



# Croí Mor



IRISH  
HEART  
FOUNDATION

CARDIOMYOPATHY SUPPORT GROUP

JUNE 2006

## NOTICES

- It's your group. Let us know what you want—events, contacting each other, medical information, etc.
- Support group committee members work voluntarily from their homes. Please contact us via the IHF 01 6685001 if you would like to contribute to the group in any way

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## Cardiomyopathy Information Days

Many of you will be know that the Support Group, in conjunction with the Irish Heart Foundation, holds two Information and Support days every year—an Autumn/Winter event in Dublin and a Spring/Summer event in a regional location to facilitate those who cannot travel to Dublin. To date, we have tried to cover as much as the country as possible, taking into account availability of speakers and ease of access, for those wishing to attend. So far we have been to Limerick, Galway, Cork, Kilkenny and Enniskillen.

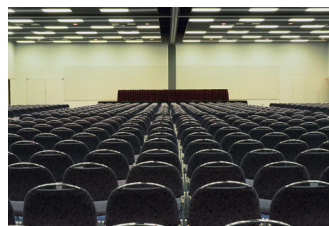
All our speakers give their time and expertise on a voluntary basis so it important that we get a good attendance to justify holding these events. Unfortunately, this year, for the first time, we had

## Donations

Several families have made donations to the Irish Heart Foundation following the death of a family member as a result of Cardiomyopathy. Firstly we offer our sincere sympathy to all those who have lost a relative during the year.

to cancel our Information Day in Cork due to the small number of registrations received. Was this because

- of an unfortunate clash with the Rugby Match in Cardiff?
- the month of May is not suitable?
- of lack of interest?



Can you help us plan for the future? Perhaps one meeting per year is sufficient?

If you have any comments please let us know so that we can plan for the future. Apologies to those who registered for

the Cork event and who were contacted at short notice about the cancellation.

### Suggested dates for 2006 -2007.

At the moment we are hoping to hold our next outings on **OCTOBER 14<sup>th</sup>** in the Clarion Hotel in the IFSC in Dublin and the Spring meeting in the River Court Hotel in Kilkenny on **FEBRUARY 24<sup>th</sup>** 2007.

Obviously these dates are dependent on availability of speakers but especially on a good response from you by letting us know your views and whether there is any topic or area you would like included. Please make your views known by contacting the Group through the Irish Heart Foundation 01 - 6685001.

We also thank those who have been so generous at a time of great loss in thinking of the IHF. You may not be aware, that as a group, we are totally dependent for financial support on the Irish Heart Foundation. All our events are funded by

them. As 90% of IHF funding comes from voluntary donations, your help is vital. All donations on behalf of Cardiomyopathy patients goes towards our group's activities. Your help is very much appreciated.

## Health Professionals

We know that many of you have found out about the existence of the **Cardiomyopathy Support Group** by chance or ironically by making contact with the **UK Association**.

All **General Practitioners (GPs)**, **Cardiologists** and hospitals are aware or should be aware of the **Cardiomyopathy Support Group** as we are listed in

the **Medical Directory**. All hospitals have been notified of the service and receive information about upcoming information days.

We ask you to remind your health professionals about the **Support Group**, so that they can tell other patients where to get help and information.

We can provide your health carers with booklets and leaflets on the main types of **Cardiomyopathy** and on the **Support Group**.

If any of you attend **Heart Failure** or **Heart Efficiency** clinics please take the opportunity to pass on the information.

Please remind your healthcare personnel about the **Support Group**

*“Kind words can be short and easy to speak, but their echoes are truly endless”*

*Mother Teresa*

Please let us know if your contact details have changed

## Making contact

We have been trying to think of various ways for people to make contact with each other.

As we do not give contact details of those on our mailing list without consent we have been looking at other of helping members communicate beyond meeting at information days. Some ideas we have are:

- Internet chat room
- Informal regional groups

- Group for young people to make
- contact with each
- other.

If you have any ideas or could help in progressing these ideas please make contact.

It would be wonderful if some of our young people with **Cardiomyopathy** would contact us and let us know if there is any service they would like us to provide for them.

### Updating Our Contact List

Please let us know of any changes in your contact details so that we can avoid undue distress or confusion at a later date. If we have caused any distress to anyone, by making contact with a deceased member, please accept our apology but we can only use the information supplied to us.

## Cardiac Screening

It is important to screen all first-degree relatives of a person with **Hypertrophic Cardiomyopathy (HCM)**, as the condition may be present without any symptoms. A first-degree relative is a father, mother, son, daughter, brother, or sister.

Screening involves an interview, physical ex-

amination by a specialist plus an **ECG** and an **echocardiogram**. Most cases of **HCM** can be identified using this method. Screening can be arranged via your **GP**. The **Irish Heart Foundation** recommends that ideally children of affected parents should be screened every 3 years until puberty and then annually until 20 years.

**30-40% of patients with Dilated Cardiomyopathy (DCM), will have an affected first degree relative.**

Screening may identify an early form of **DCM** called **left ventricular enlargement (LVE)**. Patients with **LVE** or **DCM** should be followed up annually and undergo the same tests mentioned above.

# A New Heart, A New Life

I was diagnosed with Hypertrophic Cardiomyopathy (HCM) when I was 18 years old. I got my first pacemaker at 21 years old, the first of five.

Over the years I had a number of ablations\* and cardioversions\*. However my condition deteriorated quickly. I became wheelchair-bound and was permanently exhausted. I remember looking at my dinner plate one evening and thinking that I didn't even have the energy to eat.

