

By raising awareness of heart health, I want to honour my cousin Jenny

After a tragic family loss caused by Sudden Cardiac Death, Jack Ebbs and some of his relatives were tested for their risk of the condition. He is now passionate about spreading the word and raising funds for a charity that helps children and families affected, he tells *Arlene Harris*



Although he was only a child, Jack Ebbs clearly remembers his cousin Jenny O'Riordan as being "kind and beautiful with a really lovely smile".

"She had a great presence about her and everyone who was ever in her company just loved her," he says. "I have so many fond memories of colouring or painting with her and just wanting to be around her. She was in our house a lot and was just someone that everyone loved."

But Jenny had an underlying heart condition called cardiomyopathy, which tragically took her life when she was just 26 years old.

Devastating loss

"In May 2002, she had recently come back from a trip to America and was just at home with a friend when suddenly she collapsed and died," says Jack. "I was too young to remember much of the detail, but I know that everyone who knew her was completely devastated. It totally broke the whole family, as she was just such a lovely person."

"I think everyone should be heart and health aware – and anyone with concerns or a family history should talk to their GP for best advice"

"It was such a shock and an incredibly tough time for everyone, especially her mother Kate, who is my godmother, and her brother JJ, who is her only sibling."

"She was just 26, beautiful, bright, kind and had so much to live for. Her friends and colleagues were heartbroken, too. Of course time helps you to live with it, but you never forget. Nothing is ever the same and no family event or occasion ever happens without us all knowing that someone is missing."

Twenty-three years after Jenny's death, she is still sorely missed. Because her condition, cardiomyopathy, which causes the heart muscle to weaken and can lead to Sudden Cardiac Death, can be genetic, Jack and other family members were tested to see if they too were at risk.

"It is recommended that first-degree relatives are tested, and I know a GP referral is needed," says the 33-year-old.

"So, along with Jenny's family, my two brothers and I all got tested to see if we had cardiomyopathy. We were tested three times over the years and monitored in the CRYP Centre (Centre for Cardiovascular Risk in Younger Persons) Screening Centre in Tallaght. But thankfully we did not test positive."

"And although I have no medical experience myself, I think everyone should be heart and health aware – and anyone with concerns or a family history should talk to their GP for best advice."

Although the Dublin man did not show any risk for developing the condition, he is keen to raise awareness and has taken part in several fundraising activities to raise money for CRY, an all-island charity which supports families impacted by the Sudden Cardiac Death of a

young person and those living with a diagnosis of an inherited cardiac condition.

"I have always liked to challenge myself and have done a few things already to try and raise funds for CRY, including the Beara Ring Cycle, the Ring of Kerry Cycle and the Westport Cycle," he says. "Along with those 100km-plus bike races, I also completed the Waterford Viking Marathon for CRY and have just signed up for the Dublin Marathon and will also be running that in aid of the charity."

"I just feel that they do such amazing work and need any help they can get financially. I am hoping to raise €1,000 and if I can get that, the company I work for will match it, so that would be €2,000 raised, which would be brilliant."

"There is no-one else really doing the kind of work that CRY is doing, providing support and services for families affected by Sudden Cardiac Death. So it is a really important charity and there are many people out there who are affected by this, so the work they do is vital."

Approximately 100 young people die annually in Ireland from Sudden Cardiac Death and the charity provides free screening and assessment services for individuals at risk of or with inherited heart conditions at the CRYP Screening Centre at Tallaght University Hospital.

This is a free heart screening service which is available to everyone throughout the country. But, it does not receive any direct government funding and is currently almost entirely run as a result of charitable donations and fundraising efforts of CRY and its supporters.

"I'm delighted to have a CRY race number for the Dublin City Marathon to run for them in Jenny's memory," says Jack.

"This is one of many ways people can help



Jack Ebbs' cousin, Jenny O'Riordan

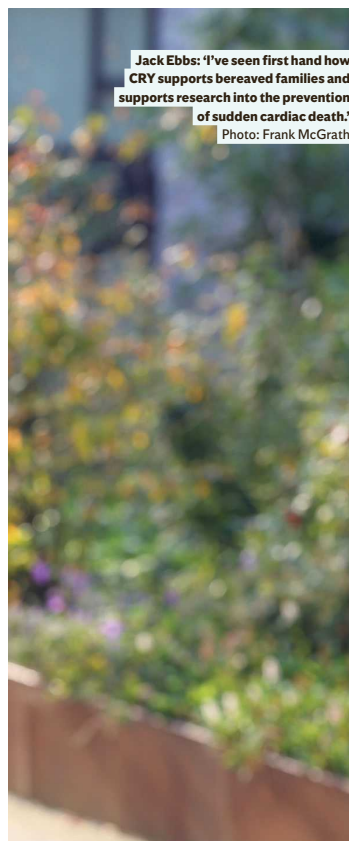
raise to vital funds and it will be my first time to run the Dublin City Marathon for the charity. I would encourage others to consider fundraising for them, or taking one of their Dublin City Marathon charity places, as they will be helping them to be able to continue to support the families affected."

"This includes helping them to provide their freephone helpline and their family support programme after a sudden loss or a diagnosis of an inherited cardiac condition. They also run family days, workshops and various events throughout the year."

