

Upcoming meetings

Meetings are held in the South East of England, the North of England and the Midlands. For details of upcoming meetings please visit www.myheart.org.uk/meetings. Meetings are free to attend and give members an opportunity to meet and discuss their experiences in an informal but supportive environment.

The next meetings will be in Birmingham on Sunday 20 May and Sunday 9 September 2012 and Leeds on Sunday 16 September 2012.

If you have any queries about *myheart* meetings please contact *myheart* Coordinator Karla at myheart@c-r-y.org.uk or on 01737 363222.



- P2** Members' meeting experiences
- P3** Counsellor's meeting experience
- P4** About *myheart*

Joseph Tanner – Brugada syndrome



I first attended a group meeting in early 2009. I was fed up with NHS cardiac support groups – always being surrounded by people a lot older than me. So when I found out about CRY and this group it was good to know that I wasn't the only one.

The meetings are very informal and begin with psychotherapist Alan who is there to help with the flow of conversation. We start with a quick introduction of ourselves and our condition; although you don't have to disclose anything you don't want to.

I get something different out of every meeting I attend. I've learned different things about my condition, learned about things that we're entitled too and we're able to discuss our feelings. It's good to meet other people that feel the same.

We then break for lunch; this time is for the group to chat between ourselves and to get to know each other better

without Alan.

After lunch we have a group session with a cardiologist, in recent meetings it has been with Dr Michael Papadakis (fourth from left in above photo). This is where we get to ask questions that we forgot to ask our own cardiologist, or questions that came to you during the meeting. I'm getting to the stage of running out of questions to ask, so if you don't have a question you don't have to worry.

Through these meetings I've met lovely people and when I'm having a tough day, I write a facebook status and people from *myheart* always give support. I continue going to the meetings because I hope to be a support for the new people that attend.

When you are first diagnosed with a condition, you feel like you can't do anything, you go through the 'why me?' syndrome. After a *myheart* meeting, you realise you're not the only one and gain some new friends and hopefully feel a little better inside.

In the future we hope that *myheart* will be able to do group fundraising together.

Members' meeting experiences

Paula and Anna – Brugada syndrome



We found the meeting very refreshing and helpful. There were lots of other people of similar ages in similar situations and circumstances. After coping with losing our fit and healthy brother, who died at 31 a year and half ago, we then had to cope with being diagnosed as a whole family with having Brugada syndrome.

The meeting really helped with day to day questions we had about defibrillators and other questions you feel a bit embarrassed about asking a surgeon or consultant. We found it nice not to be alone in this horrible nightmare, that we are trying to learn to live with, realising that other people are going through the same.

The people at the meeting were lovely and very real! I think these meetings are very positive, hard to cope with at the time but make you overall more informed about these delicate issues and after a few days you feel so much stronger. It helped us acknowledge what we had just been diagnosed with and how to deal with it.

Thank you to everyone involved.

Laura Lees – isolated cardiac sarcoid



I went to my first *myheart* meeting in December 2011, after being diagnosed with isolated cardiac sarcoid and having an ICD fitted in the August. I didn't really know what to expect but everyone at the meeting was really friendly and welcoming, and we all got on really well. There were a couple of other new people there and some that had been before.

In the morning we had a group chat with a counsellor where we all chatted about our experiences and how having a heart condition had affected us mentally, emotionally and socially. It was good to hear other peoples' take on things and their experiences. It made me feel better and not as alone in what I was feeling.

After a lovely lunch, a cardiologist answered any questions we may have thought of since seeing our doctors and wanted answers to. Most people in the group had questions and it was good to get a different medical opinion on some aspects. Overall I found the group a really good source of support as we are all young. There was the serious side to the meeting but we also had a really good laugh and I would definitely recommend people come along.

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

I was diagnosed with Wolff-Parkinson-White (WPW) syndrome in May 2009 following a CRY screening at Myerscough College in March 2009 and I underwent a catheter ablation procedure in November 2009.

I have been symptom free for almost two years now. I will be forever grateful to CRY for all the help and support they have given me and for saving my life. I am a very lucky young man, thanks to CRY. I have been raising money in various ways over the year including a tombola at my swimming club presentation evening, a name the teddy bear, sponsorship from a 2 mile open water swim in Windermere, £100 was given in donations for my Mum's 50th Birthday which she requested rather than receive presents. I am already under-way with this year's fund-raising as I am organising a raffle at my swimming club's presentation evening in February.

Many thanks for the invitation to the *myheart* meeting; it was enjoyable, informative and nice to meet everyone.



Chris Smith handing fundraising cheque of £749 to Alison Cox.

Counsellor's meeting experience

**myheart peer support group:
Sharing your experiences with each other**
By Alan Jones



INTIMIDATED, LOST, ANGRY, SCARED, EMBARRASSED TO ASK?