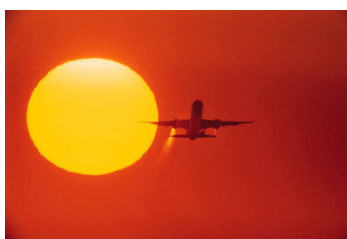
A heart transplant became the only option for me. I was put on the transplant list and given a bleeper for immediate contact when a suitable heart became available.

I waited 16 months for the call. It came on All Ireland Hurling Final Day 2005, 11th of September. I was given a Garda escort to the Mater Hospital. It took 7 minutes to travel from my home in Drimnagh (west Dublin) to the

Mater—no mean feat on an All Ireland day.

Happily, all went well with the surgery and I haven't looked back since.

I'm full of energy and able to enjoy traveling again, which I love. I can do the supermarket shopping, enjoy evenings out with my husband and lead a normal life. The world is truly at my feet.



I do have to be careful to avoid infection. Some unusual sources of bacteria are fresh flowers and plants and shower-heads. So I have to forgo the red roses on Valentines day and I have to let the

shower run of full heat for at least ten minutes when stay in hotels and other places away from home.

One of the strangest sensations for me is to hear and feel a strong, healthy heart beating inside me.

I know that it was the loss of a life that gave me my new life. I will never forget that and never take one moment for granted.

**Helena Buckley**  
**Cardiomyopathy Support Group**

\***Ablation** is a medical procedure that destroys a small amount of heart tissue to treat an abnormal heart rhythm.

\***Cardioversion** is also used to treat an abnormal heart rhythm. Using a defibrillator, the electrical activity of the heart is briefly interrupted using a controlled electric shock to encourage the heart to return to its normal rhythm.

**“Life is something that everyone should try at least once”**

*Henry J Tillman*

# Robbie Simpson

Robbie was the youngest of three brothers, Craig and Conor and a delightful son to Ann and Derek. He suffered from a genetic heart condition, Dilated Cardiomyopathy, otherwise known as an enlarged heart. Although his condition was quite advanced when diagnosed, his symptoms (mainly tiring with only moderate exercise) crept up slowly.

Despite the support of Robbie's family, and the innovative and expert care of the Mater Misericordiae University Hospital in Dublin, including the first artificial heart in Ireland,

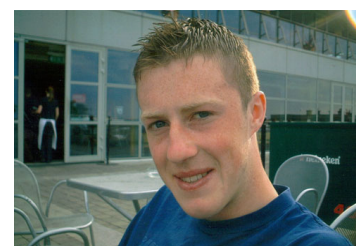
(funded by the Irish Transplants Patients Association) he passed away, aged nineteen, on the 12th of May 2005.

Robbie, who's family live in Dublin, was an active, sports-loving young man who remained brave and optimistic in the face of grave illness. The Robert Simpson Trust, established in his honour, will promote research into Cardiomyopathy and related areas such as sudden cardiac death and Sudden Adult Death Syndrome (SADS) as well as providing life saving equipment, such as defibrillators for sports

campuses and centres, and colleges. The first two portable AEDs (Automated External Defibrillators) will be presented to:

St Andrew's College Booterstown (Robbie's former school) and CBC Monkstown.

Robbie's father, Derek, is a former committee member of the Cardiomyopathy Support Group



**Robbie Simpson**  
**July 10 1985—May 12 2005**

# Thanks

On behalf of the Group I would like to take this opportunity to thank Michael O'Shea and the staff of the Irish Heart Foundation for all their help and support in the last year. Their help, both financially and in providing speakers for our Information Days has made life very easy for us. In particular I would like to thank Tracy Egan for her invaluable help over the last few years and who has solved so many problems for us.

I would also like to take this opportunity to thank Carmel Spollen who retired from the post of secretary of the group this year. Carmel made an invaluable contribution to the group during her time as secretary. It is not always easy to give the time required but Carmel gave her time and expertise willingly. Thank you, Carmel.

We wish you all well and good health in the coming year.

*Eithne Malone ( Chairperson)*

## Task Force on Sudden Cardiac Death

The Department of Health & Children's Task Force on Sudden Cardiac Death published its report, *Reducing the Risk: A Strategic Approach*, earlier this year.

About 5,000 people in Ireland die from Sudden Cardiac Death (SCD) each year. Most of these deaths occur from late middle age onwards as a result of coronary artery disease.

Unfortunately 70-100 younger people die SCD annually. The Task Force concentrated on examining the causes and reducing the number of these sudden deaths.

Most of these deaths are due to undetected cardiomyopathy and electrical disturbances in the heart (channelopathies).

Recommendations in the report deal with the following areas:

- Prevention of SCD
- Detection of those at high risk
- Risk assessment of those engaged in sports
- Equipment & training programmes to improve the outcome in those suffering a sudden cardiac collapse
- Establishment of appropriate surveillance systems.



The Irish Heart Foundation will be working closely with the HSE and the Department of Health and Children on implementation of the Task Force recommendations. The IHF will shortly appoint a project co-ordinator who will be tasked with overseeing implementation work.

The report can be viewed on the Department of Health Children's web site [www.dohc.ie](http://www.dohc.ie)

### SCD in the young Support Group

If you've lost a young family member to Sudden Cardiac Death, this support group can be contacted via the Irish Heart Foundation on 01 6685001.

### Other Support Groups

There are four patient/family support groups affiliated to the Irish Heart Foundation:

**Cardiomyopathy Support Group**

**Implantable Defibrillator (ICD) Support Group**

**Long QT Syndrome Support Group**

**Sudden Cardiac Death in the young Support Group**

All of these groups can be contacted through the Irish Heart Foundation on 01 6685001