



*The alliance of international heart patient organisations established to provide a voice for those living with, or affected by, cardiovascular disease.*

# Inaugural Report 2020 & 2021



## COMPANY INFORMATION

### Board of Directors:

Kevin O'Reilly, Chairman  
(Ireland)

Susan Campbell  
(USA)

Pat O'Donnell  
(Ireland)

Ellen Ross  
(Canada)

### Executive Director:

Neil Johnson

### Registered office: Ireland

*The Global Heart Hub is registered in Ireland as a company limited by guarantee and as a not-for-profit organisation.*

---

*Global Heart Hub is a member of:*



## CONTENTS

WELCOME	1
OUR GROWING COMMUNITY	3
HIGHLIGHTS IN NUMBERS (2020 - 2021)	5
RESPONSE TO THE PANDEMIC	9
HIGHLIGHTS FROM THE HEART VALVE DISEASE COUNCIL	15
HIGHLIGHTS FROM THE HEART FAILURE COUNCIL	21
FOCUS ON ASCVD	25
CAPABILITY BUILDING UPDATE - EDUCATION AND TRAINING	27
UPDATES ON WORKING GROUPS	29
AWARDS	29
EVENTS AND COLLABORATIONS	31
OUR FUNDERS	35
CONTACTING GLOBAL HEART HUB	37





## VISION.

Our vision is to create a **united, informed and empowered community** of patient organisations. Our mission is to create a global cardiovascular disease community that **supports and educates patients, caregivers and healthcare providers** to ensure the best possible outcomes for those living with heart diseases.

## AIMS.

One of the fundamental aims of the Global Heart Hub is to identify and **unite heart disease patient organisations across the world**. We do this by creating disease specific alliances (global patient councils), who work together in their disease area. Collectively, these patient councils share a common purpose in addressing the challenges of cardiovascular disease.

The primary objective of the Global Heart Hub is to **strengthen the patient voice** through patient organisation and individual advocate capacity and capability building.



# WELCOME

## We are delighted to present the inaugural report of the Global Heart Hub!

This organisation has its origins in the work of a small group of international patient organisations who came together as far back as 2014 to establish a community of patient organisations working in the area of heart failure. This initiative led to an alliance of over 25 international patient groups who began to raise awareness of the unmet needs of those living with heart failure and their carers. It quickly became apparent that similar unmet patient needs existed across all heart conditions and unlike in other disease areas, the heart patient community was disconnected and unorganised. Furthermore, heart patient groups which had largely formed as patient support groups were keen to develop their capacity and capability to engage in disease awareness and advocacy.

Accordingly, in 2019, the Global Heart Hub was launched as an umbrella organisation of international patient groups working in all areas of heart disease. Since then, over 70 patient organisations across almost 30 countries have affiliated to the Global Heart Hub. We are building our alliance through special interest working groups which then form patient councils focused on specific cardiac conditions or issues. Additionally, we are building a network of individual patient advocates and associate

organisations who are patient-centric and patient focused. The ultimate objective is a united and strong community, giving a voice to all those living with or affected by cardiovascular disease. We do this to support and empower patients and their caregivers to engage with their healthcare systems and healthcare providers as equal stakeholders. The role of patients in their own healthcare; in healthcare systems development; in medical education and research, and in medicines and medical technology development is changing rapidly. The power of the patient voice has become a catalyst for change across many disease areas and the Global Heart Hub aims to achieve the same in the area of heart disease.

**“The power of the patient voice has become a catalyst for change across many disease areas and the Global Heart Hub aims to achieve the same in the area of heart disease.”**

In this report you will see the highlights of our work over the past two years. We have begun building an international community of connected and engaged patients. We are committed to raising awareness of the many unmet patient needs across the patient journey from disease awareness, through detection, diagnosis, treatment and recovery. We are committed to supporting patients and patient organisations to build their capacity and capability to engage as equal stakeholders in healthcare decision making, healthcare policy and addressing healthcare inequalities in access to new and innovative treatments and technologies.

