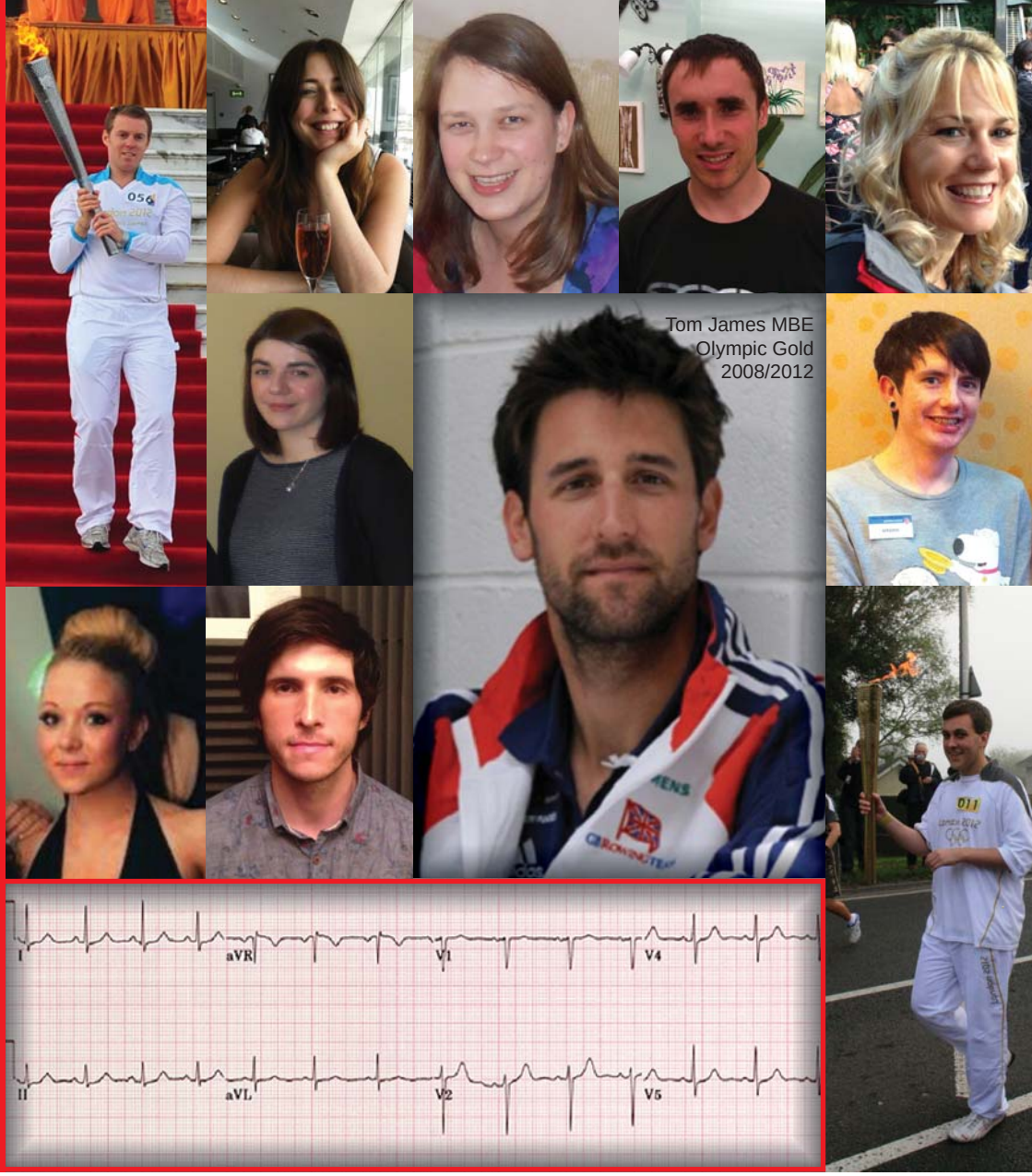

Young, fit and suddenly diagnosed with a life threatening heart condition . . .

myheart
support for young people diagnosed with life threatening heart conditions

Cardiac Risk in the Young

Editor
Alison Cox MBE, CRY Founder and Chief Executive
Contributors
Karla Griffith, Bev Katigbak, CRY *my*heart Network Co-ordinator
Nat Jenkins, CRY Online & Interactive Media Co-ordinator
Kerry Gray, CRY Office Manager

Produced by
Cardiac Risk in the Young (CRY)
Unit 1140B The Axis Centre, Cleeve Road, Leatherhead, KT22 7ND
Web: www.myheart.org.uk www.c-r-y.org.uk
Phone: 01737 363222 Email: cry@c-r-y.org.uk

With thanks for their contributions to:
Tom James MBE
Alan Jones UKCP BSc (Hons)
Dr Michael Papadakis, MRCP MBBS
Professor Sanjay Sharma
Images of Tom James © Peter Spurrier Intersport Images

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Foreword

Lonely. Frightened. Isolated. The stunning realisation for an apparently fit and healthy young person that they have been unknowingly harbouring a dangerous heart abnormality can have a catastrophic psychological impact as they struggle to cope. These conditions are usually genetic and if the diagnosis comes in the wake of a sibling's death, it makes the possibility of it striking again very real, both for the individual and their parents. If made after having symptoms, there can be relief that it will now be treated appropriately; but fear cannot help but permeate if it is after a tragedy. For parents, their relief at their child being diagnosed 'in time' is muted as they witness the subsequent difficulties of coming to terms with something that will shape the rest of their lives. The natural frippery or immaturity of youth can be swiftly and brutally swept away in the tidal wave of emotions of all involved. Poised on the threshold of their lives, just establishing their independence, the response can be fierce and difficult for family and friends to deal with. Those affected may not want to share worries and fears, or start being obliged to anything or anyone.

Accepting they must now be responsible for addressing their own vulnerable health issues, and readdressing their quality of life balanced against risk, is seldom satisfactorily achieved with those desperate to protect them. Being with young strangers in a similar position to their own can be cathartic. Listening to their questions liberates their own. Learning more, improved clarification of risk, being able to contemplate and discuss strategies with those of the same age with similar social problems can develop a way forward not otherwise achievable. Asking questions of the cardiologist that they would not entertain initiating at their own appointment can be empowering and often provides the first steps to them being able to come to terms with their condition. Having the option of staying in touch - or choosing to walk away - gives them the space and freedom to place their feelings where they can be reflected upon when they are ready. The CRY *my*heart group can offer a safe haven.

My hope is that this booklet provides the opportunity for both those affected and those that care deeply for them to facilitate discussion, understanding and perhaps even reframe a perspective on what is an extraordinarily challenging issue. As you will learn from these stories, their courage in coping is a lesson for us all.

Alison Cox MBE, CRY Founder and Chief Executive

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Tom James MBE - Introduction

On the following pages you'll find the stories of 10 young people who have all had to deal with major heart conditions, and the difficult choices and challenges that come with this. Such as that of James Bailey, who after screening required two heart operations to cure him of WPW at 17; or Sian Donnelly, who following the loss of her older brother to SADS at 17, found she had the same condition and required an ICD surgically fitted. You will see that these are very real cases, with real consequences that can affect anyone; the young are by no means exempt.

I have since found out my own situation is actually relatively common amongst athletes. I am certainly not the first oarsman in their twenties to be diagnosed with atrial fibrillation (usually more associated with 60+ overweight smokers) and nor will I, unfortunately, be the last. The fact that the heart is hidden from view behind the ribs and lungs may explain why its function was never a daily concern of mine. Nor should it have been perhaps, but having it perpetually beating away, tirelessly responding to the body's demands was something I very much took for granted. Yet, it is the single most important muscle in the body and complications to the heart are still the main cause of death in the UK today.

In my own case I was very much struck by this realisation. In the 27 years that I had been walking the planet, my heart had been beating away quite ordinarily and regularly without a problem. However, towards the end of 2011, I had woken up one morning unaware that a large part of it had simply shut down, and for the first time in those 27 years it was doing something very unordinary and irregular. My own diagnosis came as a shock and it was difficult to know how to react to it. It is not a sprained wrist that you can hold up and test, a knock that you can ice or a fractured bone that can be put in a cast and allowed to heal. An injury of the heart becomes very personal, private and frightening, particularly as its constant working is essential to survival. In rowing we talk about our bodies as though they're engines, vehicles we train, race and have to maintain. At the centre of this frame there is one component you don't rest or switch off - it is always ticking over in the background. Should it stop or falter, you can't just turn an ignition key, start it up and drive off again – you are quite simply either alive, or not.

In the same way that we routinely visit the dentist, dealing with the health of the heart from an early age warrants a minimum standard for our attention. Screening is that minimum standard. Not only is there significant evidence that it is a major preventative mechanism for serious heart conditions in the young, but it raises awareness both for young people and their parents that the health of the heart is paramount in all our lives. The more of us who are screened, educated and encouraged from an early age to consider our health, the greater the likelihood the stories that you read on the following pages will become increasingly hard to find amongst the young. I became a CRY Patron following my own treatment and from finding out the very positive effects that the charity has. Raising awareness of these potentially fatal heart conditions and how they can be treated if identified in time, is crucial. I hope that by telling my story more young people will consider it is worth having their heart tested by CRY.

Lastly, I would like to say thank you to CRY Founder Alison Cox and all the supporters, parents, young people and doctors (particularly Professor Sharma in my own case) who have taken the time and effort to promote CRY and help CRY realise its aims. Without them the lives of so many fit and healthy young people would have been otherwise tragically cut short.

