



## myheart Meetings

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CRY's *myheart* network holds regular meetings for those young people living with a heart condition who would like to meet others in the same position as themselves and discuss their experiences and medical concerns in an informal but supportive environment. It does not matter how long ago you were diagnosed or whether you are currently undergoing any treatment; members attend *myheart* meetings for different reasons but they all leave having gained something new.

**Lucy Challis:** My initial reason for going to *myheart* meetings was simply to meet other people who have heart conditions and had gone through comparable experiences. I wasn't sure what to expect at first but everyone was so friendly and had lots of advice and suggestions to offer. Emotions sometimes run high but people are so supportive and make you feel comfortable. Early on in my diagnosis I had lots of questions and the informal session with one of the doctors is a great place to ask questions you wouldn't normally ask. What I hadn't expected to gain was such a fantastic group of friends who have such a unique bond. This is now the main reason I keep attending! It's great to meet up with old friends and make new ones. I feel comfortable living with my condition now, but continue to attend meetings with the hope that I can now be that friendly face that first welcomed me and offer advice or simply talk through my experiences. Everyone has a different story but we are all linked by a common bond.

**Tim Butt:** I was initially apprehensive about going along to the *myheart* group, having suffered a cardiac arrest and been diagnosed with a heart condition 8 months

before. My circumstances had dramatically changed in this time and I was starting to question many things, as well as feel disconnected to my normal way of life; a sport-filled life. I am so pleased that I attended the *myheart* group for the first time. I found the day very encouraging, both by talking to expert cardiologists and also young people of my own age that had been through the exact same situations as myself. I will definitely be returning to the *myheart* group, come the next meeting.

**Rachael Marchant:** I started attending *myheart* meetings in 2009 and attend regularly now because I find that meeting people who are a similar age with similar conditions to me means that for that period of time we are technically the 'normal ones'. Meeting people who I can then keep in contact with is also a big help. Being able to meet with the cardiologist at *myheart* meetings is always useful because I find that I always forget to ask my usual cardiologist something and do not have to wait to see him to ask.

**Jessica Maranzano:** Attending the *myheart* group helped me meet other young people living with similar symptoms who understood how I felt physically and emotionally. Everyone was so supportive and friendly, and made me appreciate that I am by no means alone in experiencing the effects of a heart condition. It was great to compare experiences and recognise the difficulties many of us have experienced getting a diagnosis (or not, in my case). Being able to speak to Dr Papadakis was invaluable in order to help point me in the right direction and to go back to my own doctors with more concise questions.

## Cat Burns – Brugada syndrome



This is a brief outline of how I came to know CRY, join *myheart*, and join MedicAlert...

Shortly after university finals in 2010, I had a second ajmaline challenge (drug-assisted ECG) in London under Professor Sharma's team, with the unexpected result that I was positive for

Brugada syndrome – unexpected because 18 months previously I'd received the all clear at a local hospital. However unequivocally grateful and relieved I'd been with the negative result, the registrar's approach and manner had failed to inspire confidence - leading me to undertake the tests again in London and then in turn receive my final diagnosis with Brugada.

Prior to 2008 our family had never heard of Brugada syndrome and I had little knowledge of sudden arrhythmic death syndrome (SADS), let alone appreciated the frequency with which it strikes young adults - plus those of all ages.

That quickly changed when one of my cousins, Ralph, collapsed and died after crossing the finishing line of a half marathon; he was just 28 and had been fit, athletic and healthy all his life. Subsequent testing of Ralph's immediate and extended family demonstrated a relatively strong inheritance of this cardiac condition.

Between tests for the condition I focused on enjoying university life, studying and seeking out new experiences, including sailing with the Jubilee Sailing Trust - which for me was a challenge due to seasickness, fear of boats and fear of heights. Now I can't wait to go back.

In 2010, post university, I decided to set myself a new task; and undertaking a physical fundraising event appealed. However, as I'd allowed my fitness to slip following some back problems, it was going to push me significantly out of my physical comfort zone.

This, coupled with learning Mum had inherited the condition (meaning I had a 50:50 chance) and the poor attitude of the local registrar, meant I sought reassurance for total confidence and peace of mind, prior to committing to a physically demanding training regime and event.

Professor Sharma, Dr Papadakis and the team could not have been better during the process of my diagnosis with Brugada; and one month later, after having had time to consider things, I accepted the option of having an ICD fitted. Six months after that I received my defibrillator locally, under the care of another professor who has subsequently been fantastic. Not being a straightforward patient at times, I feel very lucky to have benefitted from the expertise and care of two leading cardiology professors.

I received a newer type of device; the subcutaneous implantable cardioverter defibrillator (S-ICD). Implanted under the skin on the left side of the chest, with the electrode tunnelled under the skin, it is less invasive than traditional ICDs. Unlike a traditional ICD/pacemaker scar - with associated visibility of the generator in some people - the S-ICD is mostly unnoticeable; thereby reducing the likelihood of immediate recognition in an emergency, which is what led me to joining MedicAlert.

I rarely ever remove my MedicAlert bracelet, which is very unobtrusive. In the event of injury or illness and if I'm unable to communicate, medical staff who're trained to check the wrists and necks of patients for medical ID will be alerted that I have Brugada syndrome and the S-ICD. I chose a MedicAlert bracelet for several reasons, including:

- the facility to translate individual data in over 100 languages, 24/7, whether I am home or abroad, via the London Ambulance Service - who are well versed in data protection, patient confidentiality, and communicating vital and sometimes complex information clearly and professionally.
- the ease of amending information, which includes next of kin details, personal wishes and any other information I choose.
- a wide range of jewellery designs, with a choice of styles, materials and prices.
- a flat rate of £30 a year (about 8p a day), which for me is a small price for peace of mind and effective medical attention.
- the Rod of Asclepius is the symbol used and is internationally recognisable.
- flexibility in having ID engraved with condition(s), allergies, devices and medications as appropriate.

