Defibber News
May 2025
Wythenshawe Hospital ICD Patient Support Group
https://www.wythenshaweicdsupportgroup.uk

GUEST SPEAKER

‘Goran Lukic’ Principal Clinical Psychologist

Hello, my name is Goran Lukic. I am a Clinical Psychologist working in Cardiac Rehabilitation at Wythenshawe Hospital. My role involves supporting patients in their adjustment process to cardiac events, conditions and interventions.

This sometimes means therapeutic work. At other times, it focuses on helping people work towards their rehab goals, often through changing specific behaviours.

As well as this, I try to provide forums to colleagues, to reflect on the psychological aspects of the work and become more confident responding to it.

I do this through offering training, consultation and supervision. Lastly, I conduct research on themes relating to the above. I will be coming to talk to you about the psychological aspect of having an ICD or CRT-D and I am very much looking forward to meeting you.

Wednesday May 7th 2025
All Saints Church, Hale Road,
Hale Barns WA15 8SP
Tea, Coffee, Cordial, Biscuits & Raffle 1.15pm
Meeting Starts at 2.00pm

INSIDE THIS ISSUE

- Remembering Jeremy our Support Group Chairman - **Adrienne**
- Surviving against the odds – **Christopher Graham**
- My journey so far with Hypertrophic Obstructive Cardiomyopathy – **John Dainton**

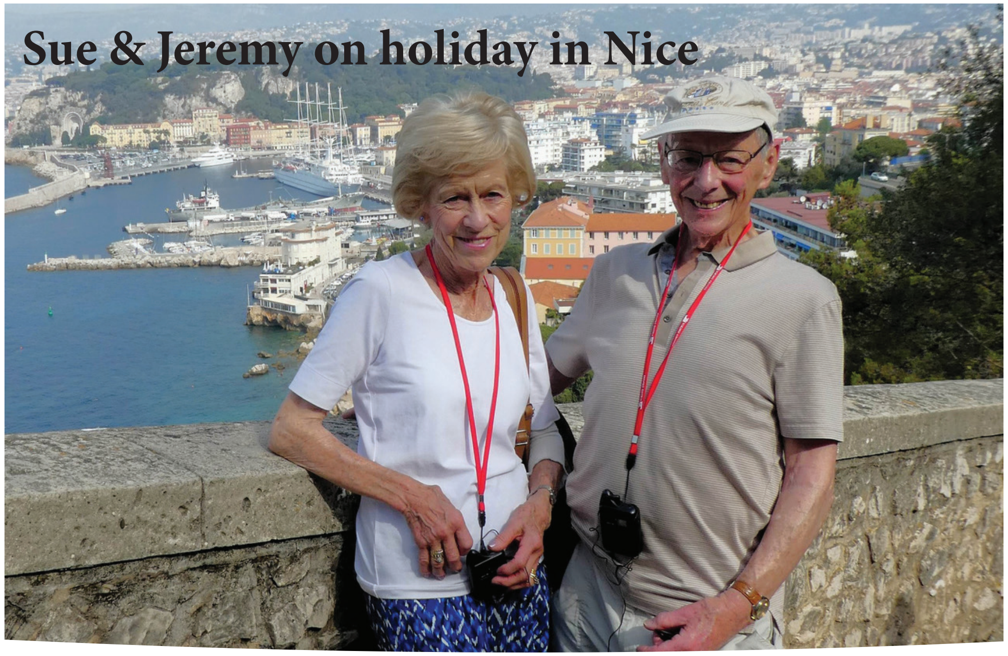
Mr Jeremy White Chairman of Wythenshawe ICD Support Group Eulogy.

I am very sorry to announce that Jeremy, the Chairman of the Wythenshawe ICD Support Group has passed away in Wythenshawe Hospital. His wife, Sue and son, Chris were by his side.

Jeremy joined the Support Group a few years ago and took over as Chairman after the departure of Paul Davis. Jeremy did a great job as Chairman, although he never quite got the hang of using the headset microphone! Jeremy had a long cardiac history which resulted in him having a CRT-D implanted in November 2016. The CRT-D did a good job in improving his heart pump function, but on several occasions, this deteriorated, and he would become unwell. The Heart Failure team would alter his medications, and he would improve again. Fortunately, he never had a shock from his defibrillator.

In 2024 Jeremy developed some complications with his swallow and was admitted to Wythenshawe twice for aspiration pneumonia. In February this year he was admitted again for this, and with other complications he just didn't have the reserves to recover. He passed away on 6th March 2025. Jeremy was a true gentleman always polite and courteous to the nurses, his committee colleagues and patients. He was a keen supporter of Wythenshawe hospital, serving for over 20 years as a Chaplaincy helper. Jeremy will be missed and on behalf of the nurses and his committee colleagues I send our sincere condolences to Sue, Chris and all of Jeremy's family.

