Defibber News

October – November 2015

WYTHENSHAWE HOSPITAL ICD SUPPORT GROUP

Thursday October 22nd
1.00pm – 2.00pm for Tea,
Coffee and Biscuits
Meeting starts at 2.00pm

Venue
Education & Research
Building
Wythenshawe Hospital
Southmoor Road, Manchester

Boston Scientific Presents

‘ICD’s,
New Technology,
The Future’

Boston Scientific is one of the leading companies in the UK that develops and makes ICD’s and therefore they are at the forefront of new technology.

Ask your questions about the future of ICD’s, remote monitoring & MRI safe technology.

Ted Robbins tells his Story

Before

You'll often hear one comedian say to another" how did your gig go?" and sometimes if it hasn't gone too well they'll reply," I absolutely died!" Well on Saturday 31st of January 20015 in front of almost 20000 people I did, sort off, but not in a metaphorical way. On the opening night of Peter Kay's Phoenix Nights Live in aid of Comic Relief at the Manchester Arena my heart stopped beating and I collapsed. 19996 people roared with laughter (so I'm told) as they thought it was part of the act. My heart had gone into ventricular fibrillation and I lay there, as my dear old dad would have said," going out in the betting fast". The four that weren't laughing were my wife Judy, our daughter Molly and the two medics that saved my life.

The first on stage Yorkshire paramedic Gary had the wisdom to spot that I was in trouble and seeing my family's desperate faces he knew something was amiss. Within a minute he was on the stage pumping my chest with life saving CPR breaking 12 ribs and my sternum in the process, ably assisted by a consultant cardiologist Mr. Donald Adam from the Midlands. Obviously collapsing in front of such a huge crowd was in some ways a stroke of luck for which I shall be eternally grateful as after several minutes they got me back. All I remember is coming round and telling my lovely wife that I loved her" Ah!"

My second stoke of luck was that the ambulance made the decision to take me to Wythenshawe Hospital. Where do I begin to list the number of people on the cardiac team that helped me? At first I was in a very bad way. My chest and rib cage resembled a jigsaw puzzle. I had bitten through my tongue and I had to have a catheter inserted into my heartnot the usual end to a comedy gig! As I say I don't have the space or time here but everybody from the nurses, doctors, consultants and all the medical team, the porters and physios and not forgetting the kind souls who tenderly took me to the shower and bathroom.

Anyone who has been through an thing similar will not need me to tell them about the huge range and depths of feeling that you and your family go through at such a time - all I will say is that almost miraculously after two and a half weeks I was heading home.

Shortly before my discharge that wonderful Lancastrian cardiologist Dr Fox said that he and his colleagues thought that I would benefit from an ICD - my own personal Defibrillator. At first I suppose like many people I didn't like the idea of an alien body implanted in my chest, however after Adrienne and her great team explained how much more secure my future was with it fitted it seemed like a no brainer. The ICD was fitted in less than an hour with minimum discomfort and 6 months on I hardly notice it.

And now?... I'm three stones lighter, I go to regular clinics at Wythenshawe and guess what? I've just landed a part in Coronation St. I don't know what you believe in, personally I think I'm e tremely blessed that my time wasn't up and I thank the Good Lord, my lovely family and Wythanshawe hospital.

Contributions to Defibber News

Hello, everyone! I hope you have had a happy and healthy summer. It has been two years since I started my new job as an Arrhythmia Nurse and I can't believe how quickly time has gone.

Many patients tell me they find it comforting to know that their ICD is working quietly in the background, getting the job done as they get on with their lives. If you have never had a shock from your ICD, do you think how lucky you are? If you have had a shock, do you too, think how lucky you are? The Defibber News loves to receive your letters and stories. Everyone's ICD journey is unique and important. But there's one thing you all have in common. You have a defibrillator. Why don't you write about your own journey? Your experiences, illness, condition and symptoms are all what make you special. Some people find it therapeutic to put it all down on paper. How they felt when they were diagnosed, when they suffered a dangerous heart rhythm which needed a shock from the Paramedic's defibrillator, how their families and loved ones felt. If you have an ICD, what does your husband, wife, partner or child feel about you having an ICD? Do they fancy putting pen to paper and telling others about their experiences? They may have been the ones who called for help and saved your life. Are they the unsung heroes?

