

Network

Newsletter 02 Summer 2010

News and information for young people living with cardiac conditions



Joseph after one of his previous races



Joseph Tanner and James Doherty at an SSN meeting

- P2** Parliamentary Reception 09
- P3** Members News
- P4** About the CRY SSN

Joseph Tanner was a marathon runner until in 2008, aged 26, he collapsed after competing in the Hastings half marathon. This is his story.

Since March 16 2008 I haven't run a mile, to feel my feet pound the ground, to run into my void, for so long I've not had my escape.

On Sunday I finished reading the book 'What I Talk About When I Talk About Running', maybe I shouldn't have read it. It is sort of the memoirs of Haruki Murakami a long distance runner, who has done many marathons.

I've not been able to switch that side of me off, the many times I've walked along the seafront at night and the runners pass me and I've broken down in tears.

I didn't think I'd ever put on my running shoes again, but by the time you read this I've probably run a couple of miles.

I'm not going to run a marathon again, though I would never say never, a man can have dreams. On Sunday 22 November 2009 at the CRY SSN meeting cardiologist Dr Sanjay Sharma was there and he said that I could run again, whilst advising against marathons and pushing myself.

I won't lie, I am still a little scared that something may happen or go wrong, dying not fun!

If I was to die tomorrow, be it by running would it not make you happy knowing that I died happy? I was able to be me again.

If my little box does go off and I have a shock, I'd contact a couple of people from SSN and hopefully they will be able to pick me up from this dark place.

I know I'm one of the lucky ones, I don't have to take medication like beta blockers, all I have is my little friend to the end!

On Saturday 28 November, I finally stopped making excuses and went for a run. I have to admit it felt weird to be running again after so long, I also had to get used to my box while running.

I sent a couple of text messages to members of the CRY SSN while running and they were all very supportive. I ran for over an hour, I probably covered roughly 7 miles, I just felt so alive.

I think everytime I lace up my trainers there will always be a little fear in the back of my mind that I need my little back up.



CRY hosted its annual Parliamentary Reception at Westminster on Wednesday 21 October as part of its raising Awareness Week.

New CRY Patron Phil Packer was Guest of Honour at the proceedings which was attended by more than 40 MPs.

Other guests at the event included members of the CRY Surgery Supporters Network, CRY families and supporters, CRY Bereavement Supporters and CRY Patrons Ben Brown and Andy Scott.

Alison Cox launched the new Surgery Supporters Network (SSN) Newsletter, declaring that CRY would be increasing the number of meetings of the SSN in other UK regions. Alison then handed over to James Doherty, Jade Moore and Danni-Marie John to share their experiences.

James Doherty collapsed while playing tennis in 2008, his heart actually stopped for 11 minutes. James was a Junior County Champion and tipped to be one of the UK's future 'stars' of the game.

James was diagnosed with long QT syndrome and fitted with an ICD. Whilst this was the end of his tennis career, he had the opportunity to toss the coin on centre court, representing CRY, at the Men's Singles Final in 2009.

Jade was screened by CRY within the FA at Loughborough University, where a problem was found. Further tests showed she had 2 holes in her heart. However, after several surgical procedures, she was back to full training. In July 2009, she was part of the England Women's U19 team who won the UEFA European Women's U19 Championship.

Danni-Marie and her sister Laura were tested for 2 years and found to have long QT syndrome. At ages of 14 and 10 they were fitted with ICDs. Danni-Marie said "If it wasn't for CRY I really do think that we wouldn't be here and if I wasn't here now, neither would my 2 children."



Members of CRY SSN from left to right: Danni-Marie John, James Doherty and Jade Moore

Members News

Congratulations

Marriages

Our very best wishes to Lucy Attridge and her husband Paul. They got married in April at Penshurst Place, in Kent.



Births

Having been diagnosed with Wolff-Parkinson-White syndrome when she was 16 years old, Kerry Shephard was told that having children was off the cards.

Two ablations, and 15 years, later Kerry and her husband Matt are now the proud parents of Jessica Elizabeth Shephard who was born on 8 May 2010 at 5:01am weighing a healthy 7lbs.

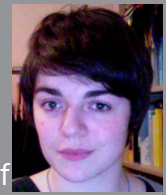
"She is just perfect," said Kerry. "I honestly didn't think we would ever have children, but just over a year ago, we got the go-ahead from my cardiologist. Although I had a problematic pregnancy and birth, Jessica was fine throughout and continues to thrive. She is a happy baby and has a strong heart!"



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

Member Profile

Emma Jackson, London



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

Six years later, on 24 November 2008 I had my first shock, after walking up the stairs I sat down and woke up on the floor! Over the next two months whilst trying various beta blockers I had six more shocks and blackouts due to VF. At the start of February 2009, I started on Amiodarone, a strong anti-arrhythmic drug.

I haven't had a shock since starting on the new medication and I will be on it as long as is safe.

Originally I was annoyed at having a defib, but obviously now it was been completely worth it, I barely even think about it. Recently I had my defib changed and got to keep my first one, I'll treasure it forever!

Moments going through security

Tony Eames Sears Tower, Chicago



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

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

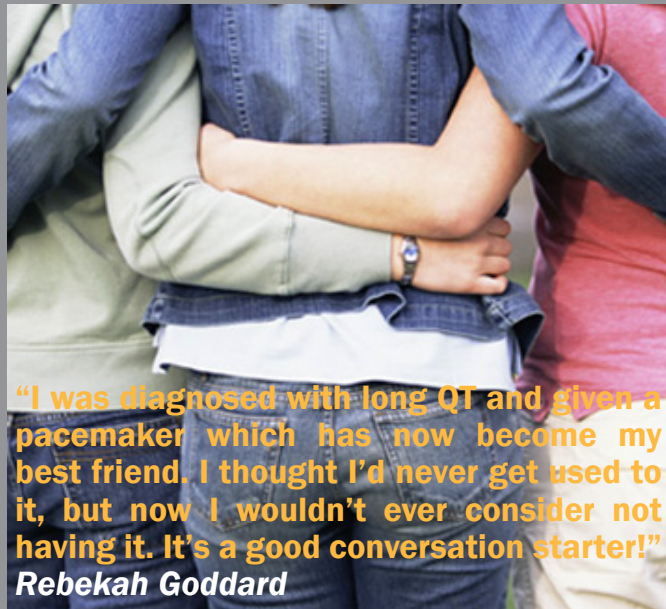
My only logical response was 'I have a scar'. To my amazement, he responded 'yes that's it, can I see the scar.' Seconds later after revealing the scar I was through security heading to the viewing gallery 412 metres above the rather inquisitive security guard!!!"

About the CRY SSN



What we can do for you

It is estimated that one 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

The CRY Surgery Supporters Network (CRY SSN) was created in 2002 to offer support to young people (and their families) who have been diagnosed with a heart condition, who are recovering from cardiac surgery or perhaps living with a pacemaker or ICD.

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

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

Members meet up twice a year to socialise with each other, take part in group counselling and talk to an expert cardiologist in comfortable surroundings – a unique opportunity.

What you can do for us

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.

How to become involved

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

If you would like to join the CRY SSN or contact network members, you can email our SSN Coordinator, Julie Mills, at julie_mills@hotmail.com

Your help would be greatly appreciated.

Useful links...

www.c-r-y.org.uk/surgery_supporters.htm


The CRY SSN webpages

www.c-r-y.org.uk/living_with_condition.htm

Personal stories from young people living with rare heart conditions

www.c-r-y.org.uk/Implantable_Cardioverter_Defibrillators.htm

Useful information about implantable cardioverter defibrillators (ICDs)

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