



# Defibber News

December 2014

Issue Number 3

Our Next Meeting features  
a talk by

Fiona Green  
Cardiac Rehabilitation  
Lead Physiotherapist  
& Team Manager

On

Physical Activity and  
Exercise for Individuals  
with  
Implantable Devices

Monday December 8th  
Education & Research Centre  
2.00pm Start  
1.00pm for Tea, Coffee & Mince Pie

Fiona will talk about how regular physical activity and exercise play a substantial role in enabling individuals with heart conditions to take control of their life.

At UHSM, the cardiac rehabilitation team currently assess and treat individuals with implantable devices following a heart attack, surgery or when referred from the heart failure clinic.

The benefits of physical activity, along with the considerations and precautions when exercising will be discussed. There will be time for questions, which Fiona will be pleased to answer.



## Tom Hindley - A Man With Nine Lives -

I am writing on behalf of my husband to say a very big thank you to the ICD Support Group. Tom and I attended the group meetings. At our first visit we were welcomed by Jeanette and Sue who quickly made us feel at home. Over refreshments members chatted to us and soon we felt part of the "club"

Exchange of stories as well as information was good for Tom's morale. On one occasion Tom was saying that we were going on a cruise, the only drawback was the high cost of travel insurance! Tom's medical history made it expensive. A member told us about the insurance cover he had, Tom contacted the company and yes, it was half the price of other companies. Tom was overjoyed!

The speakers are excellent. The content is varied and interesting. We always came home feeling better informed and happy that we had attended. Tom enjoyed reading the Defibber News. Indeed I have since found that he has kept every copy!

Tom was "a man with nine lives" In 1990 he suffered his first heart attack and then a second closely followed. After the second attack he was given an angiogram which showed he needed a five way heart bypass. He undertook the operation and after three months recuperation was up and running again. He played golf and snooker with his friends as well as football with his grandsons.

Had he indulged too much? May be, because there followed further spells in hospital. First he had a hernia operation and then a partial knee replacement. But none of this daunted his spirit.

In 2003 another blow. Tom was diagnosed with prostate cancer. The news came like a bolt from the blue. We decided to go home and eat a piece of cake along with a

cup of tea. The surgery he later underwent was successful. Six monthly check ups continued to show that he was clear of danger.

In 2009 Tom was referred to the cardiac unit at Wythenshawe. During one of these visits it was decided that he should have a pacemaker fitted. Six monthly check ups followed. At one of these appointments, the monitor that was harnessed to the pacemaker showed that Tom's heart was racing to such an extent that immediate attention was needed. He was taken to the cardiac ward where later he had a defibrillator fitted.

Sadly Tom died last February but it was in the way he wished to go-suddenly and with very little pain. Throughout the above years Tom stayed cheerful and active. He was very grateful to all the doctors and nurses who attended to him as indeed were his family. **All donations in his memory have been sent to the ICD Support Group.**

We firmly believe that the ICD support group is helping to extend the knowledge about cardiothoracic surgery, medicines and therapy worldwide. All who knew Tom showed great interest in the wonderful work undertaken by the cardiac unit as a whole. Indeed the grandchildren were keen to hear and read about Fabrice Muamba and delighted to receive the gift of his autograph!

**Mrs Hindley**



### A BIG THANK YOU FROM LINDSAY

To all my patients, I would just like to say a big thank you for all your gifts you gave me when I retired. I have got to know many of you over the years and will miss you all.

I would also like to express my appreciation to all the committee members for the beautiful flowers and the generous John Lewis vouchers which were presented to me at the last ICD support group meeting. Finally may I say it has been an honour and a privilege to have known and worked with you all over the last few years.

Thank You.

We only live once (well, you know what I mean!)

*I know this sounds very cliché, but Saturday the 29<sup>th</sup> August 2009 was just a normal Saturday in my life. I was 26 years old and had played football for my local football team that afternoon and that evening had been to my friend's house-warming party with my wife (Claire) and our two young children (Daniel and Oliver).*

We didn't stay too late as Oliver was only 9 months old at the time and when we got home we put the boys to bed and were just settling down to watch Match of the Day when I decided to call my parents to catch up with them as they had been away on holiday. Whilst I know that is what actually happened on the 29<sup>th</sup> August, the only reason I know this is from what my wife and friends tell me as I actually remember precious little of the day as a few minutes into the phone call I had a Sudden Cardiac Arrest (SCA) and the subsequent time unconscious made my memory of the day very hazy indeed.

