World Heart Rhythm Week
4th-10th June 2018: Take Fainting to Heart

Award Winners at Heart Rhythm Congress
Kathryn’s story
Heart devices
Beta Blockers and your lungs
Graham’s story
Fundraising
For World Heart Rhythm Week 2018, our focus is to ‘Take Fainting to Heart’, and we will be again joining with sister charities (STARS and AF Association) to increase detection of arrhythmias around the world. It is a significant year for ‘big sister’ STARS (Syncope Trust And Reflex anoxic Seizures) as it celebrates its 25th Anniversary.

There is no such thing as a simple faint, and with 50% of individuals experiencing a faint in their lifetime, we want to make sure that those caused by an arrhythmia are correctly diagnosed and treated.

In 2017, our aim was to ‘identify the undiagnosed person’, and for Arrhythmia Alliance World Heart Rhythm Week we exceeded our goals to:

- Make 1 million people pulse rhythm aware
- Take 10,000 pulse rhythm checks
- Identify 1,000 people with an irregular heart rhythm

Hold 100 ‘Know Your Pulse’ events

For more details about how to get involved with Arrhythmia Alliance World Heart Rhythm Week 2018, please check our website page www.heartrhythmalliance.org/aa/uk/heart-rhythm-week or call +44 (0)1789 867 501
Arrhythmia Alliance US staff are still diligently working to grow and expand throughout the United States. Being firmly established in Hilton Head, South Carolina, our goal was to expand in one additional state by the end of 2017. Our staff were able to exceed that objective by expanding into New Hampshire, West Virginia, Iowa and New York by securing partnerships within those states.

Our staff conducted over 70 awareness events reaching approximately 100,000 people through actual events and social media activities. Over 500 EKG readings were conducted and more than 1,000 pulse checks were additionally completed. During AF Association Global AF Aware Week, four events were held locally over five days and with more than 100 resource packets distributed and 100 EKG readings and more than 200 pulse checks. Our social media (Facebook) reached more than 25,000 individuals during this week. Arrhythmia Alliance US also placed 46 AEDs (automated external defibrillator) in America in the year.

The single largest and most productive event was held in New York City (Times Square). During this, more than 36,000 people were reached in one day through our Know Your Pulse event. We found that approximately 24% of those tested had possible previously undiagnosed AF. We provided much needed guidance and resources to those in need and we continue to work with those people today. This single event assisted us in spreading the knowledge and understanding of arrhythmias (heart rhythm disorders) and atrial fibrillation.

2017 was the foundation to grow and expand even further in 2018 through our educational/patient advocacy, Know Your Pulse events and Defibs Save Lives. We will continue to strive to ensure the term arrhythmia becomes as well known as diseases such as cancer and HIV/AIDS by 2020.
The Bangles sang about a manic Monday – Here’s my manic week!

Monday brings a 7am start, catching the train into London, not without checking in with the UK-staff in the office, to recap from the weekend and touch base ahead of the coming week.

Upon arriving into London, I quickly scramble for the tube and make my way across London as I embark upon today’s activities, primarily involving Global AF Aware Week and a media day tour. The first interview commences at 11.05am and they run back to back throughout the day.

“I never say ‘no’ and rarely, if ever, stop. Phone calls are regularly carried out long past 5.30pm and into the evening. And when on the go whether that be travelling by road, rail or air, my time is always utilised with emails and telephone calls.”
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**Tuesday** is day two of Global AF-Aware Week and the media tour. 7.10am and 8.10am, two interviews with BBC Radio Oxford. From then on, back to back meetings in various locations around London up until 5pm, when it’s over to Westminster for the APPG-AF (All-Party Parliamentary Group on AF) meeting on AF awareness. Finishing at 6.30pm, a quick turnaround, and off to the next meeting at 7.30pm, still in London. Come 10pm it’s not quite bed time yet, not until I have spoken to the US-team to catch up on their activities and whereabouts.

**Wednesday**, and it’s another day in London, this time at St Barts Hospital, then in the afternoon, it’s over to Pancras Square to the Google Headquarters for a meeting with their team. At 4pm, Some of my staff and I meet to set up for the Patient Focus Group meeting on Thursday. Following this, another dinner meeting, and then a repeat of last night’s routine, catching up with the US team to find out how their Know Your Pulse event went at their local gymnasium in South Carolina.

**Thursday** begins at 8am with the Patient Focus meeting taking place, then come 12.30pm, it is time for me to attend a Parliamentary reception in Westminster; ‘Identifying the Undiagnosed Person with AF’ building on our Detect, Protect, Correct & Perfect campaign; as part of AF Association’s 10th Anniversary Celebration. This runs until 3pm, then quickly on to the next meeting with MP Mike Gapes, which was due to take place at 3.10pm.

Finally, it’s **Friday**, it’s back to London for more meetings and to support Global AF Aware Week. Friday evening, and the weekend is upon us. Another Know Your Pulse event on Saturday from 11am-2pm to attend. What a week!

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Hello! My name is Charlene and I joined Rachel and Jenni in the wonderful Patient Services team at the end of August.

I’m sure that I have spoken to lots of you already, but let me introduce myself if I haven’t yet. I joined this amazing charity through a love of what it stands for, and for the opportunity to be able to truly help people who need my help.

I’m the proud owner of Jasper the German Shepherd and Otis the cat, and enjoy spending my free time with friends, family and my lovely husband. Please do get in contact with us if we can help at all.

