

July 2008

Sudden Cardiac Death (in the young) Support Group



Support Group to meet Oireachtas Committee



In July the SCD in the Young Support Group will be appearing before the Oireachtas Joint Committee for Health and Children.

We will be joined by Dr Joe Galvin, Consultant Cardiologist from the Mater & Connolly Hospitals. Dr Galvin runs the Heart House screening centre at the Mater Hospital, Dublin.

We hope to raise more awareness amongst TDs of sudden cardiac death in the young, and express our concerns about certain issues.

This is a great opportunity to educate our public representatives and to advocate for services to identify those at risk and to help prevent SCD in young people.

Our last visit in 2006 was very successful and generated widespread media interest.

We know that since 2006 many more young people have tragically lost their lives to undetected heart conditions, we will be bringing some of their stories along with us.

Soccer Hero Survives

27 year old soccer player Clive Clarke from Newtownmountkennedy, Co Wicklow was on loan from Sunderland to Leicester football club last August when he collapsed in the dressing-room at half time during a match.

The Irish soccer player suffered a cardiac arrest and was resuscitated by prompt CPR and the use of an AED.

Clive was happy to speak to students in his local second-level school, Coláiste Craobh Abhann,

where Maureen Kelly of the SCD in the Young Support Group presented an AED.

The students were very impressed by having their own high-profile survivor come to tell the tale!

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L-R: Alan Moran, Hibernian Healthcare, Maureen Kelly, SCD in the Young Support Group, Shane Eivers, Principal, Clive Clarke



Relaxation Days

Meditative day in Newcastle, Co Wicklow in May.

As we all go about our day-to-day life it is important to take time out to relax and focus on you.

This is why we organised a relaxation day in May and it proved a great success.

We snuggled into bean-bags and practiced "Mindful Living" directed by Ann Twohig. The sole focus was relaxation which our members found extremely beneficial. (One member relaxed so much he started snoring!)

gentle yoga exercises to help us focus on mind, body and soul.

Throughout the day we grew together as a group and freely talked about our feelings of loss. We talked, we cried and we laughed. It was a very sharing and supportive experience for all.

In the evening, we rounded up a perfect day with another lovely meal in the Summerhill Hotel in Enniskerry where most of us stayed the night. The next day we went our separate ways smiling with the memory of the time we'd had together and the bonds we had forged.

UPCOMING HEALING WEEKEND - CORK SEPTEMBER 13, 2008

Following the success of the relaxation & healing weekend in Wicklow, we will hold another in September in St Dominics Retreat Centre, Cork on Saturday 13th September 2008.

We have 14 single and 2 double rooms reserved (bed and breakfast) at the centre on Friday 12th September for those not from the area who need to travel the day before.

The programme for Saturday has not yet been finalised, but we will be offering a variety of therapies. Ann Twohig will again take part guiding us through mindfulness stress relaxation. We will offer some Yoga and reflexology. We hope to have a Trauma Counsellor attend the day. Liturgy readings and a prayer session will be held for those who would like to take part.

The whole weekend will be one of healing. There will be no

pressure on anyone to attend a session they are not comfortable with. The grounds of St Dominics are lovely, if you want to have some quiet time. It will be your weekend.

Lunch and dinner will be provided for those staying at the centre. For those attending on Saturday only, tea and coffee and lunch will be provided .

This is also an opportunity to meet others who have suffered the devastating loss of a young person to sudden cardiac death.

If you are interested in attending please contact Mariane Foley for prices and further information as soon as possible, on 021 4883 307 or email mariane_foley05@hotmail.com



Dinner at the Relaxation Day in Newcastle, Wicklow, May 2008

As part of the day, we enjoyed a lovely lunch followed by a refreshing walk on the beach.

In the afternoon Maura Broaders demonstrated

For more relaxation tips see www.irishheart.ie and search under stress.



The grounds of St Dominics Retreat Centre

SCD in the Young Information Day - Croke Park, June 6th, 2008

The Sudden Cardiac Death in the young Support Group held its second Support and Information Day on June 6th in Croke Park.

Some participants had attended the first day in May 2006, but for others it was their first time. Most attendees were from families who had lost loved ones since 2006 to SCD. This highlights the ongoing tragedy of young people dying of undetected heart conditions.

We were privileged to have Sharon Bates attending. Sharon is co-founder of the Parent Heart Watch Group in the USA. She also founded the Anthony Bates Foundation in memory of her son who died in 2000 of undetected hypertrophic cardiomyopathy (HCM) at the age of 23.

Sharon Bates



Sharon outlined her work with Parent Heart Watch. Along with raising awareness she has also provided 35 free cardiac screenings for hundreds of young people. She estimates that at every screening, 10% of those screened are shown to have cardiac abnormalities which warrant further investigation.