I was extremely fortunate that I was in the room with Claire at the time of my SCA, but more importantly than that I was extremely fortunate that it turned out that Claire was so incredibly quick thinking and brave when it came to such an emergency situation. Claire literally saved my life as she amazingly managed to provide me resuscitation treatment via phone instructions from '999' until the paramedics arrived and were able to shock me back to life.

From that point, after a few days in intensive care and a few more days on the heart & respiratory ward in Preston I was transferred to Wythenshawe where following more tests



Phil on the Left with his Junior Football Team

I was fitted with an Implantable Cardioverter Defibrillator (ICD). 13 days after the incident I was back home and back with my family all thanks to the incredible support offered by all the doctors and nurses at Preston and Wythenshawe hospitals.

Whilst I know the above story is incredible to most people, and believe me I recognise how lucky I was that day and how lucky I am to still be here today, I guess a lot of people reading this will have equally incredible stories. So what I would like to focus on in this article is the 5 years post this incident, which I guess is why Adrienne asked me to do this article.

I have always been a very laid back individual and been able to take most things in my stride, but even those closest to me struggle to believe how quickly I got my head around what had happened to me and how I have handled myself since my SCA (sometimes to the chagrin of Claire who has had cause to remind me to be more sensible at times). I can remember lying in hospital 4 or 5 days after the incident and, I don't know how to describe it, but I just thought that this has happened now and there's nothing I can do about it and that I am fortunate to still be alive and I am going to make the most of that fact and not let it get me down in any way.

I don't want to make out that I have some kind of special mental strength, there was a day a few months down the line when I can remember crying on my wife's shoulder as I wondered why this had happened to me and what the future would hold but I think that was a positive experience to get it off my chest and move on.

My recovery from the surgery took a few weeks in terms of regaining full use of my arm but after that, with a very understanding work situation, I was allowed a few months to fully recover mentally and this allowed me to spend a large amount of time with my young family which I felt very lucky to have. Slowly but surely I returned to work, which was difficult without being able to drive but with the help of my very supportive colleagues this was made much easier.

All this meant that life had almost returned to normal, me and Claire had put it down to a one-off incident and told ourselves that my ICD was there as protection but that it shouldn't stop me from living a normal life. The one thing missing for me was playing football, it was a huge part of my life and I didn't quite feel the same if I wasn't playing – that probably sounds over the top for something that's 'just a game' in many people's eyes but it was how I felt. I was fortunate to play semi-professional football even winning the FA Vase competition in front of 20,000 people at Wembley just a year earlier in 2008, so it really was a big part of who I was. My consultant, Dr Davidson, recognised that I was still a young man and encouraged me to be as active as possible and to return to what I was doing before my SCA and so I tentatively began training with my team again.

I had discussed me potentially starting playing competitive football again with my wife and parents and whilst I'm sure they were apprehensive, they could see how much I wanted to do it. Dr Davidson had expressed that from a physical point of view there was no reason why I should not play, his main concern was any damage to my ICD that might occur if I was to sustain heavy impact on the area. At that point, I did some research on-line looking into how I might be able to protect the ICD area

and found an American site which sold 'Rifle Recoil Shirts' designed to protect people's chest from the impact of a rifle recoiling when shot. I contacted the company, explained the situation, sent some pictures so they could put the 'pocket' in the right place and then they sent a shirt and 'shield' across. It works like a protective mould over my shoulder coming down over my ICD and is quite sturdy without preventing me from full movement, perfect! This gave me the final confidence to begin playing football again and in May that year I even managed to lift another cup trophy (albeit in the less grand setting of Leyland!).

So it is now 5 years later and yes, there have been some tough times in those 5 years as my ICD has been called upon to shock me on more than one occasion but my overriding feeling when writing this piece is one of happiness and relief. Daniel is now 8 and a half and Oliver is almost 6 and I am so happy that I have been here to enjoy countless precious occasions with them. I don't feel sad in any way that this happened to me, I feel so fortunate that Claire was able to act with such unbelievable skill and bravery on that night and that I live in an age, and in a country, when we are able to provide people like me with these life-saving ICDs.

I think about my ICD every day, but I think about it in a positive way. In the last 5 years I've enjoyed raising my children, enjoyed some amazing holidays, I've played recreational sport and coach my sons football team, everything that I'd like to think I would have done if I hadn't had a SCA and my ICD fitted. If anything, I have been more confident and brave in certain circumstances – when faced with a challenging situation I remind myself how lucky I am to be here and to enjoy the challenge and not shy away from it, we only live once (well, you know what I mean!).

