Defibber News

SUMMER 2020

Coronavirus (Covid 19) Outbreak

Message from the Cardiac Rhythm Management (CRM) team and ICD Patient Support Group at Wythenshawe Hospital

Dear patients, as you will be aware, there is currently a quick moving, evolving spread of the Coronavirus (Covid 19). This will be extremely concerning for everyone, not least you and your families. The information we are being given about this is changing daily and rapidly but the most important thing you can do is follow the Government advice.

Stay home. Protect the NHS. Save lives.

At the time of writing this, the information given is correct. If anything changes, we will let you know via the website. If you keep your contact with others to an absolute minimum, you are significantly reducing the risk of becoming infected with the Covid 19 virus. This is the best thing you can do. **It is not social distancing** if your family and friends call in to see you but keep a "safe distance" away. They must stay away completely. With all the technology we have available to us now, face time, video calls, texting and social media such as Facebook, we can still be in contact with those people who are important to us. Only go out for absolute essentials like medicines and food. Keep a distance of 2 metres from others. All the public areas like supermarkets have clear guidance around their stores. Keep your hands away from your face. If you cough or sneeze, use a tissue, put it in the bin immediately and wash your hands. Wash your hands frequently (especially if you have touched items from outside your home such as shopping and deliveries). Using hand gel is not the best option for cleaning your hands. Only use this if you cannot wash your hands. If you don't go out, you have less need for hand gel and you can wash your hands at home. You can see how to wash your hands effectively by clicking this link to the BBC.

https://www.bbc.co.uk/news/av/health- 51754472/ coronavirus-how-to-wash-your-hands-in- 20-seconds

Boredom will eventually set in. Keep yourself busy with other things. Get all those jobs done which you have been putting off for months. If you find that reading the news or going online to read about Covid 19 is making you feel anxious, then limit this to an hour a day. You should still keep an eye on the news, as there may be important information you need to know .

If you need advice from us, we are still here to offer it. Although we are currently running a reduced cardiac rhythm management service, our answer machines are always on. These are checked regularly throughout the day. If you have a problem it is highly unlikely we will be bringing you to the hospital to be assessed. **Please do not come to the hospital if you have not been authorised.**

There will be occasions where you do need to come to hospital. If you are having chest pains which are getting worse and are making you feel very unwell, you need to call 999. Your ICD or CRT-D will not stop you from having a heart attack. If you experience several shocks very close together, you need to go to your nearest hospital. Your heart may be unstable and you need medical assistance. Again, you will need to call 999.

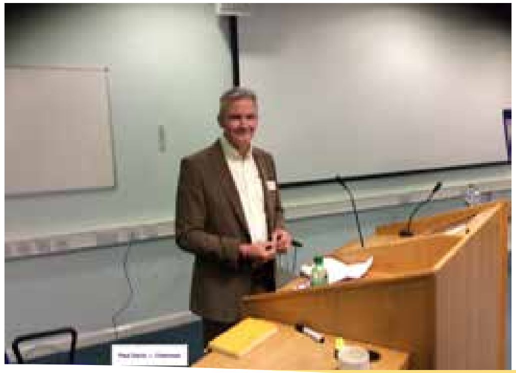
ICD Patient Support Group -

https://wythenshaweicd.wixsite.com/icdsuppor t/about-us-1 - !

If anyone does not have a remote monitor for any reasons (apart from those who cannot receive signals from the monitor) a remote monitor will be sent to you so we can perform scheduled downloads around the time you would normally be seen in clinic. This is so we can see what your heart has been doing, if there are any problems with the device and to check the device has enough battery longevity (I like to call this the battery juice!). If there are problems with your device, we will contact you to discuss it further. Some of you will be notified by letter to perform a download around a certain day and time. In many patients (especially those with a new device), we can do a download automatically.

If you think you have had a shock from your ICD or CRT-D please do a download and then call our Pacing desk on 0161 291 4640. They will look at the download and advise you what to do. Again, it is highly unlikely you will be advised to come to the hospital. Most situations will be dealt with over the telephone. This telephone is currently manned during "office hours" from Monday to Sunday. This is not an emergency service, neither is the CRM team service. You should know our phone numbers but here they are again!

