Defibber News

March 2020

OUR NEXT MEETING
GUEST SPEAKER
'CATH BROWNHILL'

Cath worked at Withington hospital as a Cardiac Technician for a long time before going on to work at Wythenshawe and MRI hospitals as a Resuscitation Training Officer. She also ran the Basic, Intermediate and Advanced Life Support courses for doctors, nurses and other health care professionals like paramedics. She also teaches CPR and defibrillator training in the community.

Wednesday March 25th 2020

All Saints Church, Hale Road,
Hale Barns WA15 8SP

Tea, Coffee, Biscuits, Cakes & Raffle 1.00pm

Meeting Starts at 2.00pm

If you require any further information about the Support Group, please contact the Chairman at:

pwdavisandsonltd@aol.com

(07973-541382)

As a Volunteer Support Group for ICD Patients we are always happy to hear from each and every one of you with any comments you may have about the Newsletter and the work of the Group.

If you do not wish to receive the Newsletter for any reason, please just get in contact with our Chairman via his e-mail and telephone number above.

Welcome to the latest edition of the Defibber News and I hope 2020 is treating everyone well so far.

As we embark on this new decade, as secretary of the ICD Patient Support Group I recently took the opportunity to glance back through past editions of our newsletter and reflect on things that have happened both past and present as well as looking forward to our hopes and aspirations for the future. If I'm being totally honest, I did this from a personal perspective as well.

I had my first ICD implanted when I was forty three years old, just before the Christmas of 2003. Looking back, it's undoubtedly been the best Christmas present I've ever had although I didn't particularly think it at the time. I'd endured a pretty torrid year or so, trips to A&E, ablations hadn't worked, I'd gone through cardioversion on several occasions and it turned out I'd got ARVC (Arrhythmogenic Right Ventricular Cardiomyopathy). Worse still, my family were very worried about me, I was concerned about my future prospects in the police and my days of being able to represent the Force at running as well as in a leisure capacity were well and truly over. Life was about to change. The staff at Wythenshawe Hospital were of course magnificent and I remember being seen by Sister Jeanette Hornsey, who was the specialist ICD nurse at the time and during my follow-up visits to the Outpatients clinic. She told me that a support group had been formed where patients and members of staff including Sue Grosvenor, from the technician's side of things were meeting up and sharing their experiences and looking at ways fellow patients could be supported. Some people were struggling with the concept of having an ICD and I was indeed no exception. In 2004, the first newsletter was circulated to all ICD patients and the first open meeting was held that autumn which I clearly remember attending.

Over the years the aims and objectives of the ICD Patient Support Group have become well established, providing a platform to assist, educate and support fellow patients and their families by giving them an opportunity to share their experiences and enable them to come to terms with having a device implanted. There were only around sixty ICD patients when Jeanette and Susan started out with those early pioneers in 2002, today we send out over 1200 copies of the Defibber News three times per year as well as holding our open meetings at Wythenshawe Hospital and All Saints Church Hall at Hale Barns.

There are presently just ten of us on the ICD Patient Support Group committee, with our former chairman, Laurence Smythe, his wife Pauline, our Treasurer, Emma Maiden, and newsletter editor, George Davies still actively involved since those early beginnings. People may not realise that we remain self-funded, have no outside help and rely entirely on donations as well as the raffle to fund the cost of the Defibber News – currently £625 per edition – as well as the hire of All Saints Church Hall at Hale Barns. A lot of thought and planning go into organizing and holding our open meetings as well as putting together the newsletter and whilst we are always heartened by the good attendances as well as the kind generosity and positive feedback from our fellow patients, we would welcome a bit of help from time to time; whether it be by looking at ways we can improve, by perhaps contributing articles or stories for the newsletter or even simply helping out at the open meetings.

Whilst we remain on the lookout for new committee members I 'm often a bit frustrated that there aren't enough of us to spend the time to circulate and chat, particularly with those new ICD patients attending a meeting for the very first time. So if anyone wishes to lend a hand in any way both our Chairman, Paul Davis and I would be delighted to hear from you.

Ian Woodward
Secretary, Wythenshawe Hospital ICD
Patient Support Group
Email: ipw883@gmail.com

Wythenshawe's Cardiac Rhythm Management Team

Welcomes two new Nurses to the Cardiac Rhythm Management team. Meet Tina Osula and Paloma Dominguez, they are experienced Nurses and worked in the Catheter Lab here at Wythenshawe hospital before coming to work with us. You may have met one or both of them when you had your device implanted! You can meet them at the next Support Group meeting in March.

From L-R

Alison Whitehead CRM secretary
Adrienne Unsworth CRM nurse
Tina Osula CRM nurse
April Hopkins Lead CRM nurse
Paloma Dominguez CRM nurse
Natasha Evenson CRM nurse
Elaine Pendlebury CRM secretary

Question from a Patient in Clinic

I had a shock from my ICD. I had VF. Now I can't drive for 6 months. How and when do I re-apply for my drivers' licence?