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New to the Team

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Helpline: +44 (0)1789 867501
Extended Continuous Ambulatory Monitoring
(A Longer-term Wearable Heart Monitor)

Currently, continuous ECG monitoring with a Holter monitor can record cardiac electrical activity for between 24 and 48 hours.

However, if a patient is experiencing only one or two episodes a week, it is a lottery whether one of these monitors would be suitable.

There is also the implant Cardiac Monitor (ICM) which is a small thin device that is fitted under the skin (as a day patient) to monitor heart rhythms if episodes are less frequent than every 30 days. These loop recorders can remain for up to three years.

What is the new extended continuous ambulatory monitoring?

Often arrhythmias (irregular heart rhythms) may occur occasionally, therefore, they may not be detected during a routine 12-lead ECG. A longer, continuous ECG may be required to capture the arrhythmia to enable your doctor to diagnose or confirm there is no irregularity.

This much-needed long-term wearable heart monitor allows a doctor to track and analyse your heart rhythm during normal activity. The monitor comes in the form of a small adhesive patch that you can wear on the upper left side of your body for up to two weeks, during which time the device will record and store data from your heartbeat and rhythm.

You can also highlight the points at which you experience symptoms by pressing a button on the patch to enable your doctor to see any correlations with your heart rhythm.

At the end of the prescribed period you can remove the patch, post it back in the box provided and a detailed report will be generated and sent to your doctor to identify whether you have an arrhythmia and to determine a diagnosis and appropriate treatment if needed.

Who is it designed for?

It would be beneficial for an individual whose symptoms are infrequent so the 24/48 hour monitor would not be appropriate. However, a monitor that spans up to two weeks is more likely to detect an episode. The device is unobtrusive and will provide all the necessary information with minimal disruption.

How is it fitted?

The patch is a one-time use monitor that can be applied by your GP/nurse. The skin is cleansed so the patch will stick effectively and remain in place for the prescribed period. Any symptom can be recorded by pressing a button on the patch and noting it in a booklet.

Will it affect my day to day activities?

This new form of monitor is designed for extended wear and to cause as little upset to an individual as possible. With no wires, you will be able to continue normal activities, including showering and exercise. You will only need to press a button to mark symptoms and mailing the patch upon completion.
Award Winners
at Heart Rhythm Congress 2017

Charles Lobban Volunteer of the Year award was awarded posthumously to Louise Power 1953-2017, one of the first ICD patients to receive this device. Louise was instrumental in setting up St George’s ICD patient support group. Despite her serious health problems, she wanted to give something back, so she became a BACAP accredited counsellor and was able to support other patients through her sensible and compassionate approach. Tragically, before we could present this award, Louise died through heart failure that was resistant to treatment. Sue Jones from St George’s Hospital who supported Louise as well as being a friend received the award.

Outstanding Individual who has contributed to Arrhythmia Services award was presented to Dr John Bourke, consultant cardiologist at Freeman Hospital, for his rich and varied contributions to cardiology and electrophysiology both nationally and internationally. As head of the EP department for ten years, he has overseen the expansion and use of new technologies in this very successful area.

Healthcare Pioneer Awards were of an exceptionally high standard this year with a very high pass rate meaning that they have been accepted into the next booklet. Topics included: “Don’t wait to anticoagulate”, “Smartphone technology” and “Patient centred care in atrial fibrillation”. Many of these innovative ideas were developed by enthusiastic teams who were eager to give their patients the best possible service.

Team of the Year award was awarded to the Whipps Cross day case AF ablation team for development of a model that provides a much-needed service to meet increasing demands of catheter ablation for atrial fibrillation.

To nominate a volunteer or your Healthcare Professional, please get in touch

Helpline: +44 (0)1789 867501
TAKE THE PULSE CHECK CHALLENGE

KNOW THE RHYTHM OF YOUR HEART – MANUAL OR MOBILE

It only takes 30 seconds – yet could save your life!

KNOW YOUR PULSE

Is your heart rhythm too fast, too slow, or jumping around (irregular)?
It could be an arrhythmia (a heart rhythm disorder)
Learn to take your pulse to monitor your heart rhythm

KNOW YOUR ECG

Monitor your heart rhythm with a mobile ECG device

It records your heart rhythm and confirms if normal, AF suspected or if you should discuss the results with your doctor

For more information contact:
info@heartrhythmalliance.org

Buy yours now for just £99 through Arrhythmia Alliance by calling 01789 867501
and a percentage of that sale will be donated to us
Patients Day 2017 proved to be a huge success! Thank you to all of our wonderful members, speakers and medical members for once again making the day so informative and interesting.

We have received some great feedback and comments in response to the day, particularly surrounding the interaction with the speakers, the opportunity to ask questions, and the support of the other patients. Here are some of your thoughts and favourite things about Patients Day.

‘The opportunity to ask questions in open discussions’

‘Expert Knowledge of the speakers’

‘The talks by patients were honest, non-clinical, and gave me a better idea of what to expect’

‘Professor Sutton and Dr Sheldon’s presentations’

‘Those who talked on the same level as the audience’

‘Discussions on CBT and mindfulness’

‘The topics of electrophysiology, ablation, exercise, and acute stress’

‘Some of the information about day to day living which came from the other attendees’
Patients Day 2018

Sunday 7 October 2018, Birmingham ICC

Arrhythmia Alliance Patients Day 2018 is already looking set to be an exciting and informative day!

We have listened to you, and the feedback that you have given us surrounding the topics that you would like covered.

Subjects that will be covered include CPVT, heart failure, cardiomyopathy and CBT, but full agendas with updates will appear in our monthly e-bulletins in the coming months.