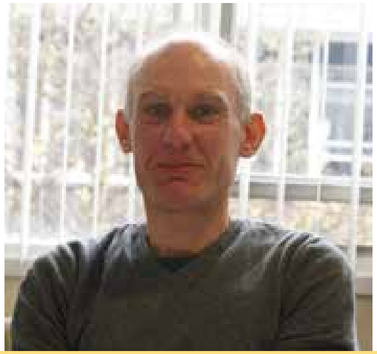
0161 291 5076 – 5443 – 5998



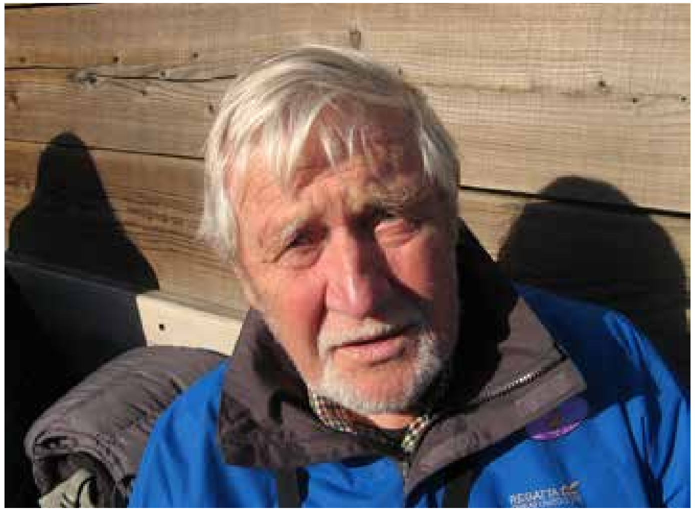
If you have had more than one shock, do a download, call the Pacing desk on the same number as above (0161 291 4640) and state you have done a download because you have had shocks. The Pacing team will advise you what to do once they have seen and analysed the download. All the important phone numbers are at the bottom. We have got plans in place for anyone with a very low battery level. The Pacing team will be in touch with you if this is the case.

All the answer phones are working 24/7 so if we receive a call from you, we will call you back as soon as we can. Leave a message on ONE PHONE ONLY, with your name and date of birth, or your RM2 number if you know it (this is unique to you at Wythenshawe hospital and enables us to find you quickly on the computer system). If you can, tell us the name of your device. Is it a Medtronic, St Jude, Boston Scientific or Biotronik? Knowing which device you have helps us to locate your download as every device company has their own website for downloads. You can find this information on your ID card.

Please try not to worry. Follow the Government guidelines on social distancing, staying at home and hand washing. Call us if you need us. It will get better. Thank you for your cooperation and understanding. Stay safe!



ME AND MY DIGI-BOX



I am a case and a half! I have been a type 2 insulin-treated diabetic for over half my life now. I am used to a pattern of four injections a day and was taught to accommodate my injections to the anticipated calorific content of my meals on the scheme known as D.A.F.N.E. (dose adjusted for normal eating). No one seems to understand that acronym any longer when I trot it out in hospital! Add to this slight inconvenience in my life a diagnosis of heart failure in recent years – hypertrophic dilated cardiomyopathy for the technically minded – plus severe hearing impairment and some Dupuytrens in both hands, and you can see why I am grateful to the NHS!

Back to my main theme. In November 2018 I was rushed into Stepping Hill with severe pains in my chest. Having eliminated any heart problems and completed various tests and scans, the medics concluded I had pancreatitis with referred pain. Drips were duly inserted and after a week or so I was wheeled into endoscopy to have a small stent introduced into my duodenum to enable better flow of bile. All well and good. The stent was to stay in place for about four months.

In the Spring of 2019 I was called back, a little belatedly, for the said reversal procedure. The preparation went fine and I was "on the slab", dreamily sedated and ready to swallow the tube when I was rudely awakened from my slumbers and told the procedure had been aborted because the monitor had been showing irregular heart rhythms. Straight back on a trolley and along to A&E Assessment for thorough coronary checks and blood samples, together with non-stop nursing care. Crisis temporarily averted – "It was the sedation that identified your unreliable heart function Mr Kendall!" – I was parked more permanently in Coronary Care and wired up all over as if I was something from "ham" radio. So, I remained for several days; all bodily functions had to be completed within the close extent of my wiring! Always in Stepping Hill my insulin injection regime was VERY closely supervised – for obvious historical reasons......