Other companies or types of ID provided similar products but with fewer additions. MedicAlert was the only one I found at the time that provided all of the above benefits

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



and as a member for just over 3 years I have always found them efficient and helpful.

Grateful I've never had to use the 24-hour service, I have found that wearing my bracelet has been helpful in certain other circumstances... most people haven't heard of Brugada (or many of the types of SADS), let alone understand it. Therefore, when I've had to declare it, in addition to other unusual things on forms for dentists, class instructors, etc, a look of alarm usually appears when I briefly explain. It's often alleviated when I reassure them I am wearing medical jewellery.

Wearing and keeping my bracelet updated also stops me needing to rely on others. If you ask yourself how many people know, let alone could remember (in what might be a stressed situation for them) important and accurate information about another's condition, allergy, medication, etc, it is unlikely you would be able to name many. For me, as this list has grown, it would be unfair on whoever might be with me in an emergency. I do have information in my purse/bag most of the time, but this could easily be separated from me.

Since diagnosis, so much is the same and yet so much is very different for a multitude of reasons. The work of CRY is invaluable to ever-increasing numbers of people - from those who have suffered a loss and those who have successfully been resuscitated and/or diagnosed without suffering a cardiac arrest or loss; to those struggling to get diagnoses. Not to mention CRY's life-saving research, clinics and pathology services; and

their bereavement support and *myheart* networks.

Thank you to all at CRY for the work you do, so many would be lost without it.

MedicAlert is in partnership with CRY, for information on our partnership visit:

[www.myheart.org.uk/medicalert](http://www.myheart.org.uk/medicalert)



MedicAlert is offering a free stainless steel classic bracelet (worth £19.95) or £19.95 off any other emblem in their range to *myheart* members.

To receive this offer you will need to quote a special discount code. To get this discount code please contact *myheart* Coordinator Bev on 01737 363222 or [myheart@c-r-y.org.uk](mailto:myheart@c-r-y.org.uk).

The annual membership fee of £30 still applies. For more information about MedicAlert visit [www.medicalert.org.uk](http://www.medicalert.org.uk)



## Upcoming events

### South East *myheart* Meeting 19 October 2014

10am-4pm, in Holiday Inn London Sutton, Gibson Road, Sutton, Surrey, SM1 2RF.

### Midlands *myheart* Meeting 16 November 2014

10am-4pm, in Macdonald Burlington Hotel, Burlington Arcade, 126 New Street, Birmingham, B2 4JQ.

To find out more or attend a *myheart* meeting please email [myheart@c-r-y.org.uk](mailto:myheart@c-r-y.org.uk). To find out more about any of the following events please email [events@c-r-y.org.uk](mailto:events@c-r-y.org.uk)

### CRY Durham Riverside Walk 4 October 2014

The 5th CRY Durham Riverside Walk will start and finish at Durham Amateur Rowing Club. The 7km walk is in the beautiful Wear Valley, following the river, with views of the city and cathedral. Please contact us to register your interest or if you would like to volunteer.

### CRY Awareness Week 22 - 30 November 2014

As well as the opportunity to hold an awareness stand or event, we look forward to building on the success of our Great Cake Bake. We are holding our third annual event on Friday 28 November and we will have special packs to send out which include recipes by top chefs, hints and tips and other goodies to help with your event.

### CRY Great Cake Bake 28 November 2014

The CRY Great Cake Bake is a simple way for people to get involved in Raising Awareness Week with their friends, family, colleagues, team mates, etc. This will be our third annual event and we are hoping to make it bigger and better! If you are interested in getting involved or would like more info email [ben@c-r-y.org.uk](mailto:ben@c-r-y.org.uk)

*Please consult your cardiologist before taking part in physical activity.*

# About *myheart*



## What we can do for you

It is estimated that 1 in 300 young people aged 35 and under who undergo cardiac screening are found to have a potentially life-threatening cardiac condition. With the increase in awareness and more young people being diagnosed with cardiac conditions, even more people are likely to need emotional support and information to help them cope with their diagnosis.



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

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

## How to get involved

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

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

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

## Get in touch

*myheart* meetings are for those young people who have had - or may be undergoing - cardiac surgery; or those who have been diagnosed with a cardiac condition who would just like to link up with others with a similar experience to share.

If you would like to join *myheart* and receive meeting details, please email the *myheart* Coordinator at [myheart@c-r-y.org.uk](mailto:myheart@c-r-y.org.uk) or visit [www.myheart.org.uk](http://www.myheart.org.uk)

Or check out the *myheart* facebook page.

 /CardiacRiskintheYoung

### Upcoming Meetings:

South East - 19 October 2014  
Midlands - 16 November 2014

## Parents of *myheart* group counselling

CRY's *myheart* group will now be holding parents group counselling sessions. This is for parents whose child has suddenly been diagnosed with a potentially life-threatening heart condition. These afternoon sessions will be facilitated by a trained counsellor who is experienced in working with families affected by heart conditions. The sessions are free to attend and provide the opportunity to meet other parents and discuss experiences in an informal, but supportive, environment. The parents group counselling sessions are held in Birmingham, Leeds and South London. These sessions can only take place if 10 people register for the event before the registration deadline.

These sessions are independent of the *myheart* meetings for young people diagnosed with a heart condition. Parents can attend regardless of whether their child attends the *myheart* meetings.

If you are interested in attending any of these events, please contact the *myheart* Coordinator, on 01737 363222 or [myheart@c-r-y.org.uk](mailto:myheart@c-r-y.org.uk).

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