Arrhythmia Alliance
www.heartrhythmalliance.org

Becoming an Advocate

Empowering yourself and helping others

"Advocacy is speaking up for those who cannot speak for themselves"

www.heartrhythmalliance.org

Your voice as a patient is valuable and needed!

Individuals who have a cardiovascular disease diagnosis have so much valuable information to share with others.

As an experienced patient you understand the journey from symptoms, to diagnosis, to treatment. Sharing your story with others can be an important step in the process.

If you are a cardiovascular disease patient, you know that getting everything sorted out isn't necessarily straightforward. Many patients could benefit from your insights and your experience, so we invite you to become an advocate for others who may be struggling to get seen and have their condition detected, to be protected and finally have it corrected. We have built a program for you and together we can change the lives of others.

Questions like;

Did you get seen by a specialist in a timely manner?

How are you now?

Is your condition under control?

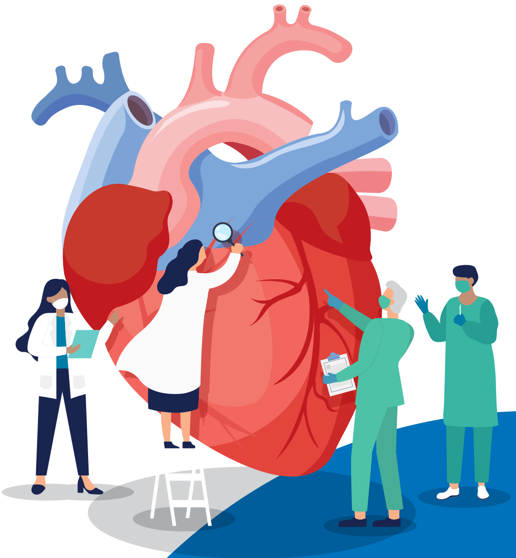
are best answered by someone who has been through it.

Why the work is so important

Cardiovascular disease (CVD) remains the lead cause of mortality for men and women globally. Around 620 million people are living with heart and circulatory diseases across the world. Many of these conditions require extensive healthcare visits, medications, and even surgeries. Even with all the technology available many people still struggle to get diagnosed, find proper treatment, and avoid complications of their condition. We have a lot of work to do to continue to improve the detection and treatment of CVD and the patient voice is an important part of that.

The patient voice is vital to not only other patients, but to healthcare professionals, industry partners, and decision-makers. Patients are the experts on living with their condition and their voice should be considered when making decisions of care.

We want to make sure that no person with CVD must live with pain or disability because they were not diagnosed early enough, did not receive the right treatment, or weren't given the support they needed to understand and manage their condition.



Our mission together is to

Detect; Protect; Correct!

Are you ready to join us?

Becoming an Advocate

This program is for everyone who has a passion for improving the lives of people living with CVD and wants to learn more about what you can do to improve the situation. Whether you are affected yourself, or are a family member, caregiver or healthcare professional, your voice can make a crucial difference.

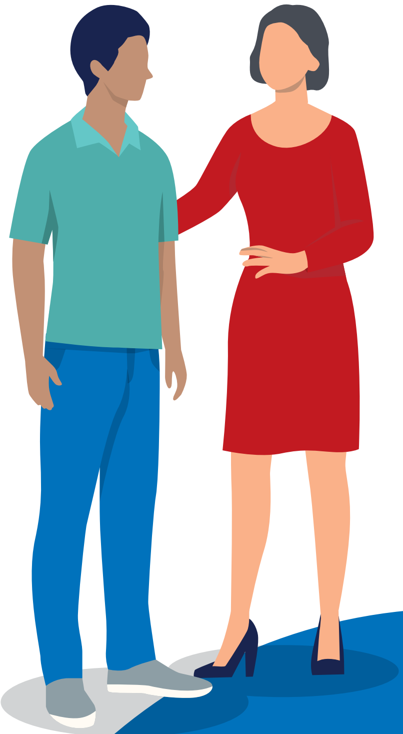
The program offers practical advice to equip you to fight for better care and treatment options for people living with cardiovascular disease – in other words, to get you started on becoming a heart advocate.

Your role as an advocate

Becoming an advocate is about standing up for people affected by CVD and perhaps engaging with health system leaders, wherever you may find them, to call for change. Your efforts would contribute to improving diagnosis, treatment, and quality of life for all those affected by CVD.