The next step was resolved. I needed a pacemaker inserting. Nay...not just any old pacemaker but a pacemaker defibrillator. Of course, as the initiated well know, these procedures are undertaken at Wythenshawe. A space in the busy schedule was sought, but was not immediately available. "We are sending you home Mr Kendall; but please take great care and don't do anything strenuous". So, what was different from before I came in to have the stent (still in situ) removed? Wythenshawe contacted me for a pre- op and procedure in the following week.

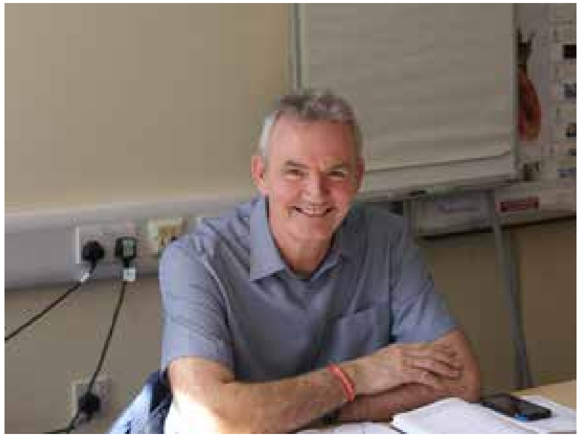
A fine way to welcome the Spring! I am sure nine out of ten cardiac catheterisations and box insertions go without a hitch. Mine didn't. The procedure took longer than expected. The local anesthetic wore off. They could not give me any more sedative when I asked because of my heart rhythms. I was aware towards the end of a lot of physical pushing and pulling and ended up in considerable discomfort. The procedure had not been completely successful because the third wire could not be completely inserted. I had a pressure dressing and was kept in overnight. The result was a lot of local bruising and a digi-box that was only working at half capacity.

For summer 2019 I knew I was only on half strength. My magic box was actually delivering very little improvement. This was confirmed back at base when I went for scheduled physiological checks and consultant clinic at Wythenshawe. One lead was not inserted and another lead was not fully functional. What would I like to do about it? Yes – it was up to me to make a decision. I had plenty to think about as it was. I had been back to Stepping Hill to have the stent removed and they could not find it! "Probably passed naturally Mr Kendall". Several centimetres of titanium tubing down the pan? I decided on a repeat cardiac catheterisation, but under a full anesthetic this time. Another complication, we had to ask for it to fit conveniently around my wife's imminent hip replacement.

Summer became Autumn. My wife had a completely successful hip operation and good rehab. I went in for the repeat procedure and was treated superbly. The opting for a full anesthetic was a wise decision. I had a very different experience. The surgery was first class and all three wires were completely installed. As my wound healed, my heart function noticeably improved. Christmas 2019 was one of the best yet. I steamed on into 2020. Bright horizons; new goals and new targets. All systems go, confirmed by the physiologists. And then..... somehow in February 2020 I broke a vertebra in my back and it all came crashing down for the time being. Added to which, at the time of writing, we are amidst the Coronavirus Pandemic. Oh well, like I said: a case and a half!

Phil Kendall 20.03.20

GREETINGS FROM THE CHAIRMAN



Welcome everyone to this edition of the newsletter. Firstly, I do hope everyone reading this is keeping well during this very strange time. As you are all aware, we had to cancel our March meeting, which was very disappointing. Unfortunately, due to the ongoing pandemic, our next meeting scheduled to take place at the hospital in July has also had to be cancelled.

We do have a very useful website, for those patients that haven't yet used it I urge you to try it out. The website address is at the bottom of this article.

I realise not everyone has access to the internet, but if not, maybe you could ask a friend or family member to check for any updates regarding our meeting, plus any other important information we think would be beneficial to you. The internet can be a great platform for sharing information quickly (I realise it can also be a pain). Our Secretary – Ian Woodward - is building up a comprehensive list of patients e-mail addresses and If you would like to be included please let Ian have your details. Ian's email is at the foot of this message. When we had to cancel the last meeting, we had to send out 1200 letters to inform people, which is very time consuming and costly, your cooperation would be greatly appreciated.