Remember to register online early to avoid disappointment.
Email info@heartrhythmalliance.org or call 01789 867 501 to secure your place at the Arrhythmia Alliance Patients Day 2018.
On Saturday 30th September, I was fortunate to be invited to join the first ever CPVT (Catecholaminergic Polymorphic Ventricular Tachycardia) patient group. It was a condition I had never heard of so while we were waiting for patients to arrive I did a bit of googling. The information I found made interesting reading as some of the symptoms overlapped with so many other arrhythmias.

CPVT is a condition characterized by an abnormal heart rhythm (arrhythmia). As the heart rate increases in response to physical activity or emotional stress, it can trigger an abnormally fast and irregular heartbeat called ventricular tachycardia.

All the patients I met were so friendly even though the subject of CPVT was full of emotion, at times I found it so hard to control my tears as I listened to how CPVT impacted on their lives. I am full of admiration to all those who live with the condition and how even though CPVT is unpredictable and cruel they continue to make the best of life.

One lady had a real impact on me and her story will stay with me for the rest of my life. Her whole family has been affected and to this day she carries the guilt that she has given this condition to her family. It was after hearing this lady speak for the first time to the group, I decided Arrhythmia Alliance needed to do more for patients diagnosed with CPVT.

Once we were back at the office, plans were put in place to include CPVT in our agenda for Patients Day on Sunday 7th October 2018. We will be launching the first of many factsheets and booklets on CPVT very soon and we also hope to hold a patient meeting for all patients and family members who have been or are affected by CPVT.

If you are interested in attending this meeting please email Julie at info@hearrhythmalliance.org
Tilly: My name is Tilly and I was diagnosed with CPVT when I was six. I didn’t really understand the condition and the treatment required when I was that age, but as I got older (I am now 17) it has become easier to understand my limitations and how to live with CPVT. I cannot pretend it has always been easy and the medicine (particularly the beta blockers) can make me tired and grumpy, which is not much fun for me or anyone else. But these are just side effects - I am able to do most things despite having CPVT and I do not let it interfere with having fun. It is also amazing how much the understanding and treatment of CPVT has improved. I have an ICD fitted which automatically sends heart readings to my hospital and recent trials have found a new treatment which could reduce my beta blockers. That would be the best Christmas present I could have.

Pat and Andrea: We are mother and daughter and both have CPVT. When we were first diagnosed we felt that our lives could never be the same again and it was all we could think about, however now 6 years on we rarely think about it. It is always at the back of our minds as we take beta blockers daily but we are very positive people and do not let it stop us doing anything.
Be a Member of Your Own Healthcare Team

The Watch BP is a device recommended by NICE to be used to routinely monitor your blood pressure at home. This way you can know for certain when you are in AF and how it is affecting your blood pressure and vice versa. Find potential triggers for your high or low blood pressure (BP), and share the results with your doctor to ensure your condition is being managed effectively.

Watch BP Home S

- Screening for Atrial fibrillation (AFIB) at home is recommended by leading medical societies
- The WatchBP Home S can detect risk factors such as high blood pressure and the presence of AFIB with high accuracy and reminds patients to contact their physician with an animated alert.
- Going-to-doctor symbol: reminds the user to visit the doctor.
- Easy-to-read: large screen displays and easy-to-read numbers.
- Lightweight and compact for convenient storage.

Save on RRP – Now only £45

Watch BP Home A

- Screening for AFIB with high accuracy (at 97%–100% sensitivity and 89% specificity) while measuring blood pressure. Easy and convenient to use
- Embedded ESH/AHA measurement guidelines lead to accurate home measurement data physicians can trust
- Automated data tabulation displays averages for morning, evening and overall measurement
- Detects Atrial Fibrillation (AF) and it is also validated for use in pregnancy pre-eclampsia
- Supplied with a Medium (22 - 32cm) size cuff but other cuffs available to purchase separately in Small (17 - 22cm) and Large (32 - 42cm) size from the manufacturer.

Save on RRP – Now only £75

Order from our online shop at www.heartrhythmalliance.org or by calling us on 01789 867501
Turn to page 28 for your chance to win a Watch BP Home S
Heart Devices
– Saving Lives and Preventing Infection

Over two million people are alive today because of cardiac implantable electronic devices (CIEDs), also referred to as heart devices. These include pacemakers, implantable cardioverter defibrillators (ICD) and cardiac resynchronisation therapy (CRT). These devices are specifically designed to help keep your heart functioning normally.

A pacemaker is a small device that is placed in the chest to help control abnormal heart rhythms (arrhythmias). It uses a battery and electronic circuits connected to the heart by one or more wires (leads) to prompt the heart to beat at a normal rate. These leads are passed along a blood vessel to your heart and the pacemaker box is usually implanted under the skin in your upper chest. The pacemaker can monitor your heart and produce electrical impulses to treat abnormal heart rhythms.

An ICD is a device that monitors the heart rhythm continuously. If the heart starts to beat dangerously fast the ICD is able to detect this and treat it, potentially saving the person’s life. There are two types of ICDs being implanted today; transvenous ICD systems (through the veins and into the heart) and the subcutaneous S-ICD, which does not touch the heart but sits just under the skin.

Cardiac Resynchronisation Therapy (CRT) devices are used to help treat heart failure, and can be either a permanent pacemaker, or an ICD. They work by making the lower heart chambers (ventricles) pump at the same time (synchronously) and improve the overall function of the heart so that you potentially feel less breathless and have more energy.