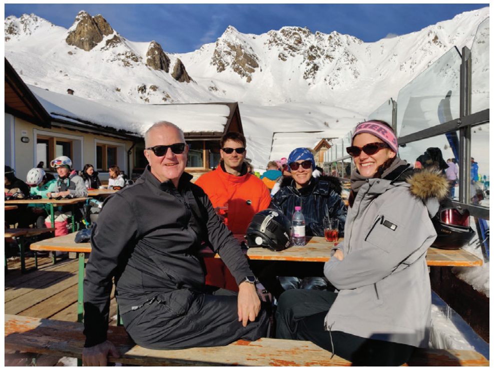
Adrienne Unsworth


Sue & Jeremy on holiday in Nice

Surviving Against the Odds: My Cardiac Arrest Story

By [Christopher Graham]

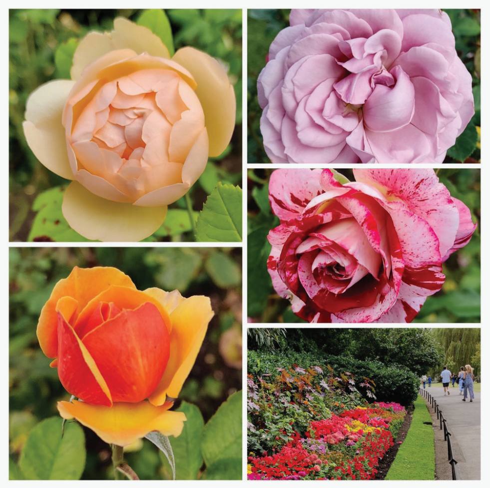
As a husband to Sharon and father to two wonderful children, George and Francesca, my life was full of love and purpose. I was relatively fit as a regular cyclist, but on the 2nd of September 2016, everything changed when I lost consciousness briefly at home. Doctors in A&E found no immediate issue and advised me to follow up with my GP, who booked an appointment with a cardiologist seven weeks later.



However, I didn't get the chance to wait that long. On the 10th of October 2016, I suffered a sudden cardiac arrest while at school, where I worked as a secondary school computing and ICT teacher. Fortunately, two colleagues Paul & Steve — who had only recently been trained in CPR and defibrillator use—reacted quickly and saved my life. I was incredibly lucky to survive an out-of-hospital cardiac arrest.

I regained consciousness about five hours later, surrounded by my family—a moment of immense relief and gratitude. For a couple of hours, I experienced temporary blindness, something I later learned can happen after being defibrillated. Before leaving the hospital, I was fitted with an implantable cardioverter defibrillator (ICD) to monitor and correct any future lifethreatening arrhythmias.

Determined to regain my strength, I embraced an active lifestyle. I took up photography while walking and even managed short 10-mile bike photographic efforts in 'Regents Park Rose Garden' during a visit to see our children.



Life seemed to be getting back on track until April 2018, when I experienced an electrical storm—multiple lifethreatening arrhythmias. My ICD saved me twice at home by delivering appropriate shocks, one at about 3am. in the morning I was telling my wife that I thought I'd been shocked during the night when it happened again! Passing out and regaining consciousness with Sharon's face inches from mine.

I was admitted to the hospital and initially stabilized, but just as I was about to be discharged, the electrical storm returned with a vengeance. Over the next two days, my ICD delivered over 80 shocks, 15 of which I was conscious for—an extremely distressing experience. I was then transferred to Wythenshawe Hospital, where an emergency ablation was performed to calm my heart.

Thankfully, over the next year, my condition stabilized.

Realizing that returning to full-time teaching would be too challenging, I decided to retire and focus on a healthier, more balanced lifestyle. Instead of cycling, I took up golf, which allowed me to stay active without overexerting myself.

Now, nearly seven years on, I am grateful for every moment. I stay active by playing golf, walking, cycling, skiing, and even doing a bit of gardening. I carefully monitor my exertion levels, following the invaluable advice of my brilliant consultant—the same man who performed my life-saving ablation in 2018.

Defibrillators and the quick actions of trained individuals saved my life not just once, but multiple times. My story is a testament to the importance of public access defibrillators, CPR training, and the incredible advancements in cardiac care. Life after a cardiac arrest is possible, and with the right support, it can still be full, active, and rewarding.

My journey so far with Hypertrophic Obstructive Cardiomyopathy (HOCM)

John Dainton

My journey with hypertrophic obstructive cardiomyopathy started in the “noughties” (2000s).

My wife Josephine (now deceased) encouraged me to sign up for the British Heart Foundation’s research project BioBank. Periodically I reported to wherever BioBank had set themselves up and blood, urine and other samples were taken for “path-lab” evaluation.

For a little less than 10 years I never heard anything back, rather I just went to the next examination. Each time the tests and procedures grew in scope to include cognisance and recognition aspects as well as eventually in the mid-2010s also imaging using all scanning technologies, except if I remember right - PET.

After the afternoon at which I underwent the scans (I was 7th to do so in the whole of the UK BioBank project) I received a letter from BioBank saying that they had spotted something of significance, and so, as stated when we signed up for the scanning, they were informing my GP.