We take this opportunity to thank all those who are collaborating with us on this mission and in particular we acknowledge the support of our funding partners who share our common goal of reducing the burden and impact of heart disease and improving outcomes and quality of life of those living with cardiovascular disease.



**Kevin O'Reilly**  
*Chairman, Board of Directors*



**Neil Johnson**  
*Executive Director*



## OUR GROWING COMMUNITY

[GLOBALHEARTHUB.ORG/AFFILIATE-MAP](https://globalhearthub.org/affiliate-map)



## HIGHLIGHTS IN NUMBERS (2020 - 2021)

**70+** Patient Organisations are now affiliated with the Global Heart Hub



Connected with **29** countries worldwide

*Argentina, Australia, Austria, Belgium, Brazil, Canada, Cyprus, Egypt, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Japan, Latvia, Lebanon, Lithuania, Mexico, Netherlands, Poland, Portugal, Romania, Slovenia, Spain, Sweden, UK, USA*



## 2020 HIGHLIGHTS



### COVID-19 response campaign

Launched in partnership with FH Europe with the message: **If you are experiencing a heart or stroke emergency – this is NOT the time to ‘stay at home’ - When your heart says so, #JustGo**

**80 million +** opportunities to see the #JustGo campaign across print, TV, radio and digital channels

**Heart Valve Disease Awareness:**  
**47 million**

opportunities to see the Heart Valve Disease campaign across print, TV, radio and digital channels



**Heart Failure Awareness:**  
**4 million +**

opportunities to see the Heart Failure campaign across print, TV, radio and digital channels

## 2021 HIGHLIGHTS

### Phase 2 COVID-19 response campaign

March 2021 - expanded the message, encouraged heart patients to be proactive in seeking care and calling on healthcare providers and systems to prioritise the treatment of heart patients

**36 million +**

opportunities to see the campaign across print, TV, radio and digital channels

Awarded '**Best Digital Campaign 2021**' by the World Heart Federation!



### Inaugural Global Heart Hub Unite Summit



2-day online event, uniting and empowering the CVD community

**400+** delegates from across

51 countries with 96% of attendees reporting being inspired by the topics discussed

## 2021 HIGHLIGHTS

**Brand development** - revamped design to reflect our growth and development



### Growing media presence

**4,000 +**

followers across Facebook, Instagram, Twitter and LinkedIn



**17 million +**

opportunities to see Global Heart Hub content across social media platforms



**72 million +**

opportunities to see Global Heart Hub content across global, traditional media outlets



**150,000 +** page views on Global Heart Hub website

<http://>





## RESPONSE TO THE PANDEMIC

### 2020 Survey outlines the impact of COVID-19 on Heart Patients and Heart Patient Organisations

A survey conducted in April 2020 by the Global Heart Hub showed an increased demand for information and support from patients, their carers and the general public, but at the same time, patient organisations themselves were battling the effects of the pandemic.

The survey on the impact of COVID-19 on patient organisations across 19 countries reported that already almost half these groups had experienced a cut in their income and a third had to reduce their staff numbers. Interestingly, across some of the organisations who reported no change in income status were those who had already received their grant or sponsorship income for 2020, but their future income may be in jeopardy if the crisis continues.

In reporting on the increased demands on organisations, the 'stay at home' message across the world forced most organisations to provide information and support online or by telephone. Many organisations reported that one of the reasons for the increased outreach from patients, carers and members of the public was the difficulty experienced in accessing GPs and Pharmacists.

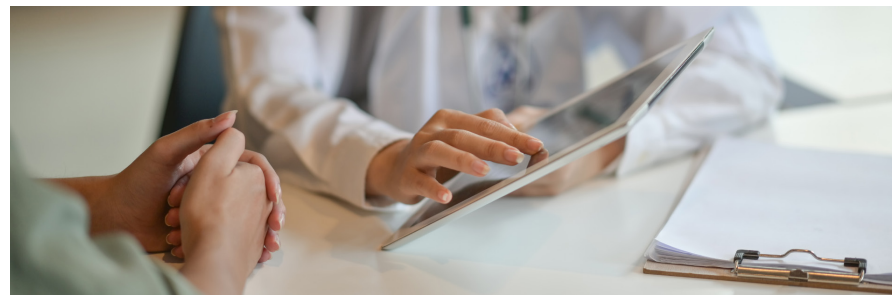
What is reassuring to note from the survey results was that patient

organisations were keeping themselves informed through reputable sources and the vast majority (81%) were in direct contact with clinical experts for advice and guidance.