There is between a 1% and 7% chance that the device will become infected at the time of surgery. Preventative measures are taken to safeguard against infection, but extra precaution is advised for heart device surgery as this procedure carries a higher infection risk.

What are the consequences of a surgical site infection?
The surgical site infections can be difficult to control. Readmittance to hospital to treat the infection with possible additional surgery to replace the device may be necessary. In severe cases, surgical site infection can be life-threatening.

How is a heart device surgical site infection treated?
A heart device surgical site infection is usually treated by removing and replacing the device. A new device cannot be implanted until the infection is treated and eliminated. This means after the device is removed, the patient will be given antibiotics for up to six weeks.

New innovative technology – The antibacterial envelope
An antibacterial envelope has recently been introduced to hospitals that can help prevent these potentially serious surgical site infections.
Clinical studies have shown that patients at high risk of heart device infection who have been implanted with an antibacterial envelope develop 70% - 100% fewer infections than similar patients who are not given this protection.

The envelope is an antibacterial mesh sleeve that holds the device when implanted in the chest. It effectively stabilises the device and reduces the chance for movement or skin erosion. It is the only antibacterial device for heart device implants that is fully absorbable. This is important to surgeons if or when a heart device may need to be replaced.

What are the benefits of the envelope over current antibiotic protection?
There are specific types of bacteria responsible for over 70% of heart device infections, many of which are becoming resistant to commonly used antibiotics.

Clinical studies have demonstrated that patients who are given the additional protection of an antibacterial envelope have significantly fewer heart device infections.

For more information about pacemakers or other devices, please see our booklets Pacemaker Patient Information and CRT/ICD/S-ICD Patient Information.
To order either of these booklets, please complete the order form on page 31

Don’t Let This Be Your Last Newsletter!

Turn to page 17 to continue receiving updates from Arrhythmia Alliance.
Beta-blockers (β-blockers) are a group of medicines which are crucial in the management of cardiovascular conditions such as atrial fibrillation, heart failure, sudden cardiac death and preventing recurring heart attacks.

β-blockers work by preventing adrenaline from binding to beta receptors in your body. When β1 receptors are activated by adrenaline your heart beats faster and works harder. Blocking these β1 receptors slows down your heart rate and reduces the demand on your heart, which is essential in managing all the conditions mentioned above.

β2 receptors are found on the airways in your lungs. When these receptors are blocked they cause your airways to narrow making it more difficult to breathe which can trigger an asthma attack. As a consequence of this, traditionally β-blockers have been avoided with asthma. Likewise, many clinicians have historically avoided the use of β-blockers in Chronic Obstructive Pulmonary Disease (COPD) as a study showed they caused a reduction in lung function and some resistance to reliever therapy i.e. salbutamol.

Despite this, there is a wealth of evidence supporting the use of cardioselective β-blockers in all patients when there’s a clinical need. Cardioselective β-blockers such as bisoprolol, atenolol and metoprolol work predominantly on the heart. It must be noted that they are relatively selective and do exert some β2 receptor blockade but to a lesser extent than non-selective β-blockers such as propranolol. There is very strong, high quality evidence which demonstrates that β-blockers significantly reduce the long-term risk of death and sudden cardiac death following a heart attack. In atrial fibrillation they are the drug of choice for treating the symptoms associated with having a rapid heart rate.

They drastically reduce the risk of death, hospital admissions and disease progression in patients with heart failure. This is extremely important seeing as heart failure is one of the leading causes of death in people with COPD.

In fact, more recent evidence suggests when added to regular inhaled therapy, β-blockers (predominantly cardioselective) may reduce COPD exacerbations and increase survival rates regardless of the severity of airway disease even without cardiovascular disease.
“They drastically reduce the risk of death, hospital admissions and disease progression in patients with heart failure.”

Most importantly, these benefits were observed with no worsening of lung function which is currently the main reason why β-blockers are withheld in COPD.

Unlike COPD, asthma is a reversible condition, therefore people with asthma are more sensitive to the blockade of β2 receptors. Nonetheless, only a small percentage of people with asthma will respond negatively to β-blockers, thus the benefits associated with their use may still outweigh the risk. In view of this, only under specialist supervision will a person with asthma be trialled on a β-blocker to monitor their respiratory symptoms and ensure the therapy is safe. If the β-blocker is not tolerated it will be stopped as the risk will outweigh the benefits. If a β-blocker is deemed to be unsuitable for whatever reason, there are alternatives that can be explored such as calcium channel blockers.

Stay In Touch

We like to keep in touch about the vital work we do for those affected by arrhythmias.

Data Protection regulations are changing and from 25 May 2018, we cannot contact you unless you give us consent.

We NEVER share or sell your details with anyone else – we treat all communication as confidential.

We want to continue to provide information, education, resources and support so please contact us by calling 01789 867 501, or email us at info@hearthrhythmalliance.org to let us know you still want to hear from us - you are important to us.
A Short Story About a Long Journey

My adventure started in August 2012 with a routine health check that concluded in an ECG. I spent the afternoon looking forward to an early finish, and a nice bottle of red waiting for me and my wife at home.

During the ECG, the doctor went into a sudden burst of questioning around whether I thought I was having a heart attack. Despite his concern, there was no evidence on my part to indicate something to be alarmed about, so after I had assured him that I felt fine we agreed that a referral would resolve the matter and allow us both to finish for the day.