Adrienne's response:

Although it can be very unpleasant to get a shock from your ICD (or CRT-D), the upside is that it has just saved your life. You can't put a price on that! The downside is you're on a driving ban The Driver and Vehicle Licencing Agency (DVLA) are very strict about driving again after a shock from your device. This includes ICD's and CRTD's. The DVLA usually asks you to surrender your licence. It is against the law to drive while on any type of driving ban.

It can feel daunting and confusing when you apply for your drivers' licence to be returned to you. You should start the process after about 4 months of your ban (providing you have not had any further shocks!). You can see more information on this on the internet. Please go to www.gov.uk/reapply-drivinglicence-medical-condition

There are different types of driving ban. This is where it can get tricky! There are currently 3 types of driving ban. I have done a "quick look" chart for you. Please see the colourful chart further down! In all 3 types of ban, you can drive where stated providing there are no other disqualifying conditions.

1. - A one week driving ban – box change

2. – A one month driving ban – new device with no dangerous heart rhythm, inappropriate therapy, medicine changes to stabilise

your heart rhythm following a prolonged episode of dangerous heartbeat (which did NOT result in you getting therapy) or lead revision.

3. – A six month driving ban – appropriate shock with or without anti-tachycardia pacing (ATP)

You need to know which type of driving ban you have. To keep things simple, just read the section relevant to you below.

1. A one week driving ban – this is for when the battery of your device is changed. Your battery will eventually run low and you need a "box change". As long as the procedure went ok and you have no other conditions which affect your driving ability, you can start driving one week after your procedure. You **DO NOT** need to inform the DVLA if you have had a "box change". Just start driving again.

2. A 1 month driving ban - there are 4 parts to this section. Firstly, if you have had your device implanted because you are **at risk of but haven't actually had VF or VT** then you cannot drive for 1 month after it was implanted. You DO need to inform the DVLA and tell them your device was implanted for **PROPHYLACTIC or PREVENTATIVE REASONS** and you have not had a shock. You can start driving again after 1 month, providing you have not had any shocks or ATP from your device.

   Secondly, if you had a shock (or ATP) from your device and it should not have given therapy, this is called INAPPROPRIATE THERAPY.Your device has got confused about what it thinks your heart rhythm is. It thinks it is seeing a dangerous heart rhythm and delivers therapy. The device may be "seeing too much electricity", miscounts your heartbeats and thinks your heartbeat is going dangerously fast but it isn't. On virtually every occasion you will feel absolutely fine just before the shock or ATP. This is easily corrected by altering the settings of your device and this can only happen in clinic. You have a one month driving ban once your Cardiologist is satisfied that the problem has been corrected.

   You **DO NOT** need to inform the DVLA if you had inappropriate therapy.

   Thirdly, if the lead(s) of your device need to be replaced or their position is altered, you have a 1 month driving ban. You **DO NOT** need to inform the DVLA.

   Finally, if you have had a run of VT but it was not long enough to make your device deliver therapy and importantly, you were completely asymptomatic, you may be given additional medicines to keep your heartbeat stable. This needs to be done to try to avoid you getting an appropriate shock or ATP (and a 6-month driving ban!). The dose of your existing medicine may be increased as well. In these cases, you have a 1 month driving ban. You can drive again once your Cardiologist is satisfied that your heartbeat is stable. You do **NOT** need to inform the DVLA.

3. A 6-month driving ban - there are 3 parts to this section.

Firstly, if you had VF or VT with loss of consciousness and pulse (this is called a cardiac arrest) and you were admitted to hospital after the event, you will have had an ICD or CRT-D implanted as an inpatient. As you have had a cardiac arrest, you must not drive for 6 months from the day your device was implanted. You DO need to inform the DVLA that you that you had a cardiac arrest and that an ICD or CRT-D was implanted for **SECONDARY PREVENTION**.

Secondly, if your device has already been implanted and you have had symptomatic VF or VT (which has made you feel dizzy or pass out) and your device delivered ATP with or without a shock, you have a 6-month driving ban. You DO need to inform the DVLA. In all situations where you have VF you will be symptomatic.

Thirdly, some people don't actually have a cardiac arrest, but a prolonged dangerous heart rhythm has been seen on a heart monitor. If you had symptoms (i.e., you felt dizzy or passed out), an ICD or CRT-D would be implanted. You have a 6-month driving ban.

Reapplying for your drivers' licence – the messy bit!

It is handy to know the date your device was implanted, so you can work out when you can start driving again. This will be found on your ID card which you are given when you go home. Make sure you do not lose this and carry it around with you all the time. If you do lose it, call the Cardiac Physiologists on 0161 291 4640 and ask for a new one. You can start the process of reapplying for your licence after 4 months from the time of your shock, providing your device has not delivered any further therapies. To be very clear, treatment or therapy from your device means "if you have had a prolonged, symptomatic arrhythmia (VF or VT) and your device has delivered ATP or a shock". You need a full 6 months without any further therapies delivered to get your license back.