Thoughts and Feelings - Extracts from their Stories

Disbelief was followed by not wanting to know. I played football daily; I didn't want to stop playing sport. I didn't want to have to change anything. I was in the middle of my AS-Level year and had enough stress without thinking about heart syndromes. Why couldn't I just forget I had ever had the ECG? Why couldn't I just ignore the results? JB

Being diagnosed has put things into perspective for me. Life is short. I wish that I had gone to the doctors before, instead of being stubborn and ultimately putting my life at risk over the years. It's made me realise that your health should be the most important thing to you. MB

The hardest thing was dealing with other people – some wanted to wrap me up in cotton wool and not let me lift a finger, others found it difficult to accept I was actually suffering from a potentially life-threatening condition as I had no outward signs. LC

My parents arrived in Bangkok to find me in a coma, on breathing apparatus, with lines and tubes everywhere. Mum and Dad sat up front with the ambulance driver moving me to Bangkok Hospital, not knowing if I would go home a cabbage or in a box. For them this was an unimaginably traumatic time. CC

…my parents were as worried and anxious as I was about the operation and had reservations about how I would cope with my scar and generally manage having an ICD fitted. As an 18 year old girl, I loved going out and they thought I might become self-conscious about my scar. Although it is noticeable - and now considerably bigger due to my second operation - mostly I forget it's there until someone points it out!! SD

For 8 years my family doctor had treated my fainting attacks as epilepsy and panic attacks. It was even suggested that I be sent to a psychiatric institution, something my parents refused to allow. No-one had thought of testing my heart and all that time I was at risk of a sudden fatal attack. I still don't understand why it took so long for someone to think it might be a cardiac problem and not mental at all. TE

Although I know how difficult it is to come to terms with a diagnosis when you are young, it does begin to shape who you eventually become. CRY provides both screening and support to those who are diagnosed, something I wasn't offered through the NHS. They offer help to all young people affected and it is not dependent on where you live or which NHS Trust you are under. EJ

…this experience has taught me not to take anything for granted and to really appreciate family and friends. For me it all boiled down to two simple choices, cry or laugh. I chose the latter, accepting my condition and carrying on with my life - and not letting this potentially depressing and life threatening condition dominate my life. AM

Some people's reaction to my scar was squeamish, it seemed as if they found it uncomfortable to look at. Personally I found this difficult and embarrassing to begin with. However, as time went on and with a few cheeky jokes about it, my confidence grew and I learnt to remember 'why it is there'. PS

I was keen to return to normal and so returned to work 10 days later, but found I needed time to reflect and come to terms with what had happened. Friends didn't seem to know how to treat me and I did not know how to act around myself. One nicknamed me "Half Dead Joe"! They were cautious, ensuring I was okay, which was appreciated but annoying too. JT

All stories have been approved for publication by family members mentioned.

James Bailey's Story - Wolff-Parkinson-White Syndrome

I was pumped up for the game. The adrenaline was rushing through my body. I couldn't wait for kick-off but as soon as the whistle blew, my body reacted in a way it had never done before. My heart beating faster than it should have done, racing so fast I couldn't count the beats. I had barely stretched my legs and sensed something was wrong. As the game progressed my body seemed to deteriorate. My vision became blurred; I struggled to chase the football down; my heart racing frantically during the second half. I didn't score; we didn't win and this incident was put down to a 'panic attack'. I was lucky this incident didn't cost me my life.

Two weeks later, the CRY screening team visited my school, QEH in Bristol. Even before the aforementioned incident I had returned my screening appointment form - which was more my parents' choice than mine, as they wanted me to be tested. I did not expect anything to be wrong. The ECG was quick and simple. In fact too quick for my liking; I would return to learning about Desiderius Erasmus sooner than envisaged. However, my friend was sent back to class whilst I was asked to stay behind. I presumed, naively, there had been an error with the processing of my results and they had to redo it. No problem. Yet I quickly sensed that was not the issue as the doctor sat me down.

I'm not sure how you are meant to take bad news; it is not something you really want much practice in. Yet I don't think my reaction to "You have Wolff-Parkinson-White syndrome" was the norm - I burst out laughing. Perhaps the combination of shock, irony and total disbelief caused this reaction to what was clearly not a laughing matter. My smile quickly faded as I realised the implications and it was very difficult heading back to class afterwards, seeing everyone who was 'normal' whereas I was the one who wasn't.

Disbelief was followed by not wanting to know. I played football daily; I didn't want to stop playing sport. I didn't want to have to change anything. At 17, I was in the middle of my AS-Level year and had enough stress without thinking about heart syndromes. Why couldn't I just forget I had ever had the ECG? Why couldn't I just ignore the results? The revelation of the diagnosis was equally as surprising, shocking and scary for my family. As hard as it was for me to deal with it, likewise it was not something that they expected to encounter with me being so fit and active.

The cardiologist at Bristol Royal Infirmary tried explaining Wolff-Parkinson-White syndrome (WPW). I still don't understand what an 'atrioventricular reciprocating tachycardia' is but the original diagnosis was confirmed and he put me on medication. I had gone from taking the occasional paracetemol to having my own pill box reminding me to take my daily dosage of flecainide acetate, which made me sick. Having to stop the car to vomit en route to school was one of the more glamorous episodes of this period.

I felt in a significantly worse position than before CRY visited my school - taking daily medication which caused nausea and having to stop playing sport. However, I was reassured that the catheter ablation operation promised almost a 100% success rate and under general anaesthetic I would be oblivious to what was going on. Surgery coincided with work experience week, so whilst my friends were visiting hospitals to learn the tricks of the trade, I was visiting as a patient.

I remember receiving the bad news that not only had the operation been unsuccessful but there was no alternative. The surgeon had tried for 7 hours. It appeared I would have

to live with WPW for life. This was without a doubt my lowest point; to say I was distraught was an understatement. I reverted to wanting to forget about it and the next day attended my school's Sports Day despite being in tremendous pain, just to erase the problem from my mind.

As my stomach struggled with the flecainide acetate my surgeon gave me the news that he was keen to try a new approach - but I was wary. I couldn't deal with another operation failing, plus this time I would be having a local anaesthetic.

I was stunned when the surgeon advised me I could listen to music on my iPod throughout the procedure and decided only the "Rocky" soundtrack would do. So as I lay on the operating bed ready to have heart surgery, I had the iconic "Gonna Fly Now" echoing in my ears and this time the surgery was successful! Returning home in a little pain later that day, I addressed my A-Level studies soon after.

Eight months after my diagnosis, the ordeal was over. That was it, I was 'cured'. Having thought I would only have a coaching role in the coming football season, I returned to playing. Though I may not have won the Golden Boot, nor been able to go on tour to Holland, I knew I would be fit for the following season and able to play to my heart's content (that's the one and only pun, I promise). After months of medication, two operations and much stress, the fact that everything was back to normal seemed more than strange. I had left hospital and the problem had just vanished. The slight scar from the operation had all but faded too, as if it had never happened.

It took time to stop worrying whenever my heart rate rose, even slightly. As a precaution I attended another CRY screening incognito - disguising my face from the one pictured in the CRY magazine, in case they recognised me! Fortunately, my heart really was fine and continues to be to this day. Since my experience with CRY, I have been staggered to read the multitude of cases reported in the press about young people who were less lucky than me. As I flick through the CRY magazines it is incredibly upsetting to see the vast majority of stories in memoriam. It is now that I see how fortunate I really was. There were times when I wished CRY had never visited my school, I had never signed up for the screening and I had never found out. However, without CRY, the reality is that I could well have been one of those sad stories; and through my experience my friends have also become more aware of cardiac problems.

When Alison started CRY in 1995, she faced opposition from consultants who told her she should not be starting a screening programme, as young people could never cope with a diagnosis. Realistically, receiving a diagnosis is hard, young or old. Learning you have a medical problem is always unwelcome news, yet without a diagnosis you cannot resolve the underlying cause. Those consultants with the negative view would be more credible if the diagnosis was for an incurable, untreatable illness. However, cardiac conditions that affect fit and healthy young people are treatable once diagnosed. Yes, I found the news hard to take and things did not go smoothly, but then life so rarely seems to. I haven't sugar-coated my experience. It certainly wasn't an easy time and there were both mental and physical obstacles to clear along the way.

Ultimately, whilst being diagnosed may cause changes to your life, it potentially saves your life. This is why I will always be thankful to CRY and continue to support their work. Although WPW is not thought to be genetic, both my sister and my mum were subsequently screened by CRY. CRY now returns annually to my former school.

Should any pupil find themselves diagnosed, I hope they too will realise they are in fact one of the lucky ones who found out before it was too late.

Mallory Brand's Story - Wolff-Parkinson-White Syndrome

I discovered I had Wolff-Parkinson-White (WPW) syndrome by chance. I manage events and exhibitions for a marketing agency in London. In July 2012, I was flying to Boston when I felt unwell during the flight, collapsed and after receiving oxygen from the cabin crew was told to see a doctor once we had landed.

The medical centre recommended by my hotel asked about my general health and I told them I had experienced palpitations my whole life. They performed an ECG - luckily there was very little waiting around - and WPW was diagnosed. *"Shit"* was the first thing that came to mind! But then a sense of relief that the fast, irregular heartbeat I had been told was 'safe' for so long, actually was *something*. Admittedly, the next few hours weren't fun. I was in Boston with colleagues, so couldn't get the hugs from family or my boyfriend that I craved. Instead I called them, arranging to fly home early to visit my doctor.

My work colleagues bought me some delicious cocktails to take my mind off it and my flight home was upgraded to business class. I spent the entire flight back sipping champagne – every cloud has a silver lining! I began researching WPW on the internet, learning that Meat Loaf, Jessie J and Marilyn Manson were all sufferers. I figured if the 'Bat Out of Hell' could deal with it, then I certainly could!

In the UK, doctors confirmed my diagnosis and referred me to the CRY Centre for Inherited Cardiac Conditions and Sports Cardiology at St. George's Hospital in Tooting, London. Over the next 2 months they performed more tests and scans, checking I didn't have any further abnormalities. They then decided that because I had been experiencing symptoms my whole life, I should skip the drugs and go straight on the waiting list for an electrical ablation procedure.

I carried on as normal, although it was difficult at times having the diagnosis hanging over me and waiting for a date for my operation. My boyfriend had the patience of a saint and always put on a Patrick Swayze movie or cooked me a big bowl of cheesy pasta if I was feeling a bit down. I worked from my London office and exercised little in those months (a valid excuse for not being a gym bunny). I was anxious about my December holiday - in Australia, to meet my boyfriend's family - so kept chasing the hospital until they confirmed my surgery date in November.

Before surgery I contacted CRY, asking to speak to someone who had been through the same experience as me and was put in contact with Chris Smith, who had been ablated a few years earlier after being diagnosed with WPW by CRY. It was incredibly useful, speaking to someone my age that had gone through the same feelings I was having. Was it weird that I was worrying about the scar I'd have? What were the nurses like? Did they mind if you swore? How long was it before you were walking around like normal? Chris was really candid and it made me realise the procedure wasn't going to be easy but gave me a realistic expectation of what was going to happen.

The nurse testing me for my pre-op assessment told me WPW was a relatively new condition in the medical world. It got diagnosed about 20 years ago, which explained why doctors used to dismiss my palpitations as nothing to worry about.