After seeing a cardiologist in London, I was referred to a highly respected electrophysiologist who dealt with heart rhythm disorders and an appointment was promptly arranged. At the appointment, we discussed how this condition had most likely been with me for most of my life so there was no need for panic, however a few tests would hopefully lead to a diagnosis.

The tests showed a possibility of Brugada Syndrome; a rare genetic condition that results in abnormal electrical activity within the heart, increasing the risk of sudden cardiac death. An MRI and a tilt table test could confirm this. Unfortunately, a few minutes into the tilt table test we received absolute confirmation of my condition when my heart stopped 6 feet in the air and the doctor had to climb on me to start CPR. Despite a worrying afternoon for those there that day, including my wife who was in the waiting room, the day finished with us knowing what was required.

“During the ECG, the doctor went into a sudden burst of questioning around whether I thought I was having a heart attack.”
“The tests showed a possibility of Brugada Syndrome; a rare genetic condition that results in abnormal electrical activity within the heart, increasing the risk of sudden cardiac death.”

With a clear diagnosis, I was scheduled for an operation the next day to have a Subcutaneous Implantable Cardioverter Defibrillator (S-ICD) fitted. However, when in theatre it was discovered that I would require a stent and due to the trauma already received, it was decided that we would complete the S-ICD implantation a few weeks later, which went without complication.

“I was scheduled for an operation the next day to have a Subcutaneous Implantable Cardioverter Defibrillator (S-ICD) fitted.”

I should mention here the moment you are told you need a metal box put into the side of your chest - it’s quite a moment to digest but ultimately you must take a leap of faith and trust the professionals around you and the box that is there to save your life. I decided on the first night after implantation to embrace the box of tricks that was going to jump in and kick my heart back to life should I need it.

Since the introduction of my new friend the S-ICD or Debbie the defibrillator, my life has been a positive one. I try not to allow my condition to affect what I do, in fact I do often show off about the fact I have a defib. It’s known for me to allow a new friend a feel of the lump on my side that houses my defib .... it’s my way of being positive about a subject that is very negative to so many people. My advice to people who face similar decisions and diagnosis is to be open to change that will ultimately protect them.

“It’s quite a moment to digest, but ultimately you must take a leap of faith and trust the professionals around you and the box that is there to save your life.”

It has been 5 years now and as I look back I remind myself how fortunate I was to be diagnosed with Brugada so early. In 2017 I was invited to speak at Arrhythmia Alliance patients day in Birmingham giving me the opportunity to share my story with other patients who are also extremely brave despite being faced with the unknown.

Graham, Essex

Helpline: +44 (0)1789 867501
After being diagnosed with SVT, Kathryn had a decision to make about what to do next – nothing, medication, or ablation…

I’d had episodes for a number of years and not really understood what they were. As I had experienced anxiety, they were put down to this.

My episodes were very irregular. I’d get palpitations, sweaty and dizzy. My heart rate has been from 150-175 bpm. On one occasion, I ended up staying in hospital overnight and then being off work for six weeks. On another occasion, I was going to go into hospital but the SVT stopped by itself, so I didn’t end up going in. It was the last two episodes within two weeks of each other that led to going into A&E, seeing a doctor on her cardiology rotation who recommended that I see my GP to be referred to an Electrophysiologist (or EP – a doctor who specialises in abnormal heart rhythms).

“I decided on the ablation with a high success rate – for me a 95% chance of stopping.”

I rang the Arrhythmia Alliance helpline and spoke to Jenni who encouraged me to make an appointment with the GP, and explain what the doctor had said; then she ‘strongly advised a referral to an Electrophysiologist’.

I then had a read of the medications and patient stories and looked up the ablation procedure on the Arrhythmia Alliance website.

I met with the EP and discussed what the options were: -

1) Do nothing
2) Take medication, with side-effects for the rest of your life
3) Have a catheter ablation operation, which due to me being young and healthy, had a high success rate of stopping the SVT

Doing nothing meant more trips to A&E, and medication meant feeling rubbish. So, I decided on the ablation with a high success rate - for me a 95% chance of stopping. It would take around 1-2 hours and would probably be in the late summer.

I had to be at the hospital early in the morning. I had bloods check and a cannula put in, and they asked about my medical history. It depends on how many people are on the list as to when you go down to the lab - there can be a lot of waiting around. There were a number of different people in the room including nurses, doctors, radiographer and electrophysiologist. I was sedated but still awake and pain free. I did have sensations of palpitations and a sweeping feeling in my chest when the wires were ablating the faulty bits.
“I did have sensations of palpitations and a sweeping feeling in my chest when the wires were ablating the faulty bits.”

When I went back to the ward, I could have sips of water. I had to lie flat for two hours - I understood why as the groin can start bleeding again. I had my BP, oxygen levels and groin checked regularly. You can have a cup of tea and food after four hours which was great and I enjoyed every mouthful. I did feel a little uncomfortable and sore in my groin. But it felt worth it to know that the SVT had stopped. The nurses will also give you paracetamol if you need it.

The doctor came to see me in the morning after I’d had an ECG, checked my groin and said I’d need to take aspirin for six weeks. I then had a visit from the cardiac electrophysiology nurse who explained that it was AVRT (atrioventricular re-entrant tachycardia); the common SVT. This means for me I had an extra slower pathway that was causing the palpitations. A little discomfort in the chest and back is usual.

“I’m writing this as I’m hoping to help anyone out there who’s worried about having the ablation or not sure about it. It’s actually not that bad, yes it might feel scary and it’s not nice. But the EP’s are specially trained and its pretty mind blowing what they do. You have a bit of discomfort and in most cases the result is no more SVT! (Written in Heart Rhythm Week).