**Phil Blackwell**

# Tribute to Herbert John Thompson (1931-2014)

We are sad to have to report that our Group Chairman, Bert Thompson sadly passed away at his home in Timperley, Altricham on Wednesday 27th August 2014.

Bert had struggled with his health for some time and will be sadly missed by his family, friends and those of us who knew him.

Bert was elected as ICD Support Group Chairman in 2012 and was a gentleman in the truest sense of the word. Although he took his role as Chairman seriously, he had a very humorous side and frequently related interesting stories about his working life at GEC and tales from the golf course at Didsbury, where he was a member.

The funeral was held at St Hugh's in Timperley on Friday 12th September and the large turnout was a testament to his popularity and the high regard in which he was held. He will be missed.

**Ian Woodward – ICD Support Group Secretary**



## Early notice

The first ICD patient support group meeting in 2015 is being held on **Wednesday 5th March**.

As always everyone is welcome. Two of our Consultant Cardiologists will be holding a question and answer session to answer all your cardiology questions. If you want to know anything about new drugs, innovations, current thinking now will be the time to ask. As with previous meetings of this format you can ask the question yourself during the meeting or send it to me before hand.

My e-mail address is [sue.grosvenor@uhsm.nhs.uk](mailto:sue.grosvenor@uhsm.nhs.uk)

## Contributing Your Story to Defibber News

If you would like to share your experience of living with your ICD and Heart Condition with the Support Group in the Newsletter, please either e-mail me or post to:

Mr George S Davies  
103 Redearth Road  
Darwen  
BB3 2AR

[Georgedavies48@sky.com](mailto:Georgedavies48@sky.com)

## **New heart drug LCZ696 could reduce heart failure deaths by 20%, scientists say**

A new drug believed to cause a 20 per cent reduction in heart failure deaths could present a “major advance” in treatment.

The clinical trial of the compound, named LCZ696, was stopped early when the “remarkable” results produced a better survival rate than the current gold-standard treatment, enalapril. The drug, which is on the World Health Organisation’s list of essential medicines, could be replaced according to scientists.

Professor John McMurray, a principal researcher from the University of Glasgow said: “We have what we believe is a much more effective replacement for one of the gold standard drugs for the treatment of heart failure.

“This is a major advance in the treatment of this terrible problem.”

Heart failure occurs when the organ has been damaged, by a heart attack for example, and cannot pump blood around the body effectively.

The body responds to the low flow of blood by producing hormones such as angiotensin II and noradrenaline that constrict blood vessels and make it harder for the failing heart to squeeze blood into them.

Over time, the constant production of these hormones further damages the heart, blood vessels and kidneys. Enalapril works by blocking or inhibiting the hormones and slowing down or reversing the condition’s decline. Professor McMurray said LCZ696 has a similar impact but also offers additional benefits by boosting the production of beneficial hormones.

According to the [research, published in the \*New England Journal of Medicine\*](#), the compound stimulates the kidneys to produce more urine and relax blood vessels, easing pressure on the heart.

Compared with enalapril, Professor McMurray said LCZ696 made patients “live longer, stay out of hospital and feel better, fulfilling all our goals of treatment”.

“This is a remarkable finding and strongly supports

using this new approach instead of an ACE inhibitor or ARB in the treatment of chronic heart failure,” he added.

The University of Glasgow said the two-year trial saw more than 8,400 patients with heart failure given either 200mg of LCZ696 twice daily or 10mg twice daily of enalapril in addition to recommended therapy in a bid to compare mortality and hospitalisation rates.

Early results indicated that 914 (22 per cent) of patients in the LCZ696 group died of cardiovascular causes, compared with 1,117 (26 per cent) in the enalapril group.

A further 711 (17 per cent) of patients receiving LCZ696 and 835 (20 per cent) of those receiving enalapril died of any cause.

This represented a 20 per cent reduction in death from cardiovascular causes and a 16 per cent reduction in death from any cause for those taking LCZ696. The new compound also reduced hospitalisation for heart failure by a fifth, experts said.

It is not yet available to the public as the manufacturers, Novartis International, must gain the approval of the Medicines and Healthcare Products Regulatory Agency (MHRA) to sell the drug.