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**IRISH HEART
FOUNDATION**
Fighting Heart Disease & Stroke

CARDIOMYOPATHY SUPPORT GROUP IRELAND



Cardiomyopathy Support Group

This is a voluntary group of people, all of whom have cardiomyopathy. It was set up in association with the Irish Heart Foundation to help people with cardiomyopathy and their families, by providing information and support. The support group also aims to create better awareness of the condition in Ireland so that more people get the help they need.

Understanding your condition is important and members receive information bulletins and invites to information meetings. If you would like to get in touch with other members or sign up to our mailing list you can contact us through the Irish Heart Foundation's National Heart and Stroke Helpline on 1890 432 787 or email info@irishheart.ie .

The support group aims to create better awareness of cardiomyopathy in Ireland so that more people get the help they need.



What is Cardiomyopathy?

Cardiomyopathy is a disease of the heart muscle. In many cases it is an inherited condition, caused by a genetic abnormality, and several family members can be affected. Most people with cardiomyopathy have a good quality of life and a normal life expectancy. However, some people experience severe symptoms and are at risk of serious heart rhythm problems and sudden cardiac death. Treatment with medicines and devices such as pacemakers and ICDs, can improve and stabilise symptoms for many people.

There are four main types of cardiomyopathy:

- Dilated cardiomyopathy (DCM)
- Hypertrophic cardiomyopathy (HCM)
- Restrictive cardiomyopathy (RCM)
- Arrhythmogenic right ventricular cardiomyopathy (ARVC)

Other types of cardiomyopathy include ischaemic cardiomyopathy due to a heart attack. A severe viral infection, long standing high blood pressure, heart valve disease and certain drugs, such as too much alcohol can also cause a cardiomyopathy.

Types of Cardiomyopathy

Dilated Cardiomyopathy

Dilated cardiomyopathy (DCM) is a condition where your heart muscle has stretched (enlarged) and become weak. When this happens your heart can't pump blood around your body as well as normal. This causes fluid to build-up in your lungs and in other parts of your body, usually in your legs and ankles, liver and abdomen. The extra fluid in your lungs can make you feel breathless. This is called heart failure. Symptoms of DCM include: breathlessness and tiredness, swollen ankles or abdomen and sometimes palpitations.

There are a number of reasons why a person may develop DCM. There is a genetic link and it has been found that about 1 in every 3 people with the condition has relatives with DCM. Other reasons include:

- viral infections
- pregnancy
- alcohol abuse
- some medicines such as the anti-cancer medicines, anthracyclines.

In all of these cases, it is not known if the infection, substance or pregnancy alone causes the disease or if people affected, already have a genetic pre-disposition to develop cardiomyopathy.



Hypertrophic Cardiomyopathy

Hypertrophic cardiomyopathy (HCM) is a genetic condition where there is an increased thickening of your heart muscle. It is also known as hypertrophic obstructive cardiomyopathy (HOCM). The abnormally thick heart muscle is stiffer than normal and affects your heart's ability to pump blood around your body. Some people with HCM have a risk of developing life-threatening heart rhythms (arrhythmias).

About 1 in 500 of the population has HCM. Even though the genetic abnormality is present from birth, HCM usually develops after puberty. Symptoms include: chest pain, breathlessness, palpitations, blackouts (fainting) or feeling light-headed.

Heart muscle can also thicken in people who don't have cardiomyopathy. This is because of high blood pressure or intense athletic training over a long period of time and is not an inherited condition. By examining the structure of heart muscle tissue, doctors can determine whether or not HCM is the cause of the thickening.


Restrictive Cardiomyopathy (RCM)

This is a rare form of cardiomyopathy where the heart muscle becomes stiff, but not thickened. As a result the heart can't fill properly with blood and can't pump blood around your body efficiently. In many cases, the cause of RCM is not known, although there is some evidence that it may be caused by the same genetic abnormalities as HCM. RCM has also been linked to some other rare heart disorders and in some cases, develops after radiation treatment for certain cancers.

Symptoms of RCM include: breathlessness and tiredness, swollen ankles or abdomen, heart rhythm problems and palpitations. Some people can have further complications such as blood clots.

Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)

ARVC is a genetic condition, mostly affecting the right ventricle. The proteins that hold heart muscle cells together have not developed properly in people with ARVC. These proteins can't hold the heart muscle cells together, particularly when you are exercising and your heart is working harder than usual. The cells break away and die. This changes the structure of your right heart muscle, making it thinner and filled with more fatty and fibrous tissue than normal.



People with ARVC are at risk of developing serious arrhythmias and can also have reduced heart pumping function. These heart muscle changes can sometimes affect the left ventricle as well as the right. ARVC is a progressive disease and symptoms tend to get worse overtime.

Symptoms include: arrhythmias (some of which are life-threatening), light-headedness and fainting, palpitations and sometimes breathlessness.

Family assessment for inherited cardiomyopathy

More often than not, cardiomyopathy is a genetic condition. Because of this, if you have been diagnosed with cardiomyopathy it is important that you talk to your cardiologist or GP about assessing other family members for the condition. It is important that all first degree relatives of a person with cardiomyopathy are medically assessed for the condition, even if they don't have symptoms. If you have cardiomyopathy, your first degree relatives are your parents, children, brothers and sisters.

Assessment generally involves a review of your family's medical history, a physical examination and tests



Assessment generally involves a review of your family's medical history, a physical examination and tests including an electrocardiogram (ECG), an echocardiogram (Echo) and exercise stress tests. These tests look at the electrical activity and structure of the heart at rest and during exercise, and are non-invasive. Most cases of cardiomyopathy can be identified with these tests. Occasionally there may be a need for further investigations, such as an electrophysiological (EP) study, magnetic resonance imaging (MRI), CT scan or angiogram.

Currently there are two Dublin-based specialist medical centres that provide diagnostic services, treatment, genetic testing information and psychological support to families with inherited heart conditions. They are located at the Adelaide and Meath Hospital, Tallaght and the Mater Hospital, in Dublin city. If you've been diagnosed with cardiomyopathy or any other inherited heart condition, your GP can refer you to one of these centres.

For more information on family assessment for inherited cardiomyopathy, call the National Heart and Stroke Helpline on Locall 1890 432 787 or email info@irishheart.ie.

Medical Terms

Angiogram

A test using dye and x-ray to see if you have any problems in your arteries, valves or the chambers of your heart.

Arrhythmia

Abnormal heart beat. The heart may beat too quickly, too slowly or in an irregular way. Arrhythmias that come from your heart's lower chambers (ventricles) can be life-threatening.

Blackout

A sudden loss of consciousness, also commonly called fainting or passing out.

Cardiomyopathy

A disease of the heart muscle which is often inherited.

CT scan

This test uses computer technology to combine several different x-ray images to show a 3-D image or cross-section of your internal organs.

Echocardiogram

An ultrasound examination of your heart to see how well the heart muscle is working.

Medical Terms

Electrocardiogram (ECG)

This test measures the rhythm and electrical activity of your heart.

Electrophysiological (EP) study

A test designed to find and analyse abnormal heart rhythms.

Exercise stress test

An ECG carried out while you run or walk on a treadmill.

Heart failure

A decrease in your heart's ability to pump blood around your body.

ICD

A small device that's placed in your chest. It uses electrical pulses (shocks) to help control life-threatening abnormal heart rhythms.

Inherited conditions

Medical problems that are passed through families and are caused by abnormalities in our genes.

Magnetic resonance imaging (MRI)

A technique using magnetic fields, radio waves and computer technology to produce detailed images of your body.

Medical Terms

Pacemaker

A small device that's placed in your chest to monitor and help control abnormal heart rhythms.

Palpitations

A feeling that your heart is beating too fast or skipping a beat. Sometimes palpitations are a symptom of an arrhythmia.

Ventricle

The lower section or chamber of your heart.

Please make a donation today

The Irish Heart Foundation is Ireland's national charity dedicated to the reduction of death and disability from heart disease and stroke. Over 90% of our funding comes from public and business donations. We depend on your goodwill and generosity to continue our work.

If you found this booklet useful, please help our charity to continue to provide heart & stroke information by donating today.