The day before my operation I was so nervous. I watched a Christmas movie and baked a pie to keep my mind from it! I barely slept that night, getting up early to go

to the hospital with my boyfriend. I was put on a day ward which was specifically for people having the same or similar types of procedure to mine. Being 25 I was the youngest, the next youngest person there was in her 50's but everyone was really friendly and the nurses were super lovely.

I was first into surgery so didn't have too much time to worry. I told the doctor in theatre that I was really nervous and wanted lots of drugs to calm me down! They happily obliged, setting me at ease and updating me throughout the procedure about what was going on. When they realised the abnormality was in a more dangerous place than they had originally thought, they needed to wait for the senior cardiologist to complete the next stage of the operation, which was definitely worse than I thought it would be. It took double the 2 hours that they had anticipated. I spent the day recovering on the ward with my boyfriend reading to me and forcing me to drink the many jugs of water the nurses kept leaving for me! I was allowed home that evening and spent the next week recovering from home.

Recovering was harder than I had anticipated. Because I knew I would be awake throughout and going home the same day, I had assumed it would be easy and I would be up and about in no time. Actually that wasn't the case at all. The scar in my groin was painful but bearable, I was expecting that. However, I hadn't realised that my heart had been 'reset' and would need time to recover. For 2 weeks I had a lot of tightness in my chest, getting out of breath easily and being uncomfortable sleeping on my side. I worried something was wrong and was relieved to learn this was normal and would continue for a few weeks, which put my mind at rest.

I needed 3 weeks off work. Mum stayed with me which was nice – a bit like when you were off school as a child! I found walking a short distance felt like I had run a marathon, so it took me a while to return to normal. However a month later, I jetted off to Australia on holiday with no issues and had the best time ever! Although experiencing the odd weird heartbeat, it was really strange not getting palpitations and out of breath like before when I exercised. Now I have no excuse not to exercise anymore!

St. George's gave me the all clear – amazing! I didn't realise the complete and utter relief and happiness I would feel, knowing I had overcome and got rid of this little glitch. Heart 2.0 is a success! My cardiologist advised I would experience weird heartbeats for a year which was all part of the heart's natural healing process.

Being diagnosed has put things into perspective for me. Life is short. I wish that I had gone to the doctors before, instead of being stubborn and ultimately putting my life at risk over the years. It's made me realise that your health should be the most important thing to you and it also made me realise how gorgeous the people around me are - my boyfriend making me copious amounts of pasta; my BFF putting up Christmas decorations on the day I came home from the operation; and my mum coming to stay and watching crap telly all day with me.

When I read that Alison started CRY in 1995 and many consultants told her that she should not be starting a screening programme to identify young people at risk, because young people could never cope with a diagnosis – I thought "What complete bollocks!" Just because we are 'young' it doesn't mean that we are incapable of dealing with something this serious.

Everyone I have spoken to about this has said how strong and brave myself and fellow young people have been in this situation, but for me that almost seems irrelevant. You get on with it because you have to. You just do it.

Lucy Challis's Story - Arrhythmogenic Right Ventricular Cardiomyopathy

On Sunday 29th January 2006, my older brother Stuart, age 25, collapsed and died playing football. I was 23 and my other brother was 27. Stuart was the fittest of the three of us. He had no symptoms. His post-mortem, confirmed by the CRY Centre for Cardiac Pathology, identified arrhythmogenic right ventricular cardiomyopathy (ARVC). Our GP explained the genetic implications and the importance of screening. I think the shock of Stuart's death meant that we didn't really take in what being screened meant – it was just another hurdle to overcome. On a Monday in April, my parents, brother and I had ECGs and echocardiograms. The doctor asked if anyone had experienced possible symptoms and when I mentioned I had fainted on a horse at 15, the look on his face got me thinking. By the time he had studied the results of the tests, I'd come to expect the answer – he thought I had ARVC too. In comparison to Stuart's death, I almost felt like this was nothing – at least I was still alive.

Two days later I was referred to The Heart Hospital and took my overnight bag, I was so convinced I would be admitted. A specialist nurse questioned me prior to retesting, which included an exercise test. Suspicions of ARVC triggered an MRI scan, a 24-hour Holter monitor and the offer of genetic testing, with a 50% chance of finding the gene. The diagnosis was confirmed, with the MRI indicating mild left-ventricular involvement and I was started on medication to control my irregular heart rhythm and offered an implantable cardioverter defibrillator (ICD), which I immediately agreed to. There was just no question of me putting my family through the possible heartbreak of losing another child. I'm a practical kind of girl and like to just get on with things. I was lucky not to be hugely sporty so didn't have to make many life changes; I was still permitted to continue horse riding and only exclude mad cross-country gallops! The hardest thing was dealing with other people – some wanted to wrap me up in cotton wool and not let me lift a finger, others found it difficult to accept I was actually suffering from a potentially life-threatening condition as I had no outward signs.

My ICD was fitted in May 2006 and I think Mum was more nervous than me! I don't tend to worry about these things, so the day just kind of happened. I was nil-by-mouth from midnight, so frustratingly I could not eat or drink and needed to occupy myself until 4pm because I was last on the list! I hadn't wanted to see an ICD before it was put in, but a rep from the ICD company was chatting to me in the lab prior to surgery and offered me a demonstration model to show the children when she learnt I was a teacher. She put it in my hand there and then – not exactly the ideal time just before I was about to have one put in me! My ICD was implanted under sedative and local anaesthetic and within half an hour of returning to the ward I was starving and demanding food. My left shoulder, arm and side were so stiff and sore my husband had to cut everything up and feed me, but otherwise I felt fine. It was odd knowing there was something metal inside me that I couldn't feel unless I moved. After a relatively comfortable night, I was allowed home.

Having to take 10 days off work was disappointing but I needed stronger painkillers than I was given. You don't realise what muscles you use until you can't use them. Standing, sitting up and sitting down, were challenging. I couldn't lie on my side, so had 2 weeks being propped up on cushions to help me sleep. My wound needed to be kept dry for 1 week and I couldn't lift my arm above my head for 6 weeks. I found it difficult to wash my hair one handed! I'm a primary school teacher, so had to be careful lifting heavy piles of books, writing on the board and teaching PE and Games for a while after returning to work.

I have always felt comfortable talking about my condition and was open with my class about my ICD. I wanted them to know what was going on and that it was fine to question me. The best bit was when they asked if they had to plug me in to recharge me! Being around kids is great because they soon forget about it all and just treat you like they always have. They looked after me and carried my things around for as long as I could get away with it!

Genetic testing on Stuart's tissue showed one gene each from Mum and Dad combined to be responsible – a million to one chance. Mum, Dad and my brother carry one gene each, unlike me and Stuart who had both. They are regularly checked and take medication as a precaution. Learning the whole family were affected was a shock, but at least we know. Some relatives have had ECGs which appear normal. Some have chosen not to be tested which I struggle to understand, but this option is always available. None have had genetic testing. After months of upheaval our family settled into a more routine existence as we learnt to live life without Stuart. Memories became happy rather than sad and 8 years later his name is mentioned without tears, on most occasions.

The first time my ICD fired was August 2007 when I was horse riding – thankfully I didn't fall off! I was retested and an 'inappropriate shock' was confirmed – it shouldn't have fired. My medication was increased and once I got over the shock (literally!) it was a funny story to tell! In March 2008, my ICD fired again. This time checks confirmed it had fired appropriately; my heart reached 220 beats per minute and my ICD charged and fired within 7 seconds. It was odd thinking that without my ICD I could have been in serious difficulty, but I felt it had done what it was meant to do – save my life. Neither shock was pleasant, but within 2 minutes of each I felt so well it was almost unbelievable it had gone off at all. I was slightly cautious for the next couple of weeks, feeling conscious of everything my heart was doing, but that worry faded and I just got on with things. Most annoying was not being able to drive for six months but my lovely friend who lives close by chauffeured me for those months which was an absolute godsend. Weekends were OK as other people were around, but my six months spanned the summer holidays and there's nothing more frustrating than being deprived of your freedom and becoming dependent on others.

My ICD was replaced in September 2011 and there have been no further episodes. My family and husband, thankfully, don't treat me with kid gloves, although I'm sure they worry every time I go horse riding or on school residential activity weeks. My recent pregnancy put my heart under more strain but I had brilliant care and my 12 week checkup indicated my heart seems to have coped well.

ARVC is a genetic condition and I have 2 faulty genes, so realise my children could be affected. However, this has not put me off having them as they can have gene testing to remove any doubts. Not having to make huge lifestyle changes has helped; if I had been severely affected I could have felt differently, but having our little boy in our life is certainly the best thing that's ever happened to us.

I understand why some think young people can't cope with being diagnosed, but my experience from the last 8 years has taught me that children have terrific reserves of resilience, adaptability and acceptance and it is important for young people to have the chance of a diagnosis. If Stuart had been screened and diagnosed with ARVC then it might have stopped him playing competitive football, meant adjustments to his social life and possibly an ICD, but he would probably still be alive. Some might find having a heart condition difficult to accept and struggle to cope but others will acknowledge their limitations and move on. For those who think young people can't cope, I ask this – is it better to know and live, or not know and die?

Chris Currie's Story - Idiopathic Ventricular Fibrillation

I was 24 and having the time of my life travelling around the world with two friends. We had made it to Bangkok when we found ourselves in a bar and I literally keeled over. I am only here today because I was talking to an Australian medical researcher (Chloe) who was up to date with her CPR. I later discovered that my heart had gone into fibrillation. Chloe immediately took charge of the situation and kept me alive until I arrived at the local hospital, where I had to be shocked a number of times before they were able to stabilise me. I suffered hypoxic brain injury because of lack of oxygen during the time between the bar and the hospital. Due to the brain injury I was extremely agitated when I came out of the coma, so was kept in a medicated coma for several days before being gradually 'woken up.'

My parents arrived in Bangkok to find me in a coma, on breathing apparatus, with lines and tubes everywhere. Mum and Dad sat up front with the ambulance driver moving me to Bangkok Heart Hospital, not knowing if I would go home a cabbage or in a box. For them this was an unimaginably traumatic time. My parents and friends took turns to be with me 24/7 until I received my 'fit to fly' certificate.