Kathryn, Mid Wales

“Five days post-op and I’m still taking the paracetamol if needed and have been out driving, just locally around town. I’m really looking forward to getting back to work.”

I am now two days post op, I do get some sensations which are normal, and my groin is still a little sore, but paracetamol helps with this. Five days post-op and I’m still taking the paracetamol if needed and have been out driving, just locally around town. I’m really looking forward to getting back to work.
Fundraising Champions
Thank you to all our fundraising heroes for supporting and raising money for Arrhythmia Alliance!

Hedley:

Hedley ran the Virgin Money London Marathon for Arrhythmia Alliance this year raising a whopping £2892.67! Hedley felt that this year was his last chance to run a marathon as he turned 50 a little while after. He ran in memory of his friend and colleague Jenny, who passed away unexpectedly from an arrhythmia, so the charity is close to his heart. Hedley says “It took me a little over five hours but I ran the whole course non-stop! Thank you for giving me the opportunity to run the marathon and represent you thereby giving me a way to mark my friend’s passing with something positive. The sun shone (but not too much!), the crowds and bands were uplifting and I had my partner, children, mum and brother out en route to cheer me on!”

Elizabeth:

Elizabeth ran the Lancaster marathon for Arrhythmia Alliance in September 2017 in memory of her late mother, Pauline, who sadly passed away from an arrhythmia.

Elizabeth raised an incredible £572 for the charity! Thank you, Elizabeth! Elizabeth said:

“I decided to run the Lancaster marathon in her memory, because I thought that it would be something that would make her immensely proud of me”.

www.heartrhythmalliance.org • info@heartrhythmalliance.org
Luke:

Luke ran the Chester half marathon in May to raise money in support of his dad and his illness. He raised a fantastic £360! He then booked on to run the “Hell Runner – Hell up North” in October to raise even more! We are so grateful to Luke for all he is doing to not only raise funds for Arrhythmia Alliance, but also to raise awareness of the charity and what we do. Luke said, “I can’t bring my dad back but I will help his memory live on”.

Gareth:

Gareth set up a Just Giving page in memory of his father Dave, for the Defibs Save Lives campaign. He has almost raised an absolutely amazing £6000, which will pay for a defib in his father’s name. Gareth has said “what a loving, generous, happy and personable man he was; touching the lives of so many that he met.”

Simon:

Simon will be running the 2018 Virgin Money London Marathon on Sunday 22nd April for Arrhythmia Alliance. Simon suffers from atrial fibrillation, but he doesn’t let that stop him! Simon says, “I am very motivated and committed to demonstrating that with appropriate treatment and a positive frame of mind, AF is no impediment to a healthy active lifestyle.”

Fundraising Packs

If you let us know that you’re planning to fundraise for Arrhythmia Alliance, we will provide as much support as possible, including sending you a fab pack of resources to share with your donors; a t-shirt, balloons and a sponsor form. If you’re planning an event and haven’t let us know, please do so! Email info@heartrhythmalliance.org.

Ways to fundraise

Regardless of your age or abilities, there are so many ways in which you can raise money for Arrhythmia Alliance: Tea parties, marathons, treks and skydiving are just some of the favourite methods!
Sudden cardiac arrest can strike anyone at any time, regardless of age or fitness. It strikes without warning, killing 100,000 Brits every year. Sudden cardiac arrest requires immediate treatment to keep blood pumping and to restart the heart to prevent brain damage and death.

An AED (automated external defibrillator) is an emergency life-saving device that can be used by anyone to help restart the heart when sudden cardiac arrest strikes. AEDs do not require any training and can be used by anyone to shock a person’s heart back into normal rhythm if they suffer a sudden cardiac arrest (SCA). They increase the chance of the individual surviving from 9% to 50% when compared with the use of CPR alone.

The chances of survival of a person in SCA decreases by 10% for every minute untreated. Survival from SCA without immediate CPR (cardiopulmonary resuscitation) and prompt defibrillation is less than 5%; administration of high quality CPR can increase survival to 9%, but when combined with timely defibrillation, survival from SCA with a shockable rhythm, can reach in excess of 50%.

**Time is the most critical factor in determining if someone will survive SCA:**

- Time for someone to start CPR
- Time for defibrillation to be administered by use of an automated external defibrillator (AED)
- Time to ROSC (return of a pulse and spontaneous circulation) and rapid administration of advanced lifesaving skills
- Time to get the resuscitated victim to an appropriate cardiac centre for treatment
All of these elements form part of the ‘Chain of Survival’ which a person must be taken through successfully in order to survive SCA and leave hospital alive and neurologically intact. Effective implementation of each step of the Chain of Survival has been proven to dramatically increase survival from SCA.

Our ‘Defibs Saves Lives’ campaign was set up to place AEDs in towns, communities, schools and sports clubs. We offer a great range of fundraising support and information including; training resources, media support and press releases, materials for fundraising and raising awareness, all of which can be tailored to your community. In addition, we link your device with your local Ambulance Service and register it with the national database, so that it can be identified and used by anyone in an emergency.

“Today across the UK, up to 250 people will be struck down by sudden cardiac arrest and less than 20 will survive - in many other places across the world MORE THAN 100 of these people would survive and continue to live their lives.”

- Trudie Lobban MBE, Founder & Trustee, Arrhythmia Alliance
Defibrillators Are For People Of All Ages!

Lilly-May Page

Lilly-May was 5 years old when she suddenly collapsed and tragically died when being collected by her mum and nan at school on 15th May 2014. Lilly-May suffered a sudden cardiac arrest.