I no longer remember the chain of events which then led me to become a patient of the then Dr, now Professor, Simon Williams! As time has passed since then I have realised more and more how lucky I had been. Not only is Professor Williams so evidently medically skilled, but also, he has a way of engaging with me in a way that makes me realise I must follow his guidance. This is remarkable because I too am a professor, but of physics and not of medicine, and it is well known in universities that finding a pair of professors who will agree is extremely rare!

So as times passed things developed, including an experience of a puzzling nature when I found myself with disorienting weird symptoms (no more than that) after I had been rearranging large, and therefore heavy, flowerpots on the balcony of our lounge for my (by then) new wife Dorothy. I didn’t understand the symptoms and I didn’t worry about them, but nevertheless bothered Professor Williams with an email description of them. I explained exactly what I was doing at the time. He quickly arranged a consultation at which I was amazed to find that he already had a proposed list of medications before I had said more than “good afternoon”. So, from then I started on a beta blocker and blood pressure suppressor taken daily with also the customary statin.

Then a year or two after with no further weird symptoms along came Covid and so the careful monitoring which any drug regime requires regularly to be completed got a bit lost (I don’t remember exactly when and so on in that I just continued taking the pills throughout Covid and making sure with Dorothy that we kept ourselves isolated from our fellow humans, something that a boring, grumpy, old physics professor doesn’t find too difficult to do!)

But throughout Covid more and more I wondered if the symptoms which I did experience, namely a lack of zest, even ability to walk as fast as I used to do were due more to the medication rather than to the diagnosed cardiomyopathy. I am still puzzled by this, and now even more so after I yielded to the persuasion of Dorothy and Prof Wiliams that I should indeed take up the offer to have an implanted defibrillator.

So, on August 8th, 2024, under local anaesthetic in went one ICD and leads during which, apart from a few stabbing pains that went as quickly as they came, the biggest discomfort was a persistent itch adjacent to my right eye alleviated by an excellent theatre nurse!

At home there then followed immediately my finding the DVLA website, completing the questionnaire concerning my ICD, and no reply for four weeks (while I didn’t drive) despite the DVLA promise in an email on August 10th that there would be a reply “soon”.

Just as the fourth week passed by since my insertion of my ICD, I wondered what I should do. When in doubt, ask a professor, so I emailed Prof Williams who admitted that he had an expert Adrienne to whom he had passed on my request concerning whether I could now drive in the absence of a notification from DVLA. After email and a phone conversation, Adrienne confirmed to me that I could drive! Admittedly between the email and the phone chat a letter from the DVLA dated August 20th did also arrive on about September 10th in which, because my ICD was said to be “prophylactic”, it was also said that I can now drive. But now do I also have perhaps evidence that Adrienne’s powers of persuasion extend to fixing the vagaries of even the Post Office?

So, I still would like to resolve what state of health I’m in, whether my medication should be optimised given now the presence of my ICD, and how to learn about others’ experiences with an ICD. Adrienne suggests the answer which I enthusiastically embrace, namely meet with other defibbers and learn with and from them! My only hesitation is that my story so far is rather insignificant and unimpressive compared with what I ‘ve already read in Defibber News. But that doesn’t make me any less enthusiastic to wear my ICD with pride amongst so many other eminent and impressive defibbers.

Adrienne’s response

Thanks so much for writing your story, John! Every patient with a device implanted is important. But just because you have had your device implanted as a planned procedure, doesn’t mean your story isn’t as important!

Many of our patients will have had their device implanted, knowing they needed it, have had a discussion with their doctor or Specialist Nurse in clinic beforehand, and been given the information booklet. We hope these patients are well prepared for their procedure when they are admitted. There are significantly fewer devices implanted as an emergency than as planned procedures.

In my experience, most patients need some amount of information and support when they get their device implanted, but it appears that those who have sudden Out Of Hospital (OOH) cardiac arrest need more support than others.

Our team is here for you all. I promise you though, I have no special powers of persuasion over the postal service but it’s nice you think I do!

Stay regular

Adrienne

The experiences of people like Christopher and John, whose stories are highlighted in this Defibber News are invaluable. Whilst each is an individual event or series of events, they are not in isolation from other patient’s stories who have gone through similar circumstances, trauma and emotion. Each story has its own impact on the patient, family and friends, but equally, on other patients too who learn from those experiences, helping them to deal with their own circumstances.
If you feel like sharing your experiences please don’t hesitate and send it to:
georgedavies48@sky.com or post it to 103
Redearth Road, Darwen, Lancashire BB3 2AR

Wythenshawe Hospital ICD Support Group Website

Have you had a look at the Support Group's Website?
The website can be accessed via
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)

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 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)

Contact details for all Patients:
If you have any concerns, please contact the:
Cardiac Physiologists on
0161 291 4615
CRM Nurse team on:
0161 291 5998 / 5443 / 5076