Numerous tests were done in the Bangkok Heart Hospital and although fantastic, they were unable to confirm a diagnosis of suspected myocarditis and I returned home three weeks later to my local NHS hospital for further investigations. After another ten days at Watford General I was transferred to the Royal Brompton where I went through all tests again; ajmaline, ECHO, ECG - to no avail. At this point I was not overly bothered by the situation that I found myself in - partly because of the brain injury and partly I just had no notion of how all this would impact on my life.

My consultant decided that my best option at this point was to try and minimise future risk with an ICD. Between my parents and the consultant it was concluded that I would have a Cameron subcutaneous ICD device. My diagnosis at this point, for official purposes was declared as idiopathic ventricular fibrillation, which actually means 'they don't know.' I had very little emotion about the implantation of the device as I was not really with it enough to understand fully what was going on. All I knew was that I didn't want it and that comes as much from not liking hospitals and needles as anything else. I was given a general anaesthetic because I could not be relied upon to behave in theatre.

As all these decisions were being made, I can remember adamantly not wanting to have the device fitted and I still very much feel the same way, despite it going off twelve times in one sitting after being violently sick. When my stomach voids, my electrolytes drop dramatically setting off my device and my heart goes into fibrillation. Unfortunately for my friends and parents this episode happened in Crete, so there was another emergency mercy mission to sort me out again, but because of the ICD there was no more brain damage, so once I was stabilised in Heraklion Hospital I was allowed to recover in my hotel before flying home. This hospital also tested me, but again to no avail.

The 'Greek' episode reduced my ICD battery life from 100 to 60% in one fell swoop, which has drastically shortened the life span of my ICD! I learnt what to expect when the ICD goes off – like being hit in the chest with a spade! I was convinced, because my chest hurt so much, that I must have at least one cracked rib, but a chest x-ray proved me wrong. I am hoping that when I have to renew my ICD, technology will have reduced the size, making it less conspicuous, as it can be awkward when I play sport. I still play

hockey, cricket, golf, squash and go skiing, but less than before.

I came home the day after my device was fitted on 15th February 2011. Being home and in my own bed was better than being in a hospital bed but nowhere near as good as fulfilling my dream of travelling around the world. I was unable to drive for the six months following surgery which angered and frustrated me. I now understand that I was in fact not fit to drive due to my brain injury, which has had much more of an impact on my life than my heart problem. I struggle with relationships within my peer group; coordination; short and mid-term memory loss resulting in the inability to work. As far as the ICD goes I am constantly aware of it and can't bear to touch it or the wire. As it is a subcutaneous machine it is conspicuous when I take my clothes off, although this doesn't bother me at all. For example on the beach when I am wearing swimming shorts I get strange looks and sometimes people ask what it is. I am happy to explain and generally this leads on to why I have it, so tell them my story as best I can remember it.

The effect all this has had on my family and friends is hard to judge, as I have to admit I have been so wrapped up in my own battle I have been unable to consider them at all. This has provided much friction due to my thoughtlessness and I have been to very dark places from time to time. I gave up my job to travel around the world and intended to re-evaluate my career on my return but have been unable to do this. However, my occupational therapist has put me forward to the Work Solutions Program, so I am hopeful I may be able to find meaningful employment again soon. I am also seeing a psychologist to try and help me come to terms with what has happened.

We have checked through our family history and cannot find any unexplained deaths or heart attacks. Mum, Dad and my younger sister have had ECG, ECHO and exercise tolerance tests and these were all clear, so my condition is still a mystery to us all. As my condition might not be genetic I have not really considered whether any children I might one day have could be affected, but don't feel it would stop me from having a family if the circumstances were right.

I have become increasingly downhearted and frustrated in not having a diagnosis as without answers there cannot be the positive outcome of a cure. I feel despondent as my whole future remains in the balance and I have no platform from which to rebuild my life. Currently I have no idea when, or if, I will have another arrest, so starting my life again is proving a huge challenge. Not having a diagnosis gives me all sorts of everyday problems too - for example, driving insurance, travel insurance, life insurance and limits on the type of work now open to me. Having to be alert to something unpredictably going wrong is difficult. Having a diagnosis would help enormously with relationships with my friends and family, as they would be better placed to understand and help if something went wrong.

I really hope the future brings me a worthwhile career but I'm unsure what. Presently my life has many different improvements as I can now manage holding down 3 different volunteering posts. I assist the Oxhey Park Golf Club green keepers with cutting the grass using the ride-on lawn mower, strimming bunker edges and collecting balls on the golf range; I also work twice weekly at Watford Workshop light industrial unit sticking tape to foam - which I find exceedingly boring, so hope I can move on soon; and lastly I work at Willows Farm Falconry Centre maintaining aviaries, moving birds around as necessary and assisting with general duties.

I would like, one day, to buy my own home. However I don't think much about the future now as without that magic diagnosis plans seem pointless and I am absolutely convinced that it is the only thing which would help me move forward.

Sian Donnelly's Story - Brugada Syndrome

Whilst on a family holiday in 2004, my brother Adam died suddenly whilst playing volleyball at our hotel. After two post-mortems we were told that he had died from SADS (sudden adult death syndrome). At the time, we were completely unaware of any heart conditions in our family and by chance came across CRY who said we should be screened.

After a day of tests by the CRY team in 2009, Mum was diagnosed with the hereditary heart condition Brugada syndrome. Not only did this give an answer to my brother's death but it allowed us to test the rest of the family, revealing that my aunt and grandmother have the same condition. This, ultimately, has prevented any more distress to my family. We also chose to have genetic testing which was inconclusive – no Brugada gene was found.

At 18, a year after my mum was diagnosed, I learnt that I too had inherited the same heart condition. It's scary thinking about this at such a young age, but knowing I have a 50/50 chance of passing this on has not put me off having children in the future. We can test early to confirm if the condition has been inherited and if so I know first-hand how to deal with the diagnosis and possible surgery.

I never felt nervous during testing as I was convinced I didn't have the hereditary heart condition. I had been tested annually for 5 years before I was diagnosed, so felt there was no reason to worry. The only time I became concerned was when I first had the ajmaline test and it made me extremely unwell because I am so small, therefore it could not be completed. Knowing that I would have to have the test again was pretty frightening but it was the only way the hospital could rule out Brugada. Even though all my ECGs and ECHO results were fine, the ajmaline test showed I had the condition. One of the well known facts about Brugada syndrome is that it can be extremely difficult to detect.

My first reaction was to cry. All my test results were 'normal' so it was a big shock. I went into auto-pilot, numbly listening to everything the doctor said. I was offered three options: lifestyle change, a medical procedure that would test the 'strength' of my heart or an ICD. I was not prepared to constantly worry about the daily things I was doing in case it would lead to a fatal cardiac arrest and I knew I did not want this change hanging over my head. Next option was a medical procedure testing the strength of my heart and how prone I was to having a cardiac arrest. However, it would involve risky surgery and if I was found to be at high risk I would have to have an ICD fitted anyway. So my only option left was to have an ICD fitted – a very quick and easy decision to make.

My operation was in June 2010 at St George's Hospital, Tooting – less than 2 months after being diagnosed. I was nervous the morning of my surgery, but knew I was in the best place should anything go wrong! Although initial tests indicated the surgery had been successful and I was sent home, the next evening my ICD initiated three consecutive shocks. This was extremely scary - being less than 24 hours since my operation - and also very painful. I often get asked by other people with ICDs what the pain of a shock feels like and to be brutally honest, it felt like someone had kicked me extremely hard in the chest.

Mum phoned St. George's who advised us to go immediately to our local A&E, but they didn't understand the seriousness of the situation and the lady on reception didn't even know what an ICD was! I sat and waited whilst a man with a sore thumb was called in

before me! My parents and I then decided to drive to St George's about 45 minutes away. Once there I was rushed straight into the resuscitation unit and they found the wire had dislodged and instead of looping from the ICD to my heart, it was in an 'S' shape at the bottom of my abdomen. After a sedated night in the Coronary Care Unit, panicking that my ICD would shock again before they were able to replace the faulty wire, they operated successfully.

I suffered panic attacks for a long while after these problems, concerned that it would happen again. During surgery my ICD was fitted this time underneath the muscles below my collar bone instead of directly under the skin – something my consultant suggested so the ICD would protrude less. Although thankful you can hardly see it, I was unable to move my left arm at all for almost a month because my muscles had been cut and it was extremely painful trying! I was signed off work for three months, but after 6 weeks felt ready to return to my routine and was pleased to be back driving 2 months later. As time went by I relaxed more and more and now feel completely at ease with the fact I have an ICD.

When I was first diagnosed, my parents were as worried and anxious as I was about the operation and also had reservations about how I would cope with my scar and generally manage having an ICD fitted. As an 18 year old girl, I loved going out and they thought I might become self-conscious about my scar but luckily that never happened. Although it is noticeable and considerably bigger due to the second operation, mostly I forget it's there until someone points it out!! We all feel that a little weight has been lifted knowing that should I have a cardiac arrest, my chances of this being fatal have been dramatically reduced.

I do not believe having my ICD fitted has changed my life in any way – if anything, it's made me more determined to live my life to the full. I love going to the gym and going out with my friends and I also had the chance to live in Ibiza for a few months.

Many people I have met since my operation don't know anything about it and wouldn't suspect that I have a heart condition. I often don't tell people about my ICD or why I need it because of the circumstances surrounding my diagnosis. I'm not one for sympathy and feel that quite often people treat me differently when they find out. Although my closest friends know, I'm sure a few of my other friends would be shocked to learn that my brother passed away and that I have the same condition! I was given a magnet after my surgery. I always make sure I have it on me, as should there be a fault with my ICD and I am still conscious while it is delivering shocks, I can temporarily deactivate it by holding my magnet over my ICD site. My friends are aware that if I am unconscious they are not to use my magnet as this could end up doing more damage than good. They also understand the precautions I have to take, for instance, at airports or going into clubs they will always go ahead and discreetly inform security that I cannot go through metal detectors. I always make sure that at least one person I am with knows what to do, but thankfully it has never come to that.

With the work that Alison and the CRY team do, they have made both my family's loss and our diagnoses a lot more bearable. They have been able to answer questions we never thought possible and have ultimately saved my family going through any more anguish. Being diagnosed at 18 was a big shock but I never felt I couldn't cope with my condition. I was given endless amounts of information and was able to attend counselling sessions with other people who had been diagnosed with similar heart conditions. Being diagnosed with a heart condition is always going to have an impact on your life, whether you're young or old – but having the opportunity to find out early enough to prevent anything happening is the key.