Her Mum Claire firmly believes that if an AED (automated external defibrillator) had been available, she may have survived. Claire is now determined to ensure that these lifesaving AEDs are made available in schools around the country, starting with her home town in Berkshire.

To date, more than twenty schools have received life-saving AEDs through the Arrhythmia Alliance - Lilly-May Page Campaign, and with your help we know this will multiply.

So, you’ve decided to fundraise for an AED in your community, but first you need to decide where you plan to place your AED and how many are needed.

Defibs Save Lives aims to ensure that all AEDs are available in public places so that life-saving equipment is available to anyone, whatever the time of day. AEDs should ideally be housed in secure, weatherproof, heated cabinets on the exterior walls of buildings such as post offices, village halls, sports centres and other visible places in the community.

Arrhythmia Alliance provides fundraising support, in addition to information, advice and guidance to help make communities across the UK safer in the event of sudden cardiac arrest.

Anybody, anywhere, could do fundraising for an AED. While some people love doing challenges such as running marathons or skydiving, there are many other ideas for events. Coffee mornings, golf days, quiz nights, bake sales and book swaps are all great ideas for community fundraising too!

For more information about placing an AED in your community, please visit defibssavelives.org, or contact us on 01789 867501 or email info@heartrhythmalliance.org

Arrhythmia Alliance works to support the placement of lifesaving automated external defibrillators (AEDs) in the community. Our current campaign, Defibs Save Lives is one that everybody can join in to make their community HeartSafe. AEDs can be critical in increasing cardiac-arrest survival rates. 80% of deaths from sudden cardiac arrest could be avoided with the use of AEDs and CPR.

www.heartrhythmalliance.org • info@heartrhythmalliance.org
Arrhythmia Alliance relies on donations to enable us to maintain our helpline, resources and support services to patients and carers.

**Ways to Donate**

- **Gift Aid**
- **Form**

**The Importance of Gift Aid** If you are a UK tax payer, declaring Gift Aid allows us to reclaim 25% of your donation from HMRC at no extra cost to you. We can claim Gift Aid on all donations, but sadly we cannot claim it on any purchases you make through us.

£5 will help to inform a family about a new diagnosis

£10 will help provide personalised support via our helpline

£25 will enable us to continue to develop our library of resources

**Post:** You can send a cheque payable to Arrhythmia Alliance to Unit 6B Essex House, Cromwell Business Park, Chipping Norton, OX7 5SR

**Phone:** To make a one-off donation over the phone, please call us on 01789 867501

**Payroll:** Give as you earn, tax-free, straight from your Payroll. Email to find out more info@hearthrhythmalliance.org

**Online:** To donate online, please visit our JustGiving page: [https://www.justgiving.com/arrhythmia](https://www.justgiving.com/arrhythmia)

**GIFT AID FORM**

Name: ..........................................................................................................................................

Address: ......................................................................................................................................

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☐ *I want to Gift Aid my donation of £____________ and any donation I make in future or have made in the past 4 years to Arrhythmia Alliance

*I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. Please notify us if you want to cancel this declaration, change your name or home address or no longer pay sufficient tax on your income and/or capital gains. Your address is needed to identify you as a current taxpayer.

**Helpline:** +44 (0)1789 867501
Win a Watch BP Home S Blood Pressure Monitor

All but one of these answers can be found in the grid – complete the form and tell us which one is not there. Entries cost £5

1. An irregular heart rhythm, is called an ... (10)
2. A ... is a small device that is placed in the chest to help control abnormal heart rhythms (9)
3. An ... is a procedure which destroys the heart tissue by freezing or burning (8)
4. A ... is a doctor who has specialised in the diagnosis and treatment of patients with a heart condition (12)
5. ... means a fast heart rate (11)
6. ECG is an abbreviation of ... (17)
7. A ... is an emergency life-saving device that can be used by anyone to help restart the heart when sudden cardiac arrest (SCA) strikes (13)
8. The ... of your heart is the number of times it beats per minute (4)
9. It is important that everybody must ‘know your ...’ (5)
10. The normal adult heart beats in a regular pattern 60-100 times a minute; this is called sinus ... (6)
11. An ... beat is an extra beat arising from the atria or ventricles (7)

Prize Draw Terms and Conditions:
• Entry for Arrhythmia Alliance 2018 wordsearch is £5 per entry.
• The closing date for the Arrhythmia Alliance 2018 wordsearch prize draw is Monday 14th May 2018
• Please return entry form together with £5 payment to Arrhythmia Alliance, Unit 6B Essex House, Cromwell Business Park, Chipping Norton, OX7 5SR
• Arrhythmia Alliance accepts no liability for any incorrectly addressed, undelivered or late entries. Any monies received after the closing date will be treated as a donation.
• The prize draw will take place on Friday 18th May 2018 at the Arrhythmia Alliance office, Chipping Norton.
• The winner will be randomly selected from all correct entries received by the closing date. Winner may be asked to provide a photograph for future promotions.
• Winner will be contacted on the draw date by phone, and will subsequently be announced on our website and social media.

Gambling Support - GamCare provides support, information and advice to anyone suffering through a gambling problem. If you are worried about your gambling, or that of someone you know, please contact GamCare on 0800 8020 133 or visit www.gamcare.org.uk.
Win a Watch BP Home S Blood Pressure Monitor

E I A M N M R T Y L X D R F L C Y S T F
R S R I D T M O L R A J H K O B C G A R
A T D L C W R D C H I N Y V E H O B L I
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N A L M I N L T G C P E S L U P L E A I
A E M V R A T E T J H M T O A F A J V M
R P T E A R H F E M E C T O P I C R B L

Name: ........................................................................................................................................
Address: ....................................................................................................................................
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☐ I enclose £5 cash/cheque entry fee
Telephone No: ..................................................