You can email us at arrhythmianurses@uhsm.nhs.uk and we will forward your story to George the Editor at Georgedavies48@sky.com or you can post it to us at:-

Adrienne Unsworth,
Arrhythmia Nurse,
UHSM, Southmoor
Road, Wythenshawe,
Manchester, M23 9LT
or to George at 103
Redearth Rd. Darwen,
Lancs. BB3 2AR

ICD support group

The ICD support group meetings are a great way to meet people who have had similar experiences to you. You and your family/friends will be made very welcome by the Committee. The date of the next meeting is always soon after you receive your Defibber News. You don't need a formal invite. Just turn up between 1 pm and 2 pm at the Education and Resource Centre (ERC) at UHSM and there will be a guest speaker who will talk about subjects, which are relevant to you. The date of the next meeting is announced in the Defibber News. You can suggest topics, which you would like to hear about by using the feedback forms, which are given out at each Support group meeting. The feedback forms are used during each meeting. They are important because they tell the Committee what you enjoyed and think needs improvement. So your opinions matter!

Bereavement

I would like to talk about the sensitive subject of bereavement. Your ICD is there to save your life and stop dangerous, fast heart rhythms. There may come a time when your heart condition becomes so severe that treatment becomes ineffective. You can choose to have your ICD turned off to stop it looking for and treating dangerous, fast heart rhythms if they occur during you last weeks or days before you die.

Part of our service to you means we can deactivate your ICD when this time approaches if this is what you wish. We want to do this in a timely manner, with discussion taking place between you, your General Practitioner (GP), significant others and your Consultant Cardiologist, so you know the full facts about turning off your ICD shock ability. Turning off your shock ability is completely painless, takes approximately 5 to 10minutes and can be turned back on again if your condition improves. Turning off your shock ability will not bring about death, nor will it prolong life. Talking to your family/significant others about what you would like to happen when the time comes helps to avoid painful and unnecessary shocks at the end of your life.

We may not know when you or your loved one has passed away and we want to avoid painful reminders of their illness or passing away by sending a copy of the Defibber News. We rely on you letting us know that someone has passed away by telephoning either Sue, the Cardiac Physiologist or the Arrhythmia Nurse team. We will not send any future copies of the Defibber News once we hear from you.

Ask the Arrhythmia Nurses

We would like to introduce a new segment to the Defibber News – Ask the Arrhythmia Nurse. You can ask us questions about your device, dangerous heart rhythms, remote monitoring or any general question you have. This does not replace a consultation, nor does it mean we can give advice on medication doses/changes. We can, however, tell you what your medicines do and what their side effects are. You can give us your name or you can be anonymous. You may have a question about something sensitive or embarrassing. We have heard it and discussed it all before!

Questions like these are all common questions we get asked: -

- What does it feel like to get a shock?
- What do I do if I get a shock?
- What happens when my battery is running low?
- Is there any new technology for ICD’s?

Send us your questions, either by post or email and we will publish them and our answers in future Defibber News issues.

New Arrhythmia Nurse

We are sad to announce that Nicola is leaving the Trust to be a District Nurse. We have enjoyed working with her over the last 18 months and we hope she will enjoy her new job! I am sure you will join me in wishing her well in her new career direction. Natasha Evenson hopefully joins the team towards the end of September and she will be learning all that is fabulous about our ICD patients! She has many years experience under her belt and like me when I first started, has probably met many of you in the past! I am sure you will make her feel welcome and we look forward to working with her. Natasha tells me she is really looking forward to meeting you all, you will be able to meet her at the next ICD support group meeting, so come and join us for an interesting meeting!