Tony Eames's Story - Long QT Syndrome

I had my first episode of fainting at 4 years old. From then on I passed out regularly, sometimes several times a day. I have a photograph of me having passed out when I was playing badminton, with my racquet beside me on the ground. It is a strange picture to look at, now that I understand what it really meant and what was happening to my heart. During this time I was not allowed to do any school sport or go out in the playground. I was never invited to other children's parties because parents were so concerned that I might pass out and they would not know what to do. I even had to be escorted to, from and around the school so that I was never alone in case I fainted. It was an abnormal and isolating schooling for a child.

These 'attacks' continued on a very regular basis until it was finally suggested, when I was 12, that I should have a 24 Hour ECG. I was diagnosed at Scarborough Hospital in April 1991 with long QT syndrome. This is a rare heart condition that can cause sudden death in the young. It is a genetic condition, but thankfully no-one else in my family has been diagnosed. For 8 years my family doctor had treated my fainting attacks as epilepsy and panic attacks - it was even suggested that I be sent to a psychiatric institution, something my parents refused to allow. No-one had thought of testing my heart and all that time I was at risk of a sudden fatal attack. I still don't understand why it took so long for someone to think it might be a cardiac problem and not mental at all.

When I eventually went for my test I was just desperate to get this thing fixed. I knew I did not want to leave the hospital until I had been told what the problem was. I was absolutely determined to get to the bottom of it and not afraid at all - just impatient! I felt this was my final chance to find out what was wrong with me.

After my diagnosis I had a feeling of overwhelming joy. I can still remember the relief and the weight being lifted off my shoulders, knowing what was the matter with me. Being told what I had was an absolutely massive moment, particularly for Mum. I wanted to get up and go as soon as I could, so I could start my new life. They had to explain to me that this was not possible; and reality sank in quite quickly about how serious my condition was. Having a diagnosis at last was only the beginning; although on medication my faints stopped, I had to take my condition very seriously.

I was transferred to Leeds General Infirmary for treatment and was - and still am - under their care. 2 years after diagnosis I was asked if I would be a 'guinea pig' for a new surgical procedure to try and remove a nerve that may be causing my problem. This time I did get really spooked as I was 13 and was told there was a high risk the surgery could leave me with a droopy eye. So I got up and walked out, as that was not a risk I was going to take after all this time. The surgeon had to come after me and talk me into it. Fortunately there was no negative effect, although the doctors did not achieve what they had hoped for, so I had to continue the medication to regulate my heart.

My family were so relieved that I could now be treated and have a relatively normal life after an extremely abnormal childhood. Unlike the experts evaluating me, they had never thought my problem was psychological – they knew me and knew I was not that type of child. What had greatly worried them was that whatever was wrong with me was not getting treated and was really quite dangerous as it was so unpredictable. Many times blackouts happened when I was on stairs and the consequences of a bad fall and no-one finding me in time, are obvious. They were actually quite elated as we finally had an answer and that made a big difference to my own confidence and stability too. We all felt

more secure and none more so than my parents.

I remember the very first day I went into town with friends, without my parents. Aged 13, I was embarking on a new 'normal' life and it felt good. At that age you adapt quickly, although it was challenging. Everyone knew me as a 'weakling'. I had never been able to mix with the 'in' crowd, but now found I could be part of the group. I could do nothing about never being able to be a great footballer; life was just a matter of getting on with the things that I could do and I enjoyed the refreshing feeling of finding ways of having a good time. In spite of all my problems I always loved school and not being able to do what others could never got me down. I think it has made me resilient - I am glad for what I have, not angry about what I have missed. Going to Uni was easier than being at school as it was a fresh start and no-one knew me, so there was no expectation of anything. People just accepted me as I was.

At 18, in my final year of A-Levels, I became ill again and required a pacemaker implant to back up my medication. My family and I were devastated as I was enjoying my teenage years after a traumatic childhood. Soon after, I left the security of home for Newcastle University and decided from the start to be open with my new friends about my heart condition and pacemaker. This gave me confidence, which was seriously lacking during my childhood. The implant has enabled me to do far more strenuous exercise, which I have relished. Table tennis, cycling, running and visits to the gym are regular activities. It is fantastic to be free to participate in so many things that for so long I could not even think about trying; and I often feel there is a lot of catching up that I still have to do with the physical challenges I want to undertake.

I was bitterly disappointed when I could not find a cardiologist to grant me permission to climb Mount Kilimanjaro, so had to accept that was a challenge that would elude me; but I was able to test my confidence and achieve a major personal goal by completing the 60km Just Walk challenge with my sister Rachel to raise awareness of CRY. This really did challenge me, my heart and my sister's feet!

I found time heals and I do not bear any bitterness or mental scars from my unusual childhood. I married a girl I had known for 20 years. Through thick and thin, no hiding! Now I have a baby and worrying about long QT being genetic was never an issue for us. We talked it through and decided my problem would not stop us. I do worry though, where the blame would be if something went wrong. However, we are taking the right steps to ensure my beautiful daughter is reviewed by doctors I trust.

I would like to conclude by saying that those doctors that feel CRY should not be offering a screening programme because young people could not cope with their diagnosis do not understand how robust and adaptable young people are. It is a very short-sighted view. Their job is not to be making inappropriate assumptions that might apply to adults! Their job is to try and help us solve our, occasionally quite complex, medical problems. I am an extreme example at one end of the spectrum of how someone can cope with a heart abnormality – even when it remains undiagnosed for so long. Coping with this made me what I am today.

Young people are adaptable and versatile. Through CRY, I hope my story may help further raise awareness with health professionals and the public of why young people may be dying suddenly and the tests that are available to diagnose them and save lives.

After hundreds of fainting episodes, a pacemaker fitted and taking daily medication, I regard myself as one of the lucky ones and intend to live life to the full. My motto has always been 'what next?' and I enjoy every moment.

Emma Jackson's Story - Hypertrophic Cardiomyopathy

I never liked sports when I was younger and was never any good. I remember having strange missed beats, tiredness and slight dizziness but thought this was normal. It was pure chance that a doctor noticed a heart 'murmur' prior to knee surgery when I was 13 in April 2001 - something not even noted on my discharge sheet! However, Mum used to be a nurse so she dragged me along to the GP to get it checked out. A few months of tests followed, visits to the local hospital in Bedford, then a transfer to Papworth for lots more tests. I was diagnosed with hypertrophic cardiomyopathy (HCM) - an enlargement of the heart muscle, especially the septum, the dividing wall between the two sides of the heart. I can't really remember how I felt when diagnosed, except it felt strange because I had never had symptoms. It seemed unreal, and didn't really sink in that HCM could cause sudden cardiac death.

The problems caused by HCM are twofold. The enlarged tissue cells are disorganised and so do not carry the electrical signals well in the heart, causing atrial fibrillation, arrhythmia or ventricular fibrillation which can lead to sudden death; but then the enlarged muscle can also cause obstruction to the outflow tract, causing inefficient pumping of blood. Because HCM is inherited, my family were advised to be screened but we were not offered genetic testing. My consultant recommended I had an implantable cardioverter defibrillator (ICD) to record any unusual heart rhythms and shock my heart back to normal if it detected a dangerous rhythm. This stunned me and I remember sitting in the car with my mum before the appointment, psyching myself up to accept the medication prior to surgery; but there is no cure to HCM so I had no option.

On 25th October 2001, aged 14, I had my first ICD fitted. As I was young my consultant ensured I had a full anaesthetic and was completely unconscious for the operation. I know they can do this surgery under local anaesthetic but there was no way that was happening! I was back at school 2 weeks later. It was strange feeling a box under my skin but eventually I barely noticed it. The scar hypertrophied - where the scar becomes thick and red and takes a long time to become flat and pale - but the placement on my shoulder means it is covered by tops most of the time.

I knew my ICD was my safety net. I worried about it going off, but if it did then the shock would be better than what could have happened! I carried on as normal, did GCSEs, A-Levels, and went to university. The heart thing was something I could choose to tell people or not. I felt much more in control and overall barely thought about my heart or the ICD. My friends were interested to hear about it and my housemates were fully informed. I didn't keep anything from them.

My first real 'incident' was at 8.25pm on 24th November 2008, aged 20. I felt dizzy walking upstairs and sat down on a chair waiting for it to pass. I came round on the floor under the chair with my whole body tingling from electricity. My housemate called an ambulance and Whitechapel Hospital kept me in for 4 days because I had suffered an episode of ventricular fibrillation (VF) with my heartbeat fluttering at 329 BPM.

Luckily my ICD shock stabilised my rhythm, but it was frustrating being in a different hospital with unfamiliar doctors inexperienced with HCM who wouldn't allow me home although I felt fine. Frequently I had to explain my condition to the doctors and nurses, but the cardiologist who said "We have to keep you here because if this has happened once, it can happen again quite soon" was right!

There were 5 more episodes over the following 2 months, mostly at home. I became experienced in recognising the symptoms and getting to my sofa or bed so I had a soft landing! It did upset me once when it happened at work, in the middle of a busy shop, because it felt so out of control. It was a nuisance, I didn't want to spend any more time in hospital but on reflection would think "Thank f**k I'm still here!" My consultant changed my medication to nadalolol, but ensuing bad headaches meant I had to go onto a more 'hardcore' anti-arrhythmia drug called amiodarone. Good for stopping arrhythmias and with more tolerable side effects, I have been on amiodarone ever since

Another quiet 'cardiac period' followed and my ICD was changed in February 2010 after 8 years of faithful service. I had used it a lot and the battery was getting low but I was grateful to be able to schedule my surgery around important university work. Having the ICD changed was a walk in the park compared to having one implanted and 2 weeks later I was travelling around Norway. After having so many shocks and then being stable for a year I appreciated it was a necessity! I was in the first *my*heart group back in 2002 and returned after being absent for a while to again benefit from sharing thoughts and feelings about the effect HCM has on my life, with others in a similar position to me.