Answer:

Helpline: +44 (0)1789 867501
New Publications

We have recently published two new information booklets; ‘Identifying the undiagnosed person’ and ‘Which ECG is right for you?’. If you would like to order a copy of either booklet, please do let us know by emailing info@heartrhythmalliance.org or call us on 01789 867 501.

Social Media

You can also connect with us and other patients through various forms of social media. For instant updates and extra information, follow us on Facebook at facebook.com/ArrhythmiaAlliance, Health Unlocked at healthunlocked.com/heartrhythmcharity and Twitter @KnowYourPulse

Support Groups

For more information about arrhythmia support groups in your local area, please look on our website www.heartrhythmalliance.org or call us on 01789 867501.
Do You Have All Of Our Up To Date Resources?

Overleaf you will see a list of all our publications. If you find that you are missing any, or would like to ensure that you have the most up to date copies, please either complete the form below, call us on 01789 867501 or email info@heartrhythmalliance.org

Resource order form

Name:..............................................................................................................................................

Address:...........................................................................................................................................

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Resources I would like:..........................................................................................................................

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### Patient Resources

Leaflets, posters and promotional materials also available

To order please contact info@heartrhythmalliance.org or download from www.heartrhythmalliance.org

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#### Booklets

- Ablation for AF
- Accessing Appropriate Treatment Options
- AF and You
- Atrial Flutter
- Oral Anticoagulant Therapy
- Preventing AF-Related Stroke
- The Heart The Pulse and The ECG
- Atrial Fibrillation Patients Information
- Cardioversion of AF
- Drugs Information

#### Factsheets

- AF and heart failure
- AF-related stroke
- Amiodarone
- Anticoagulant Alert Card
- Anticoagulation and AF
- Anticoagulation and self-monitoring
- Apixaban
- AF and Aspirin: Frequently asked questions
- Atrial Fibrillation (AF)
- Atrial Flutter
- Being a NICE patient expert
- Beta blockers
- Cardioversion
- Cognitive behavioral therapy (CBT)
- Dabigatran
- Digoxin
- Dronedarone
- Ectopic Heartbeats
- Edoxaban
- Flecainide
- Heparin
- Miniature insertable cardiac monitor (ICM)
- Pacemaker and AV-Node Ablation
- Pill-In-The-Pocket cardioversion
- Rate Limiting Calcium Channel Blockers
- Rate versus Rhythm Management
- Rivaroxaban
- Transcatheter Closure of the Left Atrial Appendage
- Warfarin therapy
- Warfarin and diet
- Warfarin and other medication
- What is a Clinical Trial?
- What is a Consent Form?
- What does Randomisation mean?

#### Checklists

- AF
- Patient & Primary Care

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#### Booklets

- Bradydysrhythmia (Slow Heart Rhythm)
- Catheter Ablation for Cardiac Arrhythmia
- CRT / ICD / S-ICD
- Drug Treatment for Heart Rhythm Disorders (Arrhythmia)
- Electrophysiology Studies (EPS)
- Genetic Testing for Inherited Heart Conditions
- Identifying the undiagnosed person
- Implantable Loop Recorder
- Long QT syndrome
- National Service Framework
- Pacemaker patient information
- Remote Monitoring
- Supraventricular Tachycardia (SVT)
- Tachycardia
- What can I do about sudden cardiac arrest?
- Guidelines to establishing a patient support group
- Which ECG is Right for You

#### Paediatric information

- Jack has RAS
- Jane’s ILR
- Bertie’s pacemaker
- How my heart works

#### Factsheets

- Brugada Syndrome
- ICD Summary for the Patient
- Inappropriate Sinus Tachycardia (IST)
- Know the difference make a difference
- Know Your Pulse Pull Out Card
- Know Your Pulse
- Miniature Insertable Cardiac Monitor (ICM)
- Travel Insurance
- Understanding your blood pressure
- Wolff-Parkinson-White Syndrome (WPW)

#### Checklists

- Palpitations
- Arrhythmia
- Your Heart in Your Hands

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#### Booklets

- Cognitive Behavioural Therapy for chronic health conditions
- Diagnostic tests for syncope
- Education information
- Frequently asked questions
- Living with low blood pressure
- Postural tachycardia syndrome
- Psychogenic blackouts
- Reflex anoxic seizures (RAS)
- Reflex syncope

#### Paediatric information

- Cognitive behavioural therapy (CBT)
- Syncope in older people: Common causes and advice
- Diagnostic tests for syncope
- Implantable loop recorder (ILR)
- Information for Anaesthetists, Dentists etc
- Inappropriate sinus tachycardia (IST)
- Long QT syndrome
- Midodrine
- Miniature insertable cardiac monitor (ICM) system
- NICE
- Pacemaker
- Postural tachycardia syndrome (PoTS)
- Reflex anoxic seizures (RAS)
- Reflex syncope (Vasovagal syncope)
- Syncope and falls in care homes: An introduction
- Syncope and diet: You are what you eat
- Syncope and diet: For teens
- Syncope causes falls in older people
- Syncope during pregnancy
- Syncope in care home residents
- Tilt table test

#### Factsheets

- Blackouts checklist