You can make your donation today:

By post: Irish Heart Foundation,
50 Ringsend Road, Dublin 4

Online: www.irishheart.ie

By phone: 01 6685001

Personal Details

Name: _____

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Phone: _____

Mobile: _____

Credit or debit card (one off donation)

Amount:

€250* €100 €50 €25 Other € _____

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* If you donate €250 in one year (or €21 per month) we can claim tax back at no cost to you.

** Last 3 digits on the signature strip on the reverse of our card.

The Irish Heart Foundation is committed to best practice in fundraising and adheres to the **statement of guiding principles for fundraising** promoting transparency, honesty and accountability. Any personal information you provide will be held in accordance with the Data Protection Acts 1988 and 2003.

SEPA Direct Debit Mandate

Unique Mandate Reference:

Creditor Identifier: IE02ZZZ306322

By signing this mandate form, you authorise (A) the Irish Heart Foundation to send instructions to your bank to debit your account and (B) your bank to debit your account in accordance with the instruction from the Irish Heart Foundation.

As part of your rights, you are entitled to a refund from your bank under the terms and conditions of your agreement with your bank. A refund must be claimed within 8 weeks starting from the date on which your account was debited. Your rights are explained in a statement that you can obtain from your bank.

Please complete all the fields below marked*

*Bank Name: _____

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*Account Number (IBAN): _____

*Swift BIC: _____

Creditor Name: **IRISH HEART FOUNDATION**

Creditor Address: **50 RINGSEND ROAD, DUBLIN 4, IRELAND**

*Type of Payment: Recurrent (Monthly) One-off Payment

* Signature: _____ *Date Signed: _____

Please return completed form to the Irish Heart Foundation.

My monthly instalment amount is:

€21* €18 €15 €10 Other € ____ per month

*A regular gift of €21 per month could be worth an additional €9 from the Revenue Commissioners per month at no extra cost to you.

Your first contribution will be taken on either the 2nd or the 20th of the next available month. Please select which date you prefer.

2nd 20th

You will be notified in writing ten days in advance of your first direct debit. If you wish to cancel within 7 days of a direct debit payment please contact your own bank.

Preferences

I would like to hear about other IHF events, activities, awareness campaigns and appeals. Yes

Do you need a postal receipt: Yes No

More information

Irish Heart Foundation

50 Ringsend Road, Dublin 4

Telephone: 01 6685001

Email: info@irishheart.ie

Web: www.irishheart.ie

National Heart and Stroke Helpline

Telephone: Locall 1890 432 787

Email: info@irishheart.ie

ICD Support Group

Long QT Syndrome Support Group

Cardiomyopathy Support Group

c/o Irish Heart Foundation

Telephone: 01 6685001 or Locall 1890 432 787

Email: info@irishheart.ie

SADS Support Group (formerly, SCD in the Young Support Group)

c/o Irish Heart Foundation

Telephone: 01 6685001, Locall 1890 432 787

or 087 3232552

Email: info@irishheart.ie

CRYP Centre

Adelaide and Meath Hospital, Dublin 24

Telephone: 01 4143058

Family Heart Screening Clinic

Mater Hospital, Dublin 7

Telephone: 01 8034354

Email: familyheartscreening@mater.ie

UK Cardiomyopathy Association

www.cardiomyopathy.org



**IRISH HEART
FOUNDATION**
Fighting Heart Disease & Stroke

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Defining tomorrow, today™

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National Heart and Stroke Helpline

Locall 1890 432 787

Monday to Friday 10am to 5pm

Web:

www.irishheart.ie

www.stroke.ie



Funding:

The Irish Heart Foundation is the national charity fighting heart disease and stroke and relies on charitable donations for 90 per cent of its funding. We support, educate and train people to save lives, campaign for patients, promote positive health strategies, support research and provide vital public information. We need your support – through donations, as a volunteer or on our training courses.

This publication is sponsored by Boston Scientific.

Published by the Irish Heart Foundation in 2013. The information provided in this publication was correct and accurate at the time of publication to the best of the charity's knowledge.



Registered charity number CHY 5507