September 2010 brought more breathlessness and exhaustion. An echocardiogram identified the enlarged muscle was causing an obstruction. For the first time (aged 23) I personally made the decision to have major treatment, taking my consultant's advice that open heart surgery called a myectomy might give me a new lease of life. I decided to get this surgery out of the way whilst I was young so that it wouldn't interfere with my career, family and future life. The surgery on 4th October 2012 was a blur but I do remember feeling really hopeful and wasn't nervous until I left my mum and brother at the entrance to the theatre - by which point it was a bit late to change my mind. Open heart surgery is not an option to be taken lightly. It's not easy and it's not fun. They removed part of my septum, replacing my damaged heart valve with a mechanical one and I am now on warfarin for life to thin my blood and prevent rejection of the mechanical valve. A myectomy is an extreme treatment for HCM and many people can cope without the need for surgical intervention, but for me it was the right choice. I was fit enough for the CRY Parliamentary Reception a month later.

Since then I have felt a great difference. It is brilliant no longer spending the whole weekend recovering from work. Cardiac rehab (with 9 elderly men) helped me rebuild my fitness. Since being diagnosed my mum, aunts and their children have had genetic testing and 2 mutated genes were identified. Four family members identified with HCM are being treated. We have found this very helpful but I do understand that others do not always want to know. I would worry about passing the genes on if I had children, but hope that genetic testing and screening would help protect them. My mum always describes herself as one of the lucky mums. I can't imagine how difficult it must be for those who are diagnosed as a result of a close family member dying.

Although I know how difficult it is to come to terms with a diagnosis when you are young, it does begin to shape who you eventually become. CRY provides both screening and support to those who are diagnosed, something I wasn't offered through the NHS. They offer help to all young people affected and it is not dependent on where you live or which NHS Trust you are under.

When Alison started CRY in 1995, many consultants told her that she should not be starting a screening programme to identify young people at risk, because young people couldn't cope with a diagnosis. As with me, most young people have no symptoms prior to their diagnosis. If Mum had not ensured my murmur was checked, things could have been very different for us all.

Alessandro Miccoli's Story - Wolff-Parkinson-White Syndrome

It wasn't until the end of 2012 that a journalist first introduced me to the charity CRY. I quickly became aware of the amazing work they do in helping promote awareness of heart conditions in the young.

Since my early teens, heart conditions have affected my family in many ways. First, losing my grandfather to a heart attack, then shortly after my father was diagnosed with atrial fibrillation. At the time it didn't occur to me that I may be destined for the same fate. I guess I was just like every other healthy young person, oblivious to the fact that heart conditions are not just limited to older people - they can affect anyone, young or old.

My siblings and I are in a band and we were playing a gig in Birmingham. Half way through the set I started experiencing severe chest pains. I became extremely light headed and my heart was racing. It felt like it was about to explode. To this day I still don't know how I managed to make it to the end of the song (must have sounded terrible) but fainting in front of all those people was not an option for me.

In hindsight this was a very stupid thing to do, as I didn't realise my life was in the balance! I collapsed as soon as I walked off stage and emergency services took half an hour to get to me (even though the closest hospital was only 5 minutes down the road). Their response for the delay was, "A young 25 year old with chest pains, how bad could it be"! My heart rate was by now at 235-250 BPM and at any point I could have dropped down dead. When I eventually got to the hospital I was rushed into A&E and they tried every drug they could to get my heart rate down, but nothing was working. Finding myself in intensive care and drifting in and out of consciousness, fear and panic had firmly set in - I thought my time was up!

They sedated me and then used defibrillation to shock my heart back into a normal rhythm. I woke a few hours later bursting into tears as the feeling of relief was immense. I was so happy to be alive. The cardiologist at Birmingham City Hospital diagnosed me with Wolff-Parkinson-White syndrome (WPW) in its most aggressive form, explaining to me that an ablation procedure was the only way to rectify the problem. The news of this diagnosis at first hit me hard. I felt so many emotions all at once - fear, anger, frustration. I was confused, uncertain about my future and constantly asking myself "Why me??!!"

The cardiologist prescribed me with flecanide acetate, which is a drug to maintain a steady heart rate, until the date of surgery. I waited 3 long months to have the procedure and within that time I battled both with coming to terms mentally and physically with my condition and the fear of having my operation which I referred to as D-Day (later finding out that my operation fell on exactly the same date as the D-Day landings). I underwent the surgery in June 2009 at the Queen Elizabeth Hospital in Birmingham and when I awoke was so relieved and happy. However, after a few weeks my symptoms returned. Later, an ECG revealed that the extra pathways that had been burnt out in the procedure had healed when they weren't supposed to, making the operation unsuccessful. I was devastated.

I then underwent a 2nd ablation a month or so later. I experienced a few heartbeat skips now and again but nothing major, assuming it was just my heart settling down after the surgery; but then one morning I woke with a heart rate of 220 BPM and was

again rushed to A&E. They tried every drug they could, just like before, to get my heart rate down but nothing worked and again they had to use defibrillation to shock my heart back to a normal rhythm. Waking for the second time from a major ordeal I simply couldn't believe my 'luck', I was still alive! Tears of joy and relief followed.

By this time it was 2011. I had been dealing with 'this' for more than 2 years, undergoing my 3rd ablation, which would turn out to be my most extensive and aggressive procedure yet. At this point, the situation started to take its toll on me mentally and physically. The side effects from the drugs to maintain my heart rate started to become more apparent. My dosage increased and so did my anxiety attacks. The constant fear of dying in my sleep was always present.

The 3rd ablation was only partially successful - they managed to suppress the WPW so that it wasn't life threatening. However, whether it was due to the aggressive heart procedures or an undetected condition, I was later diagnosed with persistent atrial fibrillation. Undergoing a 4th ablation procedure was the only way to cure the condition. My symptoms were unbearable as there isn't really any drug out there that can regulate severe and persistent forms of atrial fibrillation. The 4th ablation procedure was mostly successful, I no longer experience chronic symptoms of atrial fibrillation or WPW and just the occasional skip now and again. I'm still awaiting my last appointment from my cardiologist to finally get the all clear!

The screening carried out by CRY for young people is imperative in detecting and thereby preventing an otherwise undiagnosed heart condition reaching its fatal conclusion. Having heard of the reluctance by some consultants to promote the screening programme CRY initiated, saying young people would not be able to cope with the diagnosis that might result, I would argue the opposite. Young people, with appropriate support, are more adept at coping with the situation, dealing with the diagnosis and having a positive / optimistic outlook.

Young people don't carry life's excess baggage. Having spent a lot of time in consultation and on hospital wards, I quickly became aware how the 'older generation' found it more difficult to cope and come to terms with their condition. Whether it was at the diagnostic stage, pre- or post-surgery or even just getting their INR level checked at a warfarin clinic. It would be very true to say this experience has taught me not to take anything for granted and to really appreciate family and friends. For me it all boiled down to two simple choices, cry or laugh. I chose the latter, accepting my condition and carrying on with my life - and not letting this potentially depressing and life threatening condition dominate my life. This was the only way for me and my family to remain sane. To put it all into perspective, I am always humble and conscious of the fact that I have been allowed a second bite at life.

I would have been so grateful, had I known about the screening programme, to have caught my condition in its early stages. Looking back, it would have made sense to get myself tested, since there is a history of heart conditions that runs in my family. It would have given me time to prepare, educate myself on my condition and be aware and save myself a lot of the hardship and 'close calls' that I endured. When I was eventually diagnosed with the heart condition, the rest of my family were screened, resulting in my twin brother also being diagnosed with WPW and atrial fibrillation.

My siblings and I look forward to the future and working closely with CRY to help raise as much awareness as possible to save lives and reduce the ordeal young people might be faced with under similar situations to mine. We want to bring awareness to the public that heart conditions are not exclusive to the older generation but can affect all ages and

Paula Simmonds's Story - Brugada Syndrome

I was diagnosed with Brugada syndrome on 8th August 2011 at St George's Hospital. I am a mum of two, one of four siblings and was only 30 when diagnosed.

Our family underwent tests after my brother (Craig) suddenly died in Australia on 23rd April 2010, aged 31. Craig had two children, a daughter aged 8 and a son aged 2. Craig was such a loving, fit, healthy person who was a wonderful dad and had so much going for him. He lived in Queensland, Australia.

We all had ECG tests which were then followed by the ajmaline provocation test that showed strongly positive for the Brugada phenotype.

We didn't know how my brother Craig died, so at the time of testing we were shocked that not only were we trying to deal with losing Craig but now we had to undergo tests to see if we had an hereditary heart condition that could have led to Craig's death. I had no idea about genetic heart conditions before this and at the time it all felt alien.

The straight ECG test was fine, but I knew my 24 hour ECG test and exercise ECG test showed Brugada patterns, which made me concerned about the ajmaline test - especially putting my heart under that amount of stress. I was also trying to deal with the fact the rest of my family did not show Brugada readings on their ECG tests.

All my family had the ajmaline test on the same day. My dad, mum, sister and myself showed positive. Strangely, my other brother Gary was clear on all of the readings.

This diagnosis had a great impact on me. Initially I felt shocked and gutted but tried to stay positive. I thought that if this is why Craig died, then it's lucky we have all found out so we can take precautions for ourselves, Craig's children, my other brother's children, my sister's children and my children.

I then had an ICD fitted on 2nd May 2012 at St. George's Hospital. I wouldn't say I often get scared about things but, yes, I was scared before the operation. I decided to have this surgery under sedation but it didn't work very well, so all I can say is that it was like being in a nightmare. The surgeon was extremely good and reassuring during the op, although I was awake and felt everything, even when unexpectedly my body jumped off the bed when they tested the ICD. That was extreme pain, but only for a few seconds.

After the operation I found myself so emotional, trying to deal with the fact I had a hard box inside my chest. I was constantly thinking of my brother Craig. On the ward I was surrounded by mainly older people. There was one younger lady who had just had a cardiac arrest. She had lost her memory and was really suffering trying to cope with everything that had happened to her. This put things into perspective for me. I was in some ways coming round to the fact I felt glad that I had this precaution inside of me. Also I was thinking about my two daughters and I hope they also take the precaution of having an ICD in the future - if they need to.

The first month was extremely hard emotionally, mentally and physically to come to terms with my diagnosis and the ICD in situ. I did a lot of exercise before this op and had to have a month off after. When I went back to exercising I found myself anxious, worried about how to begin exercising again. I was embarrassed about my scar, having to tell instructors

and self-conscious about having to start exercising softly and with low weights. This was a challenge as the box kept moving around and felt weird. Also, because my muscle had been moved to the front I had lost a significant amount of strength in my left shoulder.

It appeared to me there was a lack of knowledge on the part of some exercise/gym centres with regards to young people with ICDs and heart conditions, to the extent of turning me away. This made me feel isolated and demoralised. I got great support from the CRY *my*heart meetings with other young people who had been through the same operation.

The impact of my diagnosis on my family is difficult to express, as it is strange to have both parents and my sister Brugada positive as well as me. In some ways I found this helped, as when my parents first found out my dad rang me in an emotional state and told me he was positive and it was his fault that everyone had it. Then seconds later I spoke to Mum who had just been diagnosed with it as well, so I thought at least neither of them feel like it's only their fault.

I know my brother Gary felt uneasy and sorry for the rest of us, as he is fine. I worry about my sister as I feel she is still in denial about it all. Then I started to think about my children's situation - my lovely daughters have a 50/50 chance of having Brugada syndrome and I may have passed this onto them. This makes me feel like I don't want to have any more children at this present time but my feelings may change in the future.

Thankfully we have all found out and are aware of the necessary precautions that need to be taken so we won't lose any other family member in this way.

My friends were very supportive through this time. Quite a few of them didn't have any understanding or knowledge of Brugada syndrome, or any other genetic heart condition and I initially found it hard trying to explain.

Some people's reaction to my scar was squeamish, it seemed as if they found it uncomfortable to look at. Personally I found this difficult and embarrassing to begin with. However, as time went on and with a few cheeky jokes about it, my confidence grew and I learnt to remember 'why it is there' (to protect and safeguard me if needed). With this in mind I learnt not to worry about what other people thought when they saw it.

Everything has been fine now and it has been a year since I had my ICD fitted. I exercise well and enjoy my life with the security of knowing I have the back up in place if needed.

People may think that younger people who have been screened will find it hard to come to terms with being diagnosed with a heart condition, but it would be much harder for their family to have to come to terms with losing someone so young, because they had not known they had a heart condition that could have been monitored and treated.

My eldest daughter is 8 (Chloe) and she understands why I had to have all these tests done and why I have an ICD. Chloe also understands why she will need to be tested as she gets older. Chloe joined me on the CRY London Bridges Walk last year. She took the pictures and information into her school and gave a speech to her teacher and class friends on why she did the walk and the relevance it had to her. Both my daughters will be joining me on the CRY London Bridges Walk this year.

I think screening is a necessity in the young as this is what is going to identify people at risk, save lives and prevent unexpected young sudden heart deaths.

Joseph Tanner's Story - Brugada Syndrome

On Sunday 16th March 2008 I collapsed at the finishing line of the Hastings Half Marathon and my heart stopped for 7 minutes. Before this fateful day, I ran 20+ miles a week, had completed the London Marathon in 2007 and considered myself a healthy person. I don't remember texting 5 friends to say that I wasn't feeling right, whilst jogging on the spot in the rain waiting for the race to start.

I do remember coming dreamily out of intensive care on the Tuesday night, surrounded by nurses with machines bleeping, and having everything explained to me the following day; but I couldn't take in what the doctors were saying. They gave me many booklets to try and help me and the one titled "When Someone Dies" was not a particularly encouraging read! Being wired up to these machines monitoring my heart, having my vitals checked, blood taken, seeing my dad and friends in tears, being in a cardiac ward full of old people, all contributed to me feeling sorry for myself.

My sister Debbie (my emergency contact) received the call whilst in the pub with my parents. They were told to expect the worst. Police also told my manager at work and my house mates. I was on autopilot for the next 2 days because, for the first time in my life, I was truly scared. I'd put on a brave face for visitors, post stuff on Facebook, but when everyone was gone, I was truly on my own. Nobody knew how I felt being dependent on nurses to go to the toilet, being unable to leave the ward, sponge bathing myself. I wanted this nightmare to end! It took 2 weeks to recover sufficiently to go to The Royal Brompton Hospital for an MRI scan where I was diagnosed with Brugada syndrome type 3 and advised to have an implantable cardioverter defibrillator (ICD) fitted.

It broke my heart when doctors said I must never run again. Running was my escape in life and I didn't know what impact this would have. After 2 weeks in hospital I wanted my life back, so agreed to the ICD being done at the Royal Sussex County in Brighton. Having to sign permission for this in case I died scared me more than ever and on the operating table I was so frightened I remember a solitary tear rolling down my cheek! If I could have run out of that operating theatre I would have.

I came round 4 hours later to a room full of friends, which meant the world to me. I hadn't had many visitors in Hastings and was very happy to be allowed home the next day. Although I was told to take it easy I couldn't resist enjoying the freedom of walking along the beach. The cardiac nurse had emphasised rehab was mainly for the older generation but it was still weird being 30 years younger than anyone else. I didn't care much for an 80 year old fellow patient's 'traumatic' story - he had lived his life and I felt I had barely started mine.

I was keen to return to normal and so returned to work 10 days later, but found I needed time to reflect and come to terms with what had happened. Friends didn't seem to know how to treat me and I did not know how to act around myself. One nicknamed me "Half Dead Joe"! They were cautious, ensuring I was okay, which was appreciated but annoying too.

Doctors told me I should tell everyone and for a while it felt as if my condition owned me and I was unable to be me! It was also a traumatic time for my family. My parents had come close to burying their son and this brought us closer, with past upsets becoming unimportant.

We learnt Brugada is a genetic condition and family members were encouraged to get tested, but some seemed disappointingly dismissive. Meanwhile, I was being retested every 6 months to ensure my ICD was working OK and to record any incidents. Life returned to normal and I often forgot my ICD – even though it is so prominent under my skin. I do worry that I might pass Brugada on to any children I might one day have.

I found CRY by chance through a mother whose son had died of a cardiac arrest, who contacted me after reading one of my blogs. So I chatted to Alison at CRY and put my story on their website. Through CRY I have learned so much about Brugada and the support I have received from the charity has greatly helped me come to terms with it. I wasn't aware that I should get the flu jab because of my heart condition, shouldn't get drunk and must avoid certain medication. I learnt that I have to take ownership of my condition, to always ask questions, take notes of anything that happens and generally be alert.

For the first year I didn't exercise much. I was terribly unhappy and repeatedly bugged my cardiologist and the guys at the pacing clinic about running. Finally I had a treadmill test which proved normal and freed me to exercise. On Saturday 29th November 2009, over a year and half after my incident, I put my running shoes on again. It felt weird after so long - especially adjusting to my ICD which I could feel beneath my skin while running. It hasn't gone off yet and if it did I would be thankful as the alternative would be death.

In the summer of 2011, I briefly heard a bleeping noise which I ignored. After 3 days of repeated bleepings however, I realised something was wrong with my ICD. I phoned up the NHS who weren't much help and through Google found it meant my ICD was either faulty or had low battery. Sussex County Hospital pacing clinic confirmed the latter which was a massive blow as I was informed it would last 10 years. However, it was quickly replaced and I was in and out of hospital the same day - and awake and chatting to the surgeon (weird) during the entire procedure.

It has taken years to come to terms with my condition. Many cardiologists admitted there was still so much more to learn, which made me insecure about my diagnosis. I was grateful to be retested at the CRY clinic at St George's Hospital, with my sister, including having the ajmaline provocation test. Brugada was reconfirmed in me but luckily my sister has not got it and I was told I could have the first mutation. I live in hope that other family members will want to be tested too, one day.

Being a part of the *my*heart community has helped me learn so much more about my condition. I have met so many wonderful people and whenever I have any concerns that are related to my condition or ICD they are there for support and advice. It is so good to be able to meet others in similar situations and have a spontaneous mutual understanding as to what I may be experiencing.

Having a life threatening heart condition has changed how I look at things. I'm now thankful for every day. I have made some amazing friends over the years, seen my sister getting married and live a more or less normal life. I don't let my condition own me anymore! Recently I finished a counselling course, and have been accepted for a Gym Fitness Instructor course. One day I hope to help other young people that are diagnosed.

When Alison started CRY in 1995, many consultants told her that she should not be starting a screening programme to identify young people at risk, because young people could never cope with a diagnosis. For anyone of any age, getting diagnosed with a dangerous condition is life changing, but I feel that young people are better equipped to adjust to lifestyle changes. They absolutely have the right to know.

The role of the counsellor at myheart meetings

I have been facilitating this group since 2004. Most members are in their 20's to 30's and the older members are very supportive of the younger ones in a gentle and non-parental way.

I am acutely aware that their biggest problem is a sense of isolation. This may seem strange considering that they are, in a way, the centre of attention with parents, family, friends, and the health service professionals that surround them. But their lives have been taken over - they have been taken over - and are now 'ill', 'vulnerable', good or bad 'patients', with their identities recently and radically altered.

Usually a young person close to them has died suddenly and their families have been violently disrupted. Sometimes there are others in their family identified with the same heart abnormality, but then there are so many emotional entanglements that it is often difficult to discuss mutual problems openly with them. Or perhaps there is no-one they know who has the remotest experience of what they have to deal with, or who they can talk to in a meaningful way.

In creating an atmosphere where they can be themselves, and relate to others who are in very similar situations without being 'the ill one,' for the first time they find themselves on a level playing field. There is no longer the need to explain themselves, or be careful how they say things. Instead there is a freedom to just be themselves and openly, safely, share their feelings. These young people suffer from a wide spectrum of heart abnormalities, but what they have in common is their youth and the rareness of their condition. In a hospital setting, most of those they share a waiting room with in the cardiology department are in their 50's and beyond….

The CRY *my*heart group is possibly the only place where there is no pressure to conform to the concerns of parents, siblings, doctors, and friends. I have always felt that it is the parts of ourselves we are unable to acknowledge, or admit to (sometimes even to ourselves), the things that don't get talked about, which cause us the biggest problems. No matter how frivolous they might seem to be, I find they take their diagnosis extremely seriously and are always asking questions. What does this mean? How should I attempt to live when my life has become an unclear statistical probability? What do I do if the 'experts' don't have enough information themselves to know what should be done?

It is a rewarding challenge to be facilitating such a special group who are dealing so courageously with extraordinarily complicated health issues, whilst unflinchingly trying to make the best decisions for their life ahead. When suddenly in a situation where terror and panic can be overwhelming - both for themselves and those closest to them - they especially need this clear open space to think.

My hope is they continue interacting with each other when the session is over and stay talking about what is really important to them. Feeling safe enough to communicate by phone, text, email or social media gives them a strong and vital resource which should not be undervalued. It is the members of the group who can answer each others questions with their own experiences.

The more they can acknowledge all they are thinking and feeling, the better they can adjust and cope.