The global survey reported that the top three greatest impacts of the pandemic on patients were:

- Heightened fear and anxiety from their vulnerability due to their underlying health issues.
- Concerns and fears as a result of cancelled or postponed appointments and procedures.
- Increased anxiety due to isolation and loneliness as a result of 'stay at home' or 'cocooning' policies.

As many of these individuals are older persons with already limited social interaction opportunities, the restrictions on movement coupled with the fear of contracting the virus were a cause of considerable anxiety with many commenting on their 'fear of the future'. Equally of great concern to those with heart conditions, was access and availability of COVID-19 testing. The vast majority of patient organisations (82%) across the world commented that individuals with heart conditions were not viewed as 'urgent' for COVID-19 testing.





## RESPONSE TO THE PANDEMIC

### Heart Patient Groups United in Call to #JustGo in Cardiac Emergencies

One of the unintended consequences of COVID-19 is that people suffering heart attacks and strokes delay seeking medical help, resulting in worse outcomes. Heart attack and stroke victims worldwide are avoiding hospitals, presenting too late to benefit from life-saving treatment. Also, individuals with known heart conditions experiencing new or worsening symptoms delay seeking medical attention due to fear of contracting COVID-19. Across the world, doctors are reporting that those who delay in seeking medical help are in a far worse condition when they finally arrive at hospital, often too late to benefit from the life-saving treatments that are normally available.

Global Heart Hub, in collaboration with FH Europe (the European patient network focused on Dyslipidaemia, including Familial Hypercholesterolemia) launched an international ‘patient-to-patient’ confidence building campaign in June 2020, aimed at saving lives and reducing disability by encouraging those with symptoms of a heart or stroke emergency to seek medical help without delay.

**The message was simple and clear – If you are experiencing the symptoms of a heart attack,**

**– Don’t delay – Every minute counts. If you have chest pain or other heart attack symptoms – such as pain in the throat, neck, back, stomach or shoulders that lasts for more than 15 minutes – you must call an ambulance.**

Equally, if you are living with a heart condition such as heart failure or heart valve disease and if you are experiencing new symptoms, or a worsening of symptoms, you should contact your doctor or go to a hospital as soon as possible.

The #JustGo Campaign reassured people across the world that the risk of coronavirus infection in hospital has been minimised for patients being admitted with heart attacks or strokes. The campaign reminded the public that the risk of dying from an untreated heart attack is 10 times higher than dying from COVID-19. If you are experiencing a heart or stroke emergency – this is NOT the time to ‘stay at home’ – **When your heart says so....Just Go! #JustGo**

*This initiative was endorsed by the European Society of Cardiology; the European Atherosclerosis Society; and the International Atherosclerosis Society; and was supported by the World Heart Federation; and the Global Alliance for Patient Access.*



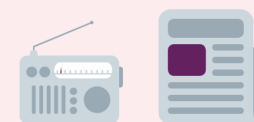
### #JustGo Campaign Highlights, June 15 - July 31

*An international collaboration between heart patient organisations aimed at saving lives and reducing disability by encouraging those with symptoms of heart or stroke emergency to seek medical help without delay.*

**WHEN YOUR HEART SAYS SO...**



**Over 80,000,000 opportunities to see the #JustGo message across print, TV, radio and digital channels**



**Press pick-up across 42 outlets - national TV, radio and print coverage**

**Translated across 14 languages**



**Endorsed by 30+ Clinical Societies and CVD organisations**

**Shared by 90+ influencers, follower total of 1,325,000+ users**

## RESPONSE TO THE PANDEMIC

### Global Heart Hub launched Phase 2 of its patient-led COVID Response Campaign as the pandemic continued across the world

The second phase of Global Heart Hub's COVID Response Patient-led Campaign launched on March 30, 2021. This campaign was an international collaboration between heart patient organisations aimed at saving lives and reducing disability.