These days are very strange and I'm sure many people are frightened, and this will cause heightened anxiety. I have learned from speaking to many patients in the past that many have anxiety issues, this is something I am familiar with myself. If any patients would benefit from talking to one of us, please feel free to contact either myself, George or Ian on one of the emails below and we will contact you. If you prefer a female voice please let us know. There are many things to help with anxiety, distraction being one of the best. A great time to peruse a hobby from home, gardening is a great one if you have one. I personally find humour gets me through, try and keep a sense of humour. Sometimes easier said than done. Also talking to someone can be extremely beneficial.

Mindfulness meditation is also very good and you don't have to be a Buddhist monk to practice it. It's all about living in the moment and not dreading the future. I say don't knock it if you haven't tried it. There is plenty of information on mindfulness out there. I am currently reading a book on mindfulness called 'Mindfulness finding peace in a frantic world'

These days will pass and I believe the world will be a nicer place for most. I hope you enjoy this edition of the newsletter, if you have any untold stories please let George have them for future editions.

We are all extremely grateful for the wonderful work the NHS have done for us and continue to do so, especially while working under considerable pressure, they all deserve medals. I do hope to see you at our next meeting, whenever this may be, meanwhile stay safe and stay well and stay positive. I will leave you with a bit of my humour. Matt Hancock on TV last night said a front door is better than any face mask. Well I tried it but finally had to put it down at Tesco's as it was just far too heavy.

Best wishes to all - Paul

https://wythenshaweicd.wixsite.com/icdsupport/about-us-1#!

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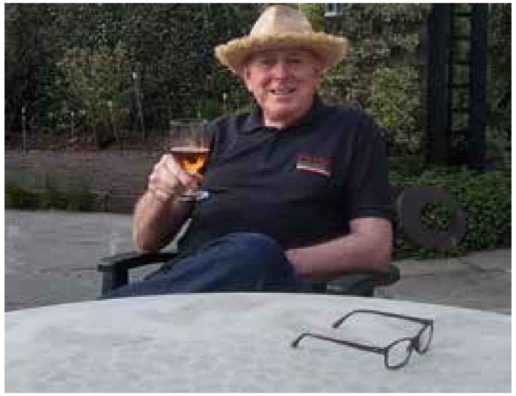
As a Support Group we want to be able to provide as much information as we can to all our patients and carers. In the current period when it is not possible to come together in meetings, it would be helpful, if all those patients who had e-mail addresses would let us have them. This would enable us to make very quick contact with you all about any and future activity. If you are agreeable, please just send it to our Secretary – Ian Woodward at
ipw883@gmail.com

I left Wythenshawe Hospital in April 2016 with my newly-fitted ICD.......

I left Wythenshawe Hospital in April 2016 with my newly-fitted ICD after having spent three weeks in hospital beds whilst wired up to various pieces of equipment. I was told that I was probably safer than most of the people out on the streets but that if something was wrong or that my device fired, I was to carry out a download, inform Cardiology and then come in to A&E if necessary.



It was nice to be free and to see outside the hospital walls and I was curious to see what was going to happen next, but my wife and family were a daunted with my return, wondering how I was going to manage. During the first few weeks I rested and regained strength, exercising as I felt able without pushing it too far. My wife Ann fed me up and encouraged me to move at first and then switched over to trying to stop me over-exerting, as she saw it.

My wound healed quickly and day by day I felt stronger. Soon I had completed a circuit of the block, attended church and pretty soon afterwards was able to navigate a trolley around the local supermarket. I felt good, stronger each day, but found that I had to make a conscious effort not to react too quickly by standing up to get to answer the telephone or reach the front door if a bell went. If I did, I felt faint and had to stop for a few seconds to gather myself. No cardiac rehabilitation had been offered to me but everything that I read and that Adrienne told me was to the effect that one should build up slowly and warm up for a few minutes before speeding up when exercising, but I found this easy to forget when I was feeling so well.

Six months after having left hospital I applied to have the driving licence that I had handed in returned. I had no medical issues, had flown on holiday and felt well. The only time that I was aware of my device was when I turned over in bed on to my left side. If I did this sometimes, I was ok. but, on many others, when my body was settling in to its new position, my chest would start to thump uncomfortably as my pacemaker timed the beating of my heart. Then I would have to find a new position to lie in.

Regaining my mobility was great and my life returned to its normal routine. I had been able to resume regular swims and hill walking, albeit at a reduced pace when it came to upward slopes. Life was good.