Her follow up research has found that HCM is far

more prevalent than previously thought.

Dr Joe Galvin, Consultant Cardiologist, Mater & Connolly Hospitals, Dublin gave an overview of the cardiac conditions that can cause the sudden death of an apparently fit and healthy young person.

He also spoke of the research he carried out in 2005 which revealed that 120 under 35 yr olds died in Ireland from sudden cardiac death in that year.

He spoke of the work of the Mater's Heart House Screening Clinic which is now looking after three families each week, and has already seen over 200 families. This is entirely voluntary funded and receives no money from the State.

It was uplifting to have the teenagers from two schools who had entered the **Young Social Innovators** competition attend our day. Both had submitted projects on SCD in the young to the competition.

The students from **Good Counsel College in New Ross** actually won first place in the health section. Their project focussed on raising awareness of SCD among their peers and the need for placement of defibrillators in public places such as schools to save lives.



The students from St Kevin's College, Finglas advocated the need for cardiac screening of young people to detect possible heart conditions, which could prove fatal.

It was great to witness the awareness among these boys and the energy and passion they put into these projects was inspirational.

Dr Conor O Keane, Consultant Pathologist, the Mater University Hospital, Dublin described the role of the pathologist in trying to identify a cause of death in the case of a young person dying suddenly.

He answered questions on the length of time an autopsy takes and the difficulty in sometimes making a definite diagnosis. He stressed that only 20% of his work involves autopsies.

Stephanie Oates, a Genetic Counsellor, John Radcliffe Hospital, Oxford spoke of the genetic aspects of the cardiac conditions that can cause SCD in the young. She explained how these conditions can be inherited from parent to child, she also outlined the genetic screening available to detect these conditions.

After lunch Mary Vasseghi briefly outlined the work of the SCD in the young Support Group and the need to move forward in order to save lives.



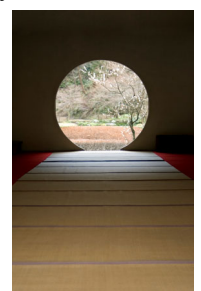
Mary Vasseghi

Marguerite Synnott a bereavement counsellor spoke of the pain and shock of having to cope with the devastating loss of a loved one, particularly losing a young person to a sudden unexpected death. She described how grief can affect family members differently and how people cope with grief in their own way. After her talk we broke up into different groups to discuss how our loss has affected our lives.

Finally, we enjoyed a truly deserved relaxing end to our day with the help of **Ann Twohig and her introduction to Mindfulness and Stress Reduction**.

With Ann's help and the sweet smell of incense wafting throughout the room we de-stressed and tuned in to our own bodies.

Many thanks to everyone who attended the day, particularly those who travelled from far to be there. And to our speakers who gave up their valuable time to attend. We hope you found the day worthwhile and gained some support and information from it.



Young Social Innovators Showcase - SCD Projects



It was wonderful to see that nine SCD projects reached the finals in the Physical Health section at the *Young Social Innovators Showcase 2008* at the RDS this year.

Young Social Innovators (YSI) invites young people between the ages of 15 and 18 to work together to make radical, innovative suggestions and actions for change that can make a real difference to people's lives, including their own.

The students researched all aspects of Sudden Cardiac Death in the young and it was awe-inspiring to see the amount of work these

young people put into their projects.

Not only did they raise awareness within their schools and their communities but they raised funds for defibrillators (AEDs).

One Dublin school, St Kevin's Community College, Finglas, even raised funds to have

themselves screened for cardiac conditions only to find that this could not be done!

The winner of this section was a project called "Don't Skip a Beat" submitted by a group of students from Good Counsel College, New Ross, Co Wexford. Well done lads!



Good Counsel College New Ross Co Wexford. Winners of Physical Health Section with their project "Don't Skip a Beat"

World Heart Day - October 5th, 2008



The Irish Heart Foundation is marking World Heart Day on Sunday, October 5th 2008 and is asking you to get involved by organising a walk with your family, community or workplace.

Why not take part with your family and friends, get some fresh air, some exercise and feel a little

better afterwards, – groups large and small will be coming together to promote physical activity and heart health. Last year, almost 500 groups organised a walk with well over 10,000 people taking part on the day.

By registering as a walking organiser you will receive:

- A helpful guide to organising and promoting your walk
- Organiser t-shirts and balloons
- World Heart Day posters and certificates
- Temporary Slí Signs to mark and advertise your route
- A regular newsletter with tips and ideas
- Free Irish Heart Week information for all you walkers.

For more information or to register as a walking leader contact: Tanya Comber-Rait on 01 6685001 or email: tcomber@irishheart.ie or register online on www.irishheart.ie/whd