The role of the expert cardiologist at myheart meetings

The *my*heart group offers a unique platform to young people with inherited heart conditions, which extends beyond the scope of customary support groups.

Participants have the opportunity to interact with individuals of similar age, affected by the same conditions and are able to draw from each other's experience. The informal and friendly environment within a group of peers empowers young individuals to ask challenging and often unexpected questions and address concerns which they are unlikely to explore within the formal setting of an outpatient cardiology clinic. Through successive meetings, participants develop a more personal relationship with their peers and the CRY doctor, which gives the opportunity to even the most reserved of individuals to open up and express their concerns.

The 'Q and A' session with a doctor who has specific expertise in the field of inherited cardiac diseases and sports cardiology provides a unique opportunity for all participants to address any anxieties or fears relating to their particular condition. Most importantly, participants get the opportunity to address concerns relating to physical activity and sport participation, which are often not addressed in the context of an NHS clinic. Concerns relating to physical activity are very common in young individuals with inherited heart conditions who are often encouraged towards a sedentary lifestyle as a result of overprotection. Additionally, they frequently receive conflicting advice and are uncertain as to what kind and level of exercise is likely to give them the maximum benefit at the lowest possible risk.

Being involved with the *my*heart group has been one of the most rewarding and at the same time challenging experiences of my clinical career. You witness friendships developing within the group. You get the honour of being part of very personal moments of our members' lives, such as the birth of a child. As a researcher, you have the opportunity to develop scientific projects that are targeted to address gaps in the care of young individuals with inherited heart conditions. I am privileged to have the opportunity to discuss research projects directly with the individuals affected.

Through their personal experiences, *my*heart members provide a unique insight in their respective conditions; what studies are likely to have a significant impact in their clinical care; and are also likely to identify potential weaknesses in a scientific idea or protocol.

You get the opportunity to witness the transition of a young person from a reserved and frightened newcomer to a confident individual who wishes to take charge of his/her condition and live life to its full potential. The young people involved in the *my*heart group gradually become more knowledgeable and wish to contest accepted practices that they consider to unnecessarily restrict their activities and quality of life. As such, the job of a doctor becomes infinitely more challenging in a field of conditions where evidence-based practice is often limited, given the relatively low frequency and novelty of some of the conditions.

Occasionally, individuals get carried away and the knowledge and confidence they acquire through participating in CRY's *my*heart group, develops into a false sense of reassurance. As a result, their desire to prove that they are in charge of their condition may lead them to daring or even unsafe practices. In most instances however, discussion within the group tames the rebellious instincts and achieves a satisfactory compromise.

The CRY Centre for Inherited Cardiovascular Conditions and Sports Cardiology at St. George's Hospital, Tooting, under Consultant Cardiologist Professor Sanjay Sharma

Sanjay Sharma, Professor of Inherited Cardiovascular Conditions and Sports Cardiology at St George's Hospital, directs the CRY centre, which combines expertise in general population screening, sports cardiology and inherited cardiovascular disease. The specialist inherited cardiovascular disease services are managed by Professor Sharma and Dr Elijah Behr - Senior Lecturer and Honorary Consultant Cardiologist and heart rhythm specialist - who have a team of specialist registrars, nurses and physiologists to provide fast track referral for NHS patients after a young sudden death or when a young person is affected. Many elite athletes seek a diagnosis from Professor Sharma* who is recognised as a world expert in these complicated and potentially dangerous conditions. Under his direction, CRY is also acknowledged as being a world leader in research.

Supporting young people in their journey from screening through to possible diagnosis and treatment; offering counselling and informal access to medical experts through the *my*heart network; and helping families understand their 'heart history' and the genetic implications is part of the comprehensive programme that CRY has continued to develop since 1995.

*CRY Patron Tom James, 29, double Olympic gold medallist, suffered from artrial fibrillation (AF) during the lead up to the London 2012 Olympics. Prompt attention from the Olympic cardiologist (and CRY consultant cardiologist) Professor Sanjay Sharma resulted in fast diagnosis and effective treatment which saved his place in the winning team. Tom won his second gold medal for rowing (coxless 4) in London, to join the gold he won in Beijing in 2008.

Professor Sanjay Sharma BSc (Hons), MD, FRCP (UK), FESC

Professor Sharma qualified in the UK in 1989 and was appointed Consultant Cardiologist and Physician at University Hospital, Lewisham and Honorary Senior Lecturer in Cardiology at King's College Hospital, London in 2001. In 2006 he was appointed Director of Heart Muscle Diseases at King's College, London and became Professor of Cardiology at St George's University of London in 2009. He is Medical Director for the London Marathon and Consultant Cardiologist for CRY's Inherited Cardiovascular Conditions and Sports Cardiology clinic at St George's Hospital; the English Institute of Sport; Premiership Rugby Union, Rugby League, England Cricket and the Lawn Tennis Association.

Professor Sharma leads CRY's screening programme, the largest of its kind in the UK. He has an active interest in medical education; is lead tutor for the international teaching faculty for the Royal College of Physicians; has 16 years experience in teaching for the MRCP exam; and has published educational books in medicine and cardiology.

Dr Michael Papadakis MRCP, MBBS

Dr Papadakis qualified at Imperial College School of Medicine, London in 2001 and obtained membership of the Royal College of Physicians in 2007. In 2008 he was awarded a CRY junior Research Fellowship and was registered for a Medical Doctorate at King's College London and subsequently at St George's University of London. In 2011 he was awarded a clinical lectureship post at St George's University. His interests include sports cardiology, conditions predisposing to sudden cardiac death in the young, prevention of young deaths and heart failure. Dr Papadakis is a member of the European Sports Cardiology nucleus and is currently credited with 22 publications in peer reviewed medical journals and more than 80 abstracts in scientific conferences. He was awarded the Young Investigators Award for the best scientific abstract in EuroPRevent 2010 by the European Association for Cardiovascular Prevention and Rehabilitation.

Alan Jones UKCP, BSc. (Hons)

Alan Jones's interest in psychotherapy from an early age developed into him ultimately obtaining an honours degree in psychology. For the past 25 years, he has been providing individual and couple therapy; supervising other psychotherapists; and providing supervision and facilitation for various charities and the NHS. He also provides training material for trainee teachers and lectures in neuro-psychology, mindfulness and other meditation forms at the Saraswati Yoga Studio. He has supervised CRY's support programme since 2004.

Alison Cox MBE

Alison Cox MBE is the Chief Executive of CRY - the organisation she founded in 1995. In 1993 she instigated the first cardiac screening programme in the UK, working with the Lawn Tennis Association - a programme that was widened to the general public in 1997. As an experienced counsellor she developed a national bereavement support programme for young sudden cardiac death. In 2002 she started the Surgery Supporters Network (now called *my*heart) for young people who have been diagnosed with a life-threatening heart condition. She has been on the board of various government advisory committees and is a well known and passionate speaker about the impact of young sudden cardiac death. In 2007 she was awarded an MBE for services to healthcare.

Some myheart members' achievements since their diagnoses

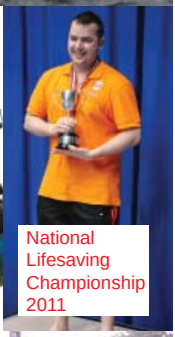

Wimbledon Men's Final 2009

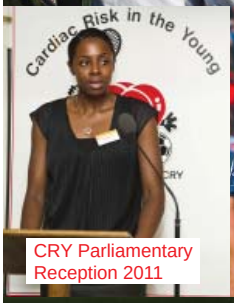

Up the Pace Bristol 2012


Ullswater Openwater Swim 2011

60km Just Walk Challenge 2010


Sponsored Microlight flight 2011


National Lifesaving Championship 2011



CRY Parliamentary Reception 2011


Wimbledon Men's Final 2004


Family Funday 2011


CRY Bridges Walk 2012


CRY Parliamentary Reception 2012

About CRY's myheart network support programme

CRY was founded in 1995 to help families affected by a young sudden cardiac death (YSCD). Started in 2002, CRY's *my*heart network (previously known as the Surgery Supporters Club) has been developed to provide support and information to apparently fit and healthy young people (and their families) who are suddenly diagnosed with a dangerous heart condition; are recovering from cardiac surgery; or living with a pacemaker or implantable cardiac defibrillator (ICD).

This group was inspired by hundreds of young people who have contacted CRY over the years needing to talk to others of a similar age, who are experiencing similar problems and difficulties to their own, which affected them in a similar way. No matter how much professional support is offered (either medical or therapeutic), the need to talk to someone who absolutely understands how they feel - because they are struggling to cope with the same issues - often helps the most.

CRY's screening programme indicates 1 in 300 young people aged 35 and under have a potentially life-threatening heart condition that needs to be fully investigated by an expert in this complicated field of medicine. Dari Taylor MP's Cardiac Risk in the Young (Screening) Private Members Bill, debated in the House of Commons in March 2004, provided the opportunity to highlight these conditions and with MPs' support they are now recognised as being far more common than had been previously thought.

CRY's *my*heart network holds regular meetings for those aged 14-35 who would like to meet with others in the same position as themselves. These unique meetings are fully funded by CRY and held in various venues around the UK. Each meeting comprises:

Group counselling: supervised by an experienced counsellor, it offers a supportive environment to address the social impact of being diagnosed with a life-threatening heart condition and coping strategies.

Informal Q&A session: providing a forum for questions relating to their heart condition, with a cardiologist who is an expert in this specialist field of medicine. Risk management is a crucial part of the quality of life of a young person confronting a serious heart condition and only an expert is able to direct young people towards what activities are (and are not!) viable.

Lunch is included: giving the opportunity to get to know others in the group, in a relaxed environment.

CRY produces 3 full-colour dedicated *my*heart newsletters annually, written for and by those affected, which aim to inspire and encourage others. These newsletters encompass a variety of articles including members' experiences of being diagnosed, fundraising events they have undertaken and updated information on relevant medical issues. CRY welcomes photos and articles from members and have a dedicated website **www.myheart.org.uk** ready for new stories. Nothing is more persuasive than group members sharing activities that CAN be pursued and enjoyed, in spite of their condition.

For more information please call CRY's *my*heart co-ordinator: **01737 363222**
or email **myheart@c-r-y.org.uk** Web: **www.myheart.org.uk**










Cardiac Risk *in the* **Young**

Tel: 01737 363222 www.c-r-y.org.uk