Stockport has an annual beer festival near to the spring Bank Holiday weekend and I agreed to assist in the set-up for a couple of days and behind the bar at the first afternoon session. The weather was very warm and on the opening morning last minute preparations were a bit hectic so I think that I had become dehydrated. Standing up after having been bending down to adjust a pipe I realised that I was going to faint and keeled over, sending the till crashing and scattering money everywhere. Apparently, I was out for about ten seconds before coming to, flat on my back and surrounded by anxious faces. I regained my feet, walked from the bar and sat in a cool spot and drank a pint of water.

I had felt no pain when my device had given its "appropriate shock". Ann collected me and took me home where I lay on the bed and did a download before ringing Wythenshawe and leaving a voicemail to tell them what had occurred and what I had done. I felt a little bit tired for a few hours in the evening but went to bed and when I arose in the morning life was back to normal, other than I was now unable to drive again. Ann and my family were a bit unsettled by events.

The summer came and went and in September we went away with friends for what had become a tradition. On our first morning an exploratory walk had been proposed so eight of us set out on the single file path up the hill behind the property. At the top, as we waited for the party to re-assemble, I felt that I was going to faint and moved towards a fence post to lean on it. I came around lying on my back with more anxious faces peering at me. I was told that my face suddenly went grey and that I had collapsed gracefully (?) on to the ground where I remained for a few seconds before my device fired and I came around, regaining my colour. I decided that I had not damaged myself and asked to be pulled to my feet before walking, escorted by two of the party back to our accommodation. The hardest part of the whole affair was telling Ann what had happened. We sat down with a cup of tea for a couple of hours and by then I felt back to near normal. We decided not to return home but assess the situation on the following morning when I would be able to inform Adrienne what had happened, how I felt and what I was proposing to do, and promising to do a download when I did return home.

The download revealed that again that the shock had again been appropriate and it was decided that, after two such events, an appointment should be made to see Dr. Brown. As a result of this meeting I had a small number of options put to me and I elected to continue on my existing medication as there may have been reasons to cause my fainting. Life returned to a normal routine and six months after my second event I was told by the DVLA that I could start to drive again. This new freedom was, however, short-lived.

Two months later, at the end of June, I had been for my routine swim followed by a relax in the hydro pool and was just finishing getting dried when again I felt faint. This time I came round on the tiled changing room floor with the usual collection of anxious faces peering at me and, after regaining my feet and dressing, I had a cup of coffee while I waited for Ann to collect me. On returning home another download was completed’ followed by a call to the cardio physiologists and a message to Adrienne to confess my deeds. It was subsequently decided that I should again see Dr. Brown.

Before this could come about, I had my next event. The new A555 road that passed near to my home on its way to the airport had a cycle path to one side near to us, but this was not visible on many other sections. Did a cycle path reach all the way to the terminal? An answer was needed so I got my bike out and went for a ride to determine the route and its end point. I did not reach my destination, however, and came to on a traffic island in the middle of the A34 at Handforth Dean, with two passing Samaritans who had seen my fall. One kindly loaded myself and my bike into his vehicle and brought me home, refusing to do otherwise. He then waited until Ann returned home from her Pilates class before leaving.

A couple of days later I had my arranged appointment at Dr Brown’s clinic, where it was decided that I should have an ablation within the next few weeks. I was told not to exert myself in the intervening period and that, as before, if anything happened or my device fired, I was to carry out a download, inform Cardiology and then come into A&E if necessary. The chances of anything happening seemed by then pretty slim as Ann was by then was watching me like a hawk, whilst fielding frequent enquiries from our two married children as to how I was.

I was taken under escort of Ann, my daughter and two grand-children, to a friend’s house in Northumberland for a couple of weeks rest and recuperation, with no excess exertion, at the end of July. The first day there we visited the glorious beach for the boys to expend their energy. In typical British summer tradition, the dry but cool morning deteriorated until the inevitable rain arrived and drove us off the beach in the mid afternoon. All the bits and pieces necessary to entertain a family for a day on a beach were carried back through the dunes, over a golf course and loaded, with the two boys, into the one car and taken home by Ann. This left three of us and a dog to walk back to the house about three-quarters of a mile away. Having completed the uphill section of the walk we were walking on a level and then a short downhill section when that by-now familiar feeling came over me and I passed out, to be brought back by my ICD as usual, the whole process witnessed by our friend and our daughter. I regained my feet, steadied myself for a couple of minutes then completed my walk back to base. After assessing how I was I left a voicemail at Wythenshawe Hospital and reported what had happened. I said that I felt well and that I intended to complete the holiday, but that I would take myself south to the Freemans Hospital in Newcastle if the situation changed. The rest of the holiday passed without incident and when we returned home in mid-August, I completed a download. My appointment for the ablation had by now been set for the end of the month so I kept myself under wraps until then