I have already said this, but I will say it again. It is against the law to drive while on any kind of driving ban! It is your responsibility to contact the DVLA. You can either do this by calling the DVLA enquiries number 0300 790 6801 or on the internet. You can do this by going online and entering the following: www.gov.uk/reapply-driving-licence-medical-condition

State you are starting the process of reapplying for return of your drivers' licence. The DVLA will send you some forms to complete. These are on the DVLA website if you want to speed things up. You must complete your forms and send the others to your hospital Consultant. Your Consultant will complete the relevant forms and return them to the DVLA. The Cardiac Physiologists will arrange for a remote download to be performed at around 6 months. You can check this has been organised by calling them on 0161 291 4640. At the end of the six-month driving ban, all forms should be at the DVLA along with a remote download which was performed on or around the six-month end. The DVLA checks all the forms and confirms from the Consultant that no therapies have been delivered and returns your drivers' licence! Yippee, happy trails!

"QUICK LOOK" DRIVING BANS

DEVICE	HEART RHYTHM	THERAPY DELIVERED	SYMPTOMS	DRIVING BAN	INFORM DVLA
ICD OR CRT-D	NORMAL – BOX CHANGE	NONE	NONE	1 WEEK	NO
ICD OR CRT-D	NORMAL – NEW IMPLANT	N/A	NONE	1 MONTH	YES
ICD OR CRT-D	VT – NEW IMPLANT	N/A	NONE	1 MONTH	YES
ICD OR CRT-D	VF – NEW IMPLANT	N/A	DIZZINESS - UNCONSCIOUS	6 MONTHS	YES
ICD OR CRT-D	VF – NEW IMPLANT	N/A	DIZZINESS - UNCONSCIOUS	6 MONTHS	YES
ICD OR CRT-D	NORMAL	INAPPROPRIATE ATP +/- SHOCK	NONE	1 MONTH AFTER PROBLEM CORRECTED	NO
ICD OR CRT-D	VT	ATP +/-SHOCK	DIZZINESS - UNCONSCIOUS	6 MONTHS	YES
ICD OR CRT-D	VT	ATP +/- SHOCK	DIZZINESS - UNCONSCIOUS	6 MONTHS	YES
ICD OR CRT-D	NORMAL – LEAD REVISION	N/A	NONE	1 MONTH	NO
ICD OR CRT-D	VT MEDICINE INCREASED / ADDED	NONE	NONE	1 MONTH ONCE STABLE	NO

From time to time, members of our Support Group have asked if they could make a donation to help finance the Newsletter and assist in the cost of organizing our Groups Meetings.

Members, if they so wish, can now make a donation direct to the Support Groups Bank, the details of which are

LLOYDS BANK

If you would like to make a donation to the ICD support group, the bank account details are:

WYTHENSHAWE ICD
PATIENT SUPPORT GROUP

Sort Code: 30-91-91

Account Number: 30781868

Emma Maiden: Treasurer,
12 The Willows, Cranwell
Village, Lincolnshire, NG34
8XG

Contact details for all Patients:

If you have any concerns, please contact the:

Cardiac Physiologists on
0161 291 4615

Arrhythmia Nurse team on:
0161 291 5998 / 5443 / 5076

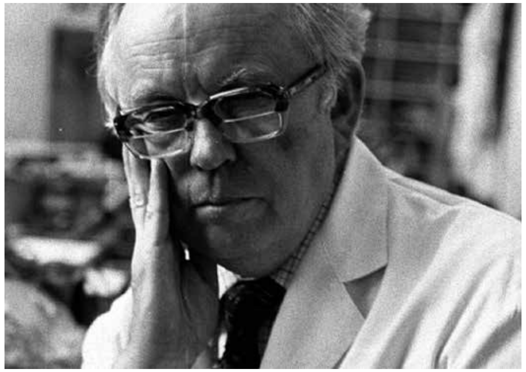
One way of finding that support - either as a patient or carer - is to share your experiences with others who are going through the same kinds of things.

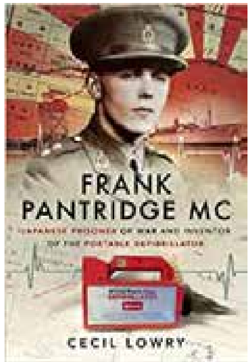
Why not write your story for the Newsletter and send it to

George S Davies

Georgedavies48@sky.com

Professor Frank Pantridge is remembered as the cardiologist who invented the portable defibrillator - a device that has helped save millions of lives over the past 50 years. At our March Meeting, Paul Jarvis will be in attendance with Flyers promoting the book about his life.





'Frank Pantridge – Japanese P.O.W and inventor of the Portable Defibrillator'

Written by Cecil Lowry who will speak at our July 15th Meeting

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!