As an advocate, you can:

- **Tell your own story and give a voice to people with the same condition:** You can work to bring much needed attention to your condition. From the public to healthcare professionals, and policymakers, you can make sure the concerns and gaps in care of people living with cardiovascular disease are heard by those who have influence and make decisions about healthcare.
- **Empower other patients to advocate for themselves:** You can share your story and support others who are newly diagnosed, help them become educated, and empower them to advocate for themselves and others.
- **Make a real difference to the diagnosis and care of others:** You can let decision-makers know what improvements are needed and partner with them to make changes that improve the diagnosis, treatment, and quality of life for people living with CVD.
- **Collaborate for greater impact:** You can work with other advocates or organisations to increase your reach and effectiveness, helping to achieve goals that you may not be able to achieve on your own.



Our mission together is to ***Detect; Protect; Correct!***

Are you ready to join us?

How to get involved

Once you have decided that becoming an advocate is for you, Arrhythmia Alliance can help guide you through the process of taking on this role. Our toolkit will give you an overview of the responsibilities involved, as well as guidance on how to apply to become a fully trained advocate by Arrhythmia Alliance.

1. Prepare

Read through this introduction and think about your goals. This pack will help you decide what kind of advocate you would like to be.

2. Apply

If you want to help improve **Detection** of undiagnosed heart disease, ensuring patients receive much-needed **Protection** against, with eventual **Correction** of their underlying condition, please apply online using this link. You will find a form that guides you through a set of questions to help you identify if this role is really for you, and if you feel that you want to devote time to this important mission.

3. Train

Once accepted as an advocate, Arrhythmia Alliance will provide you with all the necessary training to speak with confidence about the issues affecting patients.

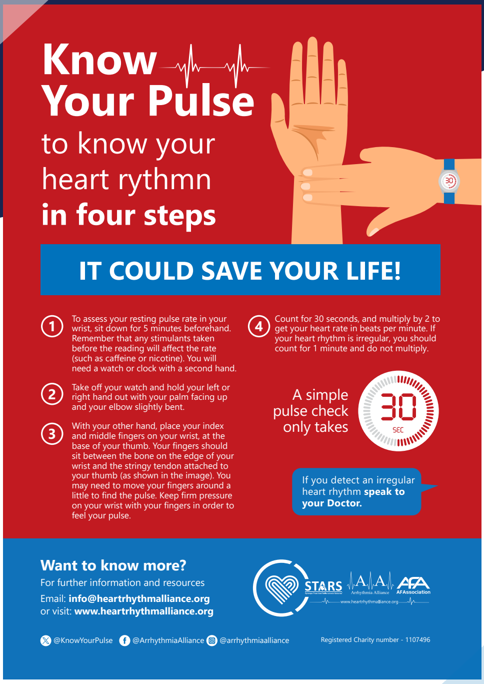
4. Define

Our training and toolkit are designed to help you define achievable goals in improving healthcare provision that matter in your local context, so you are better prepared to get started.

5. Achieve

Once trained, decided on a plan, and you have been provided with helpful resources from Arrhythmia Alliance, you are all set to achieve! Arrhythmia Alliance will support you at every step!

Steps you can take TODAY!



Know Your Pulse

to know your heart rythmn **in four steps**

IT COULD SAVE YOUR LIFE!

① To assess your resting pulse rate in your wrist, sit down for 5 minutes beforehand. Remember that any stimulants taken before the reading will affect the rate (such as caffeine or nicotine). You will need a watch or clock with a second hand.

② Take off your watch and hold your left or right hand out with your palm facing up and your elbow slightly bent.

③ With your other hand, place your index and middle fingers on your wrist, at the base of your thumb. Your fingers should sit between the bone on the edge of your wrist and the stringy tendon attached to your thumb (as shown in the image). You may need to move your fingers around a little to find the pulse. Keep firm pressure on your wrist with your fingers in order to feel your pulse.

④ Count for 30 seconds, and multiply by 2 to get your heart rate in beats per minute. If your heart rhythm is irregular, you should count for 1 minute and do not multiply.

A simple pulse check only takes 30 SEC

If you detect an irregular heart rhythm **speak to your Doctor.**

Want to know more?