Two weeks after my procedure had been completed as planned, smoothly and painlessly and hopefully with everything reset for normal activity, we then decided to have a short stay in the Lake District. Strolling through Hawkshead village on a Sunday afternoon I passed out again, with Ann trying to stop me damaging my head on the stone wall beside us, before my device again fired and I returned to the land of the living. We sat on an adjacent bench for a short time to allow me (or Ann?) time to recover before we completed our walk back to the parked car. I again rang Wythenshawe, leaving a report of the event, and said that I would do a download the following afternoon when I returned home.

A further two weeks down the line I had my next event, this time sitting comfortably in the late morning watching Scotland play a game at the Rugby World Cup. I experienced my usual half second warning feeling and leant back on the couch. This time I did not damage myself falling and felt as though that if I did pass out it was only fleetingly and was also aware of a distant jolt as my device was triggered. Afterwards I recovered for a couple of minutes before walking upstairs and completing a download followed by a phone call to the Cardio unit to inform them of what I had done. That afternoon I had a physiotherapy appointment, which I kept. As usual on a first visit to such a place my medical record was discussed. Perhaps Lyndsay turned slightly pale on my reply to her asking the question “and when was your last event?”

Two events within a month led to me being squeezed into Dr Brown’s clinic on the next Thursday. I was told that because of my repeated arrhythmias I would have to start taking Amiodarone tablets. “It does to arrhythmias what Domestos does to household germs”, I was told. So, after a number of my base

functions were checked and having had a lung x-ray (pristine lungs!) I started on my new medication.
Four months down the line everything seems to be good. After wondering if I should be walking around wearing head protection to protect my skull when I next fell, I now feel more confident than I have for some months. While I had tried to carry on as before my latest series of events, there was always an underlying trepidation as to when and where I would fall next. I felt that I was rather old to have to keep waking up in unfamiliar surroundings. And it was probably easier for me than for Ann and the family. My wife would have to field all the questions from my children as to how I was doing as they were not satisfied by my responses when the same questions were put to me. If I went out, she was the one waiting to come and redeem me from lost property.

I can honestly say that I do feel well. The only pain that I have suffered during these events, other than some minor scrapes and grazes, came from gout triggered by trauma suffered by my right ankle/foot during two of the falls. I do not have the energy that I used to have, probably a result of my condition and the necessary medication that I am taking and I am yet to learn properly that I cannot go from rest to moving quickly (relatively) to answer the door or the telephone. I also have to stop and admire the view more often when ascending an incline. I am looking forward to the next stage of my journey in life.

The team at Wythenshawe Hospital have been great, but they are so busy, probably victims of their own success in keeping people like myself alive and moving. The ability afforded by the Latitude box to send a download from the comfort of one's own bed to the cardio physiologists for interpreting fills me with wonder every time that I have had to use it. Also having the ability to leave a voicemail for an appropriate contact after an event (most events seem to happen after 5.00pm or at weekends!) is very reassuring. I have never felt the need to attend A&E as a result of an event because of this, because of Ann's years of nursing experience has allowed her to asses my condition and because I have recovered quickly after each one. I have felt that R&R would be more easily achieved in my own surroundings. If I felt otherwise, I would go straight to Wythenshawe or the nearest appropriate A&E facility.

Last but not least I would like to thank all the volunteers and medical staff who run the ICD support group. The speakers chosen for the Defibber meetings have all contributed to my knowledge and the support garnered from hearing of others' experiences both in the Defibber News and at the tri-annual meetings has been a great support, you are not alone. Well done to all.

Eamonn Munnelly

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

If you wish 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

Making healthcare better is our priority, and we believe medical technology can play an even greater role in improving people's lives. With challenges facing families and healthcare systems – such as rising costs, aging populations, and the burden of chronic disease – we are using the power of technology to take healthcare Further, Together.

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