Ask the Arrhythmia Nurses

Question from patient in clinic: - Do I need to take my medications every day and what do I do if I miss a dose? Arrhythmia Nurses – That is a good question! Yes, you should always take your medications every day unless a doctor has told you otherwise. You should take them at roughly the same time every day. This is important because your medicine is only in your body for a certain length of time and taking it later will mean you are not getting the benefit of that medicine. Your symptoms may flare up and make you feel poorly. Taking medicine regularly is especially important if of the newer ones such as dabigatran, apixaban or rivaroxaban. Poor compliance with these medicines puts you at risk of blood clots forming in your heart and causing a stroke. Sometimes a doctor will ask you to withhold certain medicines in the run up to a procedure and this is called an acceptable risk. If you miss a dose, take it as soon as you remember but if this is close to the next time you are due to take it, then just take it then. If you keep forgetting to take your medicines, you have a lot of medicines to take or you get muddled up about which medicines you have taken, you can ask your local pharmacy to make up a “blister pack” of all the medicines you need to take at breakfast, lunch, dinner and bed time. Talk to your family doctor about it. Have a wonderful, healthy and happy Christmas and a safe New Year everyone. Stay warm over winter and we will see you in clinic, on the ward or at the next support group meeting!

Adrienne

Safe Imaging for All

MRI is now an option for millions who have cardiac devices

Magnetic resonance imaging (MRI) is a powerful tool for detecting cancer, kidney disease, orthopedic injuries and more. Until recently, millions of people with implanted cardiac devices were ineligible. That all changed when Henry Halperin, M.D., professor of medicine, radiology and biomedical engineering, and Saman Nazarian, M.D., assistant professor of medicine, led a study at Johns Hopkins that resulted in the creation of a safe MRI process for these people.

Why would I need an MRI? MRI has made a huge difference in many lives. It can help us diagnose conditions that other imaging methods, such as CT (computed tomography) and ultrasound, cannot.

What are the dangers of MRI to people with cardiac devices? People with implanted defibrillators and pacemakers have traditionally been unable to undergo the procedure because of the risk of the MRI's heat, vibrations and magnetic field causing the cardiac device to malfunction. The overwhelming majority of people can undergo MRI safely, but we still need more data to make sure it is safe for everyone. We think it is just a matter of time before many of the restrictions regarding the use of MRI in people with cardiac devices can be removed.

How do you make MRI safe for me? Most cardiac devices are actually safe during MRI, but Johns Hopkins takes several precautions to make sure no harm comes to the person or to the device. We first check to make sure your cardiac device is working properly, and then we program the device into a "safe" mode for use in MRI. As you undergo your MRI scan, a specialized nurse monitors you in case there are any problems. When the scan is over, we test the cardiac device again to make sure it is working properly, and then we revert the device to the mode it was in before the MRI.

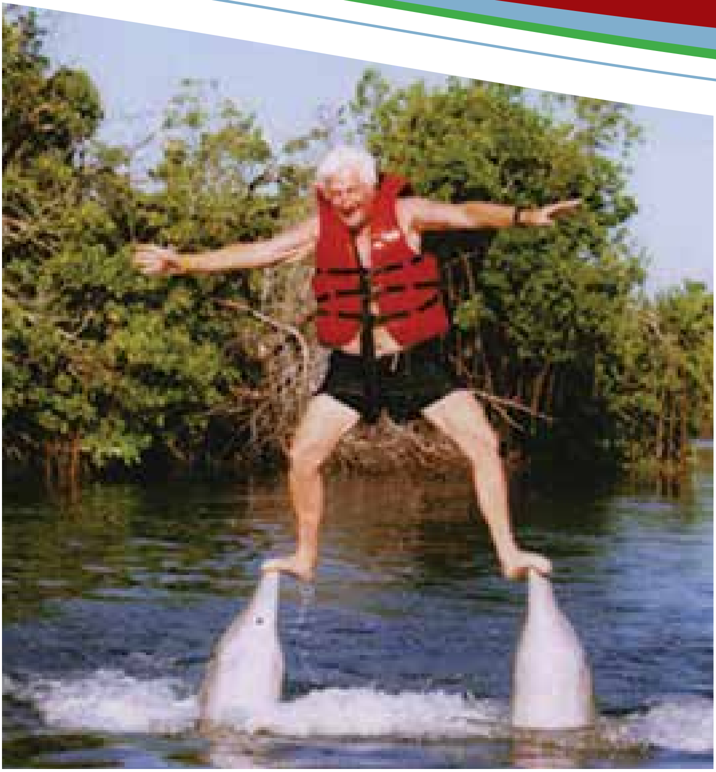
Can I travel by air?