What causes a stroke and how to treat one

A stroke occurs when the blood supply to part of the brain is interrupted or reduced, depriving brain tissue of oxygen and nutrients. Brain cells die when the blood supply is cut off for too long. There are two main types of stroke: ischaemic and haemorrhagic. Ischaemic strokes are caused by a blood clot blocking an artery to the brain. Haemorrhagic strokes are caused by a blood vessel in the brain leaking or bursting. The most common type of stroke is ischaemic, accounting for about 87 per cent of all strokes. The second most common is haemorrhagic, accounting for about 13 per cent. The third most common is transient ischaemic attacks (TIAs), which are often called 'mini-strokes'. TIAs are caused by a temporary blockage of blood flow to the brain, and the symptoms usually last for less than 24 hours. However, TIAs are a warning sign that a full-blown stroke may occur in the future. The symptoms of a stroke can vary depending on the part of the brain that is affected. Common symptoms include sudden weakness or numbness in the face, arm, or leg, especially on one side of the body; sudden confusion or difficulty understanding speech; sudden trouble seeing in one or both eyes; sudden trouble speaking or writing; sudden trouble walking, dizziness, or loss of balance; and sudden severe headache with no known cause. If you experience any of these symptoms, it is important to seek medical attention immediately. The faster you get treatment, the better the chances of a good recovery. There are several ways to treat a stroke, depending on the type and the severity of the symptoms. For ischaemic strokes, the goal is to break up the blood clot as quickly as possible. This can be done with medications like aspirin or blood thinners, or with procedures like thrombolysis or mechanical thrombectomy. For haemorrhagic strokes, the goal is to stop the bleeding and reduce the pressure in the brain. This can be done with medications like blood thinners or with surgery to remove the blood clot. For TIAs, the goal is to prevent another stroke from occurring. This can be done with medications like aspirin or blood thinners, or with lifestyle changes like quitting smoking, exercising, and eating a healthy diet.

Stroke is a leading cause of death and disability in the UK. It is important to be aware of the symptoms and to seek medical attention immediately if you experience any of them. There are several ways to prevent a stroke, including quitting smoking, exercising, eating a healthy diet, and taking medications as prescribed by your doctor.



Jack Ebbs: 'I've seen first hand how CRY supports bereaved families and supports research into the prevention of sudden cardiac death.'

Photo: Frank McGrath

"By doing the marathon and other events in Jenny's name, we can continue to keep her memory alive. She was such an important part of our lives and we don't ever want her to be forgotten"

1. A family history of unexplained and unexpected sudden death, especially under the age of 40.
2. Family history of sudden death due a condition which may be inherited, such as cardiomyopathy, which is a form of heart disease.
3. A living family member diagnosed with a condition which might be inherited, such as cardiomyopathy or long QT syndrome.
4. Fainting or seizure during exercise, excitement or becoming startled.
5. Heart palpitations, especially if they are prolonged and/or cause dizziness or collapse.
6. Chest pain or discomfort usually brought on by relatively modest exercise, which occurs repeatedly.
7. Shortness of breath during exercise.

● If a person dies from Sudden Cardiac Death, but no cause is identified, then this is classified as a sudden arrhythmic death syndrome (SADS).

About Sudden Arrhythmic Death Syndrome

● SADS stands for Sudden Arrhythmic Death Syndrome (also known as Sudden Adult Death Syndrome or Sudden Death Syndrome).

● It can affect children and infants as well as adults.

● Several conditions have been shown to cause SADS. These are usually electrical problems with pump systems found in the walls of cells in the heart which are meant to pump salts in and out of the cell.

● These pump problems are called 'channelopathies' or 'ion channel disorders' and can include 'Long QT Syndrome', Brugada syndrome, and Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT).

● It is not possible to find these at post-mortem, unless genetic tests are performed, which is not yet part of standard practice.

● People who have cardiac problems, and may be unaware of them, carry a slightly higher risk of sudden death during periods of fairly intensive activity than at other times. This is why, as a precaution, if someone is diagnosed with a cardiac disorder, they will often be advised to avoid competitive sport or endurance training as this can bring on heart failure.

● If you have any concerns relating to heart issues, seek medical advice at the earliest convenience and in any emergency call 999 or 112 immediately.

For more information visit www.cry.ie or call freephone 1800 74080 (Rep of Ireland) and 0044 800 640 6280 (Northern Ireland). To support Jack on his Dublin City Marathon challenge to raise funds for the charity, visit eventmaster.ie/fundraising/pages/JE77470803.

"I've seen first hand how the charity supports bereaved families and supports research into the prevention of sudden cardiac death – work that quite literally saves lives. So, every euro raised through me running this marathon goes straight towards that important mission.

"Another really important factor for me is to honour Jenny – and by doing the marathon and other events in her name, we can continue to keep her memory alive. She was such an important part of our lives and we don't ever want her to be forgotten."

About Sudden Cardiac Death

● Sudden Cardiac Death (SCD) is the term used for any dramatic and/or spontaneous death which is thought to be caused by a sudden change in the heart's rhythm.

● It is more common in older people, but can also affect younger people.

● There may be many underlying heart conditions which could cause this sudden rhythm change, but the most common cause, usually confirmed at autopsy or post-mortem, is coronary disease or hardening or 'blockages' of the arteries or blood vessels supplying the heart muscle.

● Other potential causes include heart muscle disorders, such as cardiomyopathy, structural heart defects which may have been present from birth – these are called congenital heart conditions – and infection or inflammation of the heart muscle (myocarditis).

● Risks include: