Defibber News
October 2024
Wythenshawe Hospital ICD Patient Support Group
https://www.wythenshaweicdsupportgroup.uk

Message from the Chairman Jeremy White

Welcome to the Autumn 2024 issue of Defibber News, and I am also looking forward to welcoming you to our next Open Meeting on 16th October. Dr Ian Temple, a consultant cardiologist has agreed to visit us to answer questions on arrhythmia and the types of device used for treatment.

Our last meeting (on CPR with practical demonstrations) was very well received, and it will be a year since we had an opportunity to put our questions to a consultant. We will look forward to a full house at our usual venue of the All Saints Church Hall in Hale Barns.

This Defibber News also includes an encouraging story of a patient's recovery from a cardiac arrest thanks to the fitting of an ICD. As we are all aware, these experiences often involve the rest of the family and not just the patient. This article has been written by the patient's wife Ann, and it is inspiring that she can look back from a successful perspective, seeing Colin "back on his bike".

I really enjoyed the touches of humour she brought into the happy ending.

Our Next Meeting will be held on Wednesday October 16th 2024 at: All Saints Church Hall, Hale Rd, Hale Barns WA15 8SP

(Tea & coffee served from 1.15pm -- Meeting starts at 2.00pm)

Guest Speaker - Dr Ian Temple

Dr Ian Temple started his career in the Northwest of England and worked in all four of the major heart centres in the region. He completed a PhD in cellular mechanisms of arrhythmogenesis at University of Manchester, which makes him really, really clever!

He has been a Consultant Cardiologist for eight and a half years and cares for patients with all forms of arrhythmia. He performs catheter ablations and looks after patients with ICD and CRT-D at Wythenshawe hospital, as well as pacemakers and loop recorders. He maintains an active interest in research and contributes to major multi-centre clinical trials.

On a personal level, Ian likes to play golf (badly…. his words, not mine!) and he is an avid supporter of Sunderland. He and his wife have two young children but when he is not busy with child friendly activities like camping, he gets out on his bike and can brag up to 100-mile rides when he was at his peak physical fitness.

Ian is looking forward to meeting you at our next “Ask the Consultant” patient meeting on 16th October 2024.

My Trauma Journey

I thought it was about time I informed all you Defibber Clubbers of my long, sometimes anxious but satisfying progress. To do just that I need to quickly go back to the beginning of what I call my ‘Trauma Journey’

In February 2008 I was at work when I felt dizzy and my speech became very slurred and my chest was pounding. Foolishly I drove my car to Trafford General Hospital. It turns out that I had gone into Ventricular Tachycardia (VT). Suddenly after a couple of hours everything went back to normal. I stayed overnight then was discharged. I went back to work and was ok until the end of March. In April, I was back in Hospital with Atrial Fibrillation (AF). My heart rate would not go below 140bpm. I eventually had an Angiogram and it showed I had two blocked arteries and would require by-pass surgery. This was done on the 16th May. For the rest of 2008 my condition got worse and I ended up having to use a wheel chair.

In January 2009 it was decided I should be fitted with a CRT-D which means ‘Cardiac Re-synchronisation Therapy Defibrillator’. This immediately improved my life. I no longer required a wheelchair and I could walk without my heart going into spasm. I was very concerned about the surgery to have the implant but I need not have worried. Even though I was awake for the procedure, I did not feel a thing. The next few years I got on with my life with the help of my wife who has been a wonder to behold.

In 2015 it was decided that I would need a replacement CRT-D due to the battery being low. Again, this was painless with no complications. These implants are to say the least a fantastic piece of equipment. They work hard all the time keeping your heart working smoothly although most of the time you don’t know it’s happening. I say most of the time because there are times when you do know. In my case I certainly felt the device working.

In 2016 I was shopping with my wife when suddenly I thought I was going to pass out. This happened several times so we had to go home. I immediately telephoned Adrienne, the specialist nurse. She asked me to conduct a remote download of my device. I later received a call asking me to go straight to Wythenshawe Hospital. They put me in ICU. Adrienne came to see me and was asking me a few questions when I felt I was going to pass out again. Then suddenly I felt this hard thump in my chest and a bright white light. Adrienne talked to me to keep me calm when I nearly passed out again this time she asked if she could hold my hand, THUMP it happened again.

I was now quite upset and emotional. Then it happened a third time. This one felt even harder. By this time the doctor had arrived. It was the first time I met Dr Ben Brown. He was very understanding and wanted me to have surgery the next day which was for a VT Ablation. For the procedure I was awake but sedated because it was over four hours long and painless. Since then, I have had two further ablations. So, my CRT-D did what it was supposed to do. Save my life. I will be forever grateful for that and of course the doctor's skill, without that I would not be here. How Adrienne felt after holding my hand during the second shock, well, you will have to ask her, only she knows. Since 2016 my life has improved. Again, with help I got on with my life. It took several months to stop being emotional every time I tried talking about the shocks, but eventually, it subsided and now I don't have a problem with it. Talking to friends and family about your trauma is certainly therapeutic. It certainly worked for me.

In 2022 I needed another change of my CRT-D again due to low a battery. The procedure went without a hitch and now feel I have become a veteran in the fight to improve life after heart failure. I will never be 100% again, but as long as I take it easy and don't overdo things and do as my wife tells me!!! then I will be fine. Because of the skill of all the Hospital staff and my wife looking after me I have been able to see my youngest grandson, who was four in 2008, grow up into a fine young twenty year old. So, life could not be better and for you people who are starting your trauma journey listen to the advice given by the nurses and doctors and like me you will lead a good safe life.

Regards to you all
Gordon.

Attending Clinic for your device check.

Hi everyone, hope you are well. I want to let you know about a small change in the way you check in for your device check at Wythenshawe hospital. As you may be aware, MFT has got a new computer system called Hive. We no longer have a set of notes for you, your information is all stored on Hive.

As part of Hive, patients can sign up to My MFT. This is recommended but is not compulsory. We do not have access to your My MFT account. All your appointments and clinic letters are sent to your My MFT account if we have included you as a recipient of the correspondence. When you come to clinic for a device check, you should go through entrance 6 as normal then go straight through the small door in front of you. There is no longer a member of staff at the reception desk at entrance 6. Immediately on the right is a "hub" called Pacing Reception where a member of the Cardiac Physiology admin team will be waiting to meet you.

You can check in on your My MFT, but it is recommended you let the Pacing Reception staff know that you have arrived. They will then direct you to the area you need to be for your device check. If you do not have My MFT, you should report to the Pacing Reception staff. They will check you in and direct you to the area you need to be for your device check.

The photo here shows the Pacing Reception and Chris, the admin staff member about to check in the next patient for his device check. See you all soon, stay regular! Adrienne

Message from the Treasurer

The ICD Patient Support Group exists because of the voluntary donations we receive, plus whatever is raised through raffle ticket sales at our patient meetings in Hale Barns. We do not receive any form of official regular funding. The income & donations raised are how we can provide patients with the newsletter and host the patient support meetings throughout the year.

We have made a couple of economic decisions in recent times, with the main one being to ask patients to provide us with their email address so we can send a copy of the Newsletter as a digital attachment. This helps us greatly with printing costs. However, this will be the patient's decision as we realise that receiving a physical copy appeals to a lot of our patients.

We do have some patients who make regular donations, and this is always greatly appreciated. If any reader would like to donate, whether ad hoc or regularly, please use any of the details below. You can also contact me for any further information or questions.

The Lloyds bank account details:

"WYTHENSHAWE ICD SUPPORT GROUP"
Sort Code 30-91-91 - Acc. No. 30781868
Emma Maiden: Treasurer, 12 The Willows, Cranwell Village, Lincolnshire
NG34 8XG.
(emma.boswell@gmail.com)

Witnessing & Experiencing

Hi everyone, I was in clinic the other week and I met Colin and his wife for the first time. Colin had an ICD implanted quite some time ago, but for some reason us CRM nurses were not informed that he was an inpatient at the time, so we never met him at the time of his device implant.

I gave Colin our patient information booklet in clinic and went through all the questions he and his wife Ann had about it. I asked Colin and Ann to write their story. Ann has written the following account, a different perspective from the patient. You may notice that what the family witnesses is quite different from what the patient experiences! Here is Ann's story and thank you Ann for taking the time to write it! Adrienne

It was an ordinary day in August, with Colin cycling to and from work as usual. Colin is a keen and accomplished road cyclist. He averages 150km per week and is proud of his completions of regular amateur Sportifs. Cycling keeps Colin mentally and physically fit and healthy - and brings him great joy!

On that unremarkable day, we went to bed as usual. Colin is not the best sleeper and getting up in the night is not unusual for him. However, I was woken at around 1am to an almighty bang downstairs. Bear in mind, Colin is clumsy and ham-fisted! He is always dropping things, walking into things, breaking things - this is usually followed by a lot of bluster and a bit of swearing! I generally ignore these 'man-rants', but this was different.

The silence following the almighty bang was ominous. I ran downstairs, calling Col's name, but all I could hear was the horrible guttural noise of distressed breathing. Colin was prone and still and completely unresponsive on the kitchen floor. My adrenaline kicked in. I whacked his chest with the might of Thor and began CPR. I was panicking and calm at the same time. Colin was becoming more cyanosed. I rang 999 and had them on speaker phone until help arrived.

The Paramedics and Ambulance crew arrived within minutes. They were beyond amazing. 5 big burly blokes packed into our tiny kitchen with resus equipment, working relentlessly to save Colin's life. They were calm, skilled and so kind. They were thinking about me the whole time too. Keeping me focused and busy but being realistic that the situation was serious. It is difficult to say exactly how much time passed. It felt like time had stopped, but I was also conscious of how long Colin had experienced little or no oxygen. At least 20 minutes had gone by in my estimation. After 5 cycles of Defib, Colin responded! It felt like a miracle. Col was alive, that's all I wanted to hear.

Colin had a long road to recovery ahead of him. He spent 7 weeks in hospital and was finally discharged on 16 October 2023 after having an ICD fitted. Colin was diagnosed with an Out of Hospital Idiopathic Cardiac Arrest. No specific cause found. He has struggled with this for some time. He needed a reason, a scientific fact as to what caused this event. His mood was affected, he felt vulnerable and anxious. He found it hard to see the positive in his survival, rather he felt 'unworthy' of it.

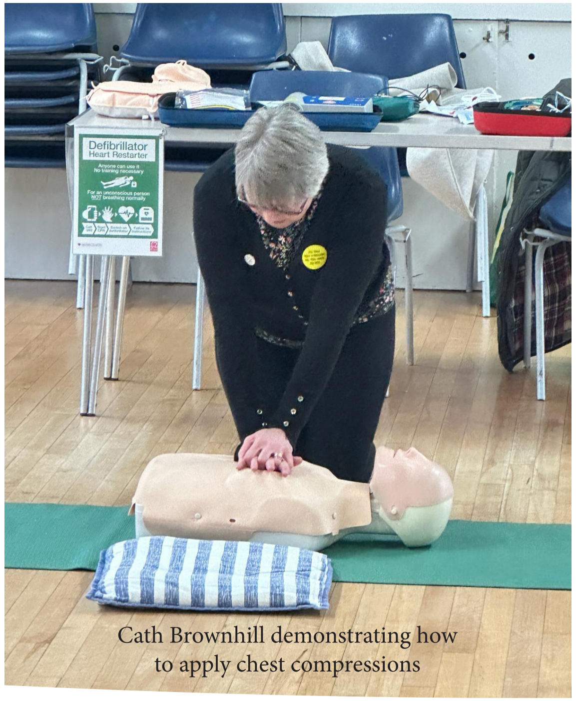
A year has passed now, and Colin has come a long way emotionally. He has come to terms with the randomness of why one person lives, and another doesn't and is back on his bike as much as he ever was enjoying the open (frequently congested) roads! For my part, I am so grateful for the lifestyle Col led to increase his chances of survival; the incredible skill and knowledge of Ambulance crews, A&E, ICU and all NHS staff; the love and support of family and friends. All these factors came together as one to give Col that second grasp of the nettle! That's him holding it now - can you hear him swearing?!!!


Adrienne & Colin

Following on from Colin & Ann's story

Our most recent meeting highlighted the importance of everyone being able to understand what to do in a situation where someone collapses and loses consciousness. All of the important points to understand were contained in an article in the last Newsletter and are also reprinted on the ICD Support Group's website – wythenshaweicdsupportgroup.uk (Articles for Patients).

Cath Brownhill gave a talk and a practical demonstration of CPR (cardiopulmonary resuscitation) to a large meeting of ICD patients, their partners and carers – involving too, members of the audience who gained some practical experience in administering CPR in an emergency situation.


Cath Brownhill demonstrating how to apply chest compressions

Colin and Ann's experience demonstrates the importance for all of us in knowing what to do, how to do it, as we never know when that knowledge may well be called upon for someone close to you as well as any member of the public as you go about your daily lives.

New Member

Hi everyone, meet Helen Seaman, our newest team member. Helen came to the CRM nurse team from the Structural Heart nurse team at Wythenshawe hospital. She specialised in looking after patients with heart valve disease and worked in Consultant led clinics. She has also worked in Cardiac Rehab and on wards F5 and F2.

She is a fabulous addition to our team, and we can't wait to get her learning everything about ICDs and CRT-Ds. We are hoping she can come to the next patient meeting so you can meet her in person!

Some of you may already be aware that April Hopkins has now retired from her post in the CRM nurse team and is enjoying life to the full. April has been involved in many developments for patients with a cardiac device and although her long established career in nursing and CRM is now over, she is now enjoying new adventures. We wish her good health and happy trails!

Adrienne and the CRM nurse team.

Wythenshawe Hospital ICD Support Group Website

Have you had a look at the Support Group's Website? The website can be accessed via this link: https://www.wythenshaweicdsupportgroup.uk which will take you to this screen.

On the Home Page there is a Menu Box that takes you to the different items which may be of interest to you from the drop-down menu.

On the site you can read all issues of Defibber News; get information that is relevant to you, find out all the details of our Patient Open Meetings, get a copy of the Information Booklet for Patients having an ICD implanted, Patient Articles and more.

Defibber News is always wanting to share the experiences of our patients, families and carers and if you would like to share your story, just send it to (georgedavies48@sky.com) and he will ensure that it is included in subsequent issues of Defibber News.

If you don't wish your name to be used, that's fine and we will publish anonymously. What really matters is that we all benefit from shared experiences and ways of coping in living with an ICD/CRT-D, those experiences being invaluable in supporting others who may have just been diagnosed and implanted.

REMEMBER – if you are happy to provide your e-mail address to the Support Group Committee please let Emma know at (emma.boswell@gmail.com)

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