According to expert guidance from the British Cardiovascular Society, most people with heart and circulatory disease can travel by air safely without risking their health. However, you should always check with your GP or heart specialist that you are fit enough to travel by air, particularly if you've recently had a heart attack, heart surgery or been in hospital due to your heart condition.

If you're given the go ahead to take a holiday that involves air travel and think you'll need assistance at the airport terminal or during the flight, then let the airport or airline know well in advance. This may include help with your luggage or early boarding to the plane. If you need to, it's safe to use your glyceryl trinitrate (GTN) spray while on the plane. If you need to take medications that are liquids, creams or gels over 100ml in your hand luggage, then you'll need a letter from your doctor and approval from the airline before you travel. If you are flying through times zones, it may be difficult to keep to your pattern of taking your medications. Your GP or Practice Nurse will be able to advise you on how best to deal with this.

Am I safe to walk through the airport security systems?

If you have a pacemaker or an ICD you should take your device identification/card with you and inform the airport staff that you have a device inserted. If you are asked to pass through the security system, walk through at a normal pace and don't linger. Most modern pacemakers and ICDs are well shielded against outside interference and so interference is very unlikely, although the metal casing may trigger the security alarm. If a hand-held metal detector is used, it should not be placed directly over your device. The Medicines and Healthcare Products Regulatory Agency (MHRA) can provide you with further advice and information on the safety aspects of airport security systems when you have a pacemaker or an ICD.



Am I at risk of Deep Vein Thrombosis (DVT)?

DVT is when blood clots in a deep vein, such as in the legs. For most people the risk of developing DVT while travelling by air is very low. However, if you've previously had DVT or had recent surgery then your risk of developing DVT is higher and you should speak with your doctor before travelling anywhere by air. If they advise you to wear support stockings for the flight, ensure they are the right size for your leg and calf measurement.

To help reduce your risk of DVT you should:

- change your position by walking up and down the aisles every hour or when it is safe to do so
- do some simple exercises in your seat, like stretching your legs and ankles.
- keep well hydrated by drinking plenty of water
- avoid drinking alcohol and caffeine during the flight.

If you're considered to be at high risk of developing a DVT, then an injection that helps to prevent blood clots, called a heparin injection, may be given by your doctor. You shouldn't take aspirin or any other medications to thin the blood without seeking advice from your doctor first. If you take aspirin regularly on prescription, you should continue to take this as directed by your doctor.

Just because you have a Heart condition doesn't mean you cannot travel. Always consult your Doctor before you Fly and if you get the go ahead……..enjoy yourself!

Message & a Joke from the Chairman

We hope you like our new style newsletter and find the articles interesting. We do like to hear patient's stories and I'm sure you will agree they make interesting reading. If you would like to contribute please don't be shy and let us have your story.

Our October meeting is fast approaching. It is frightening how fast the year is going. We hope to see you all there; it will be an interesting and informative meeting. If anyone is coming along for the first time I will be at the hospital from 1 pm, please come and introduce yourself. We are a very friendly group and here to help. It's always nice to see new faces.

See you all in October

Kind Regards
Paul Davis

"It was my sons first day back in school today. Here we go again I thought, he wouldn't get out of his bed he wouldn't eat his breakfast. Do I have to go to school dad I get bullied and picked on by all the kids? You need to man up son I said you are the headmaster!"