Life and death decisions have to be made by you. Huge amounts of scary sounding information has to be digested. You have to deal with how your family is coping with your situation. The ways in which the NHS are helpful and sometimes not so helpful. Suddenly confronted with death and making decisions about the future of your life. All of these issues and more can be enormously intimidating. Meeting others who are also making these decisions, or have already made them is often very helpful, and validating.

NOT ALONE

By the time you read this you've probably seen teams of doctors and nurses, you've talked and talked to your family and friends, but not many if any of them have got your condition or have even been through a similar experience to you. You may feel completely out of your depth, not even knowing what the questions are that you want to ask, let alone the answers! What is going on...what do I want to know....what do I want?

At the support group you don't even have to talk, you can just listen until you feel comfortable. Often hearing the

others talking and asking each other questions helps to make it clearer to you what you feel like, and want.

I'd like to invite and encourage you to come to our group to meet others in a very similar place to you. Many members of *myheart* weren't keen on the idea of a support group, until they came along and found out how relaxed, ordinary and useful it is.

SHARING INFORMATION

It may be difficult to talk to family or professionals about some issues. What people get from the group the most is discovering what others like them have learnt so far. There are so many questions, no one can answer them all for you and also there isn't one right answer for everyone, but the members of *myheart* between them probably have a few answers to most of them.

How does an implant affect sex?
What's it feel like if your ICD goes off?
What's that beeping sound?
When do you tell a new partner?
Can I have a disability badge?
Where can I get Travel insurance?

No one else can completely understand where you are in this drama. Nobody, even if they have the same condition, is the same as you, but having a few friendly people to talk to in the group can sometimes help a lot. Everyone has space to talk if they want to and don't have to if they don't want to. The group is completely confidential. I run the South East group, and I make sure that it is a safe place for talking.

MedicAlert Promotional Offer

It is recommended that anyone with a hidden medical condition carries a form of identification detailing their condition and any medication they are on. This could be in the form of a card placed somewhere visible in your wallet/purse, or an identification bracelet, such as a MedicAlert bracelet.

MedicAlert is the only registered charity that provides a life-saving identification system for people with hidden medical conditions and allergies. Each member receives an Emblem engraved with their main medical condition, vital details, a personal ID number and a 24 hour emergency telephone number allowing emergency or medical professionals to access their details from anywhere in the world. This 24 hour emergency service is housed within the London Ambulance Service, where trained staff relay your full MedicAlert emergency medical record to the first responder.

Wearing MedicAlert identification means in an emergency, medical personnel have instant knowledge of your medical condition and with one phone call to the emergency number, access to your emergency medical record, along with information such as your name and address, doctors details or implant information after quoting your ID number and clearing security checks. This 24 hour emergency phone line has an



annual charge of £25. Full details of the caller are taken, including the nature of the call and the response given.

When joining MedicAlert or updating medical information, calls are dealt with by trained nurses, who take and assess all your medical information to ensure it is correct and then decide what information needs to be included on the emblem. MedicAlert has a wide selection of emblems to choose from, with prices starting at £19.95.

Due to the importance of being able to quickly identify your condition in an emergency, *myheart* has been working with MedicAlert to put together a promotional offer for our members.

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 quote the discount code CRY1995. The offer can be redeemed online, by post or by phone.

The annual membership fee of £25 still applies. For more information about MedicAlert please visit www.medicalert.org.uk.

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 that will require treatment. With an increasing number of young people now being screened every year through CRY clinics and mobile units, even more people are likely to need emotional support and information to help them cope with their diagnoses.



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

Rebekah Goddard

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

Members 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 travelling advice, getting back to sport, recovering from surgery, living with a pacemaker or ICD etc. Tell us what you think.

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

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

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

Or check out the *myheart* facebook page.

Useful links...

www.myheart.org.uk

Parents of *myheart* group counselling

CRY's *myheart* group will now be holding parents group counselling sessions. This is for parents whose previously fit and healthy child has suddenly been diagnosed with a dangerous heart condition. The afternoon sessions will be facilitated by an experienced counsellor who is very experienced in working with families affected by dangerous heart conditions. The sessions are free to attend and will give the opportunity to meet other parents and discuss your experiences in an informal but supportive environment. The parents group counselling session will be held on:

Sunday 20th May, 14.00-16.00, Birmingham.


Sunday 9th September, 14.00-16.00, Birmingham.

Sunday 16th September, 14.00-16.00, Leeds.

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* meeting.

To attend the event you must register. To receive the registration form please contact Karla Griffith, the *myheart* coordinator, on 01737 363222 or myheart@c-r-y.org.uk.

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

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