For further information and resources

Email: **info@heartrhythmalliance.org**
or visit: **www.heartrhythmalliance.org**

www.heartrhythmalliance.org

@KnowYourPulse @ArrhythmiaAlliance @arrhythmiaalliance

Registered Charity number - 1107496

Raise Awareness!

Start by asking to place posters or pamphlets in your local healthcare provider's office. Share information about Know Your Pulse and other campaigns that Arrhythmia Alliance has to offer at your local gym or grocery bulletin board.

Write letters!

Writing a letter to your local hospital, healthcare professional, or local political representative (e.g. Member of Parliament 'MP'/European Parliament 'MEP') can be a fantastic way to raise awareness and ask for concrete actions that will improve care of CVD.

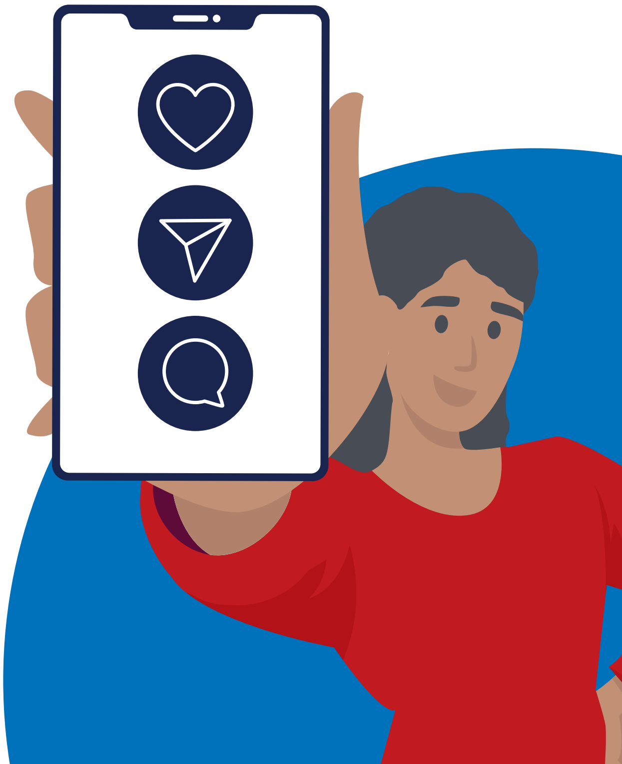
It is important to have a specific action in mind for the letter – otherwise, the individual is unlikely to know how to help the cause. There is a template letter in this toolkit which can be adapted for different circumstances.

Use social media!

Look at your list of key decision-makers and search for them on the major social networks. Once you have found out where your target audience is, you know where to direct your attention. Set up an account on the social network(s) you have identified as being most likely to reach your audience.

Building a following on social media takes time. The key thing is to do your research: look for organisations or individuals who are already advocating for CVD or related issues and follow them. Like, share and comment on their posts. The more you engage with others on social media, the more likely they are to engage with you and your content.

Follow relevant news and hashtags so that you can write timely posts and comments. Be sure to only share correct and factual information. Following and sharing from patient organisations or trusted officials/agencies is important.



AS AN ADVOCATE YOU WILL BE EMPOWERED TO:

Know the issue:
We will help you understand the current situation for CVD patients and the challenges they face

Clearly identify your problem:
You will understand the issue you want to combat, and what actions are required

Establish goals:
You will be able to clearly outline the goals you hope to achieve and the ways in which they may be realised

Learn best practices:
You will have the opportunity to learn from those working as advocates and how they have achieved change

Create a plan/campaign:
We will walk you through the process of outlining the sequence of activities required, who is involved, and where they will take place

Engage and meet with key stakeholders:
You will be able to identify leading representatives you wish to engage and organise to meet them

Use communication tools to strengthen your advocacy messages:
Coaching on how to make use of a variety of platforms to expand the reach of your communications

Track your success and share your stories:
You will be guided through monitoring and evaluating your progress, noting key lessons learnt

We welcome your interest in becoming an advocate and encourage you to consider applying for this volunteer role. Your involvement would make such a significant difference to so many.

For more information on our advocacy program or for further resources and additional links, please click here.

Arrhythmia Alliance Advocacy enquiries
a.baer@heartrhythmalliance.org

Arrhythmia Alliance General enquiries
+44 1789 867 501
info@heartrhythmalliance.org

Media enquiries
adminteam@heartrhythmalliance.org