The COVID-19 pandemic continues to disrupt the world and, in particular, our personal health care and health care systems. Many people are still slow to seek medical help when experiencing obvious cardiac symptoms. Many still remain fearful of going to their doctor or to hospital. Many are cancelling important medical appointments. These delays in seeking help and commencing treatments can be life-threatening. It's time to put heart health before the fear of COVID-19.

Following the success of the Just Go campaign in 2020, the Global Heart Hub created Phase 2 of this campaign to continue to raise awareness and drive action.

There were three aspects to the 2021 COVID Response Campaign:

#### Just Go

**If you are experiencing a heart or stroke emergency – this is NOT the time to 'stay at home' - When your heart says so, #JustGo.**

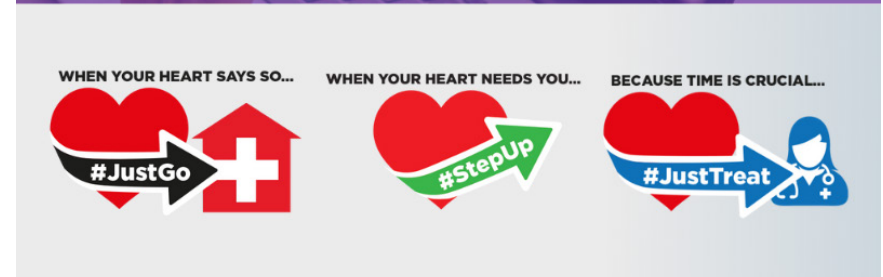
#### Step Up

**Own your heart health by recognising and tracking your symptoms, reaching out to your healthcare provider and following through with your treatment plan. When your heart needs you, #StepUp.**

#### Just Treat

**COVID-19 has upended the world, but it's time to tackle the burden of heart disease. Because time is crucial, #JustTreat.**

*This initiative was endorsed by the European Society of Cardiology; the European Atherosclerosis Society; and the International Atherosclerosis Society; and was supported by the World Heart Federation; and the Global Alliance for Patient Access.*



Shared by 95+ influencers, follower total of 744,000+ users



Translated across 14 languages



Shared across 24 countries



Media pick-up: 80+ features across 7 countries

YouTube campaign, 1,800,000+ impressions



## HIGHLIGHTS FROM THE HEART VALVE DISEASE COUNCIL

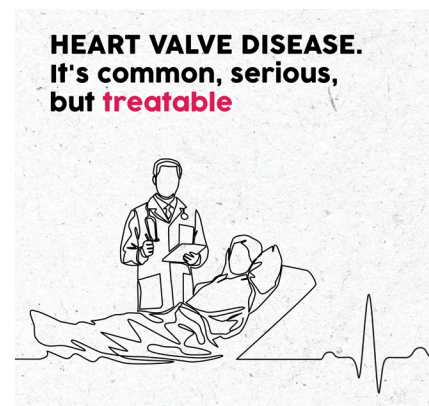
### 2020 Heart Valve Disease Awareness Week

Survey results published to mark Heart Valve Disease Awareness Week (September 14 - 20) showed that older Europeans are as unaware as ever of the risks of common, serious, but treatable heart valve disease. Data from the latest European Heart Health Survey show that only a quarter of older Europeans would visit their doctor for investigation of symptoms, including fatigue and reduced physical activity. In its most serious form, more than half of patients with severe heart valve disease die within two years of developing symptoms.

“The Survey demonstrates clearly that our older population is a key, yet underestimated, contributor to the effective functioning of our communities, families and economies, so improving the awareness, diagnosis and treatment of heart valve disease will benefit us all,” commented Wil Woan, Chair of the Heart Valve Disease Patient Council of the Global Heart Hub. “Our senior people selflessly confined themselves to protect the health of others during COVID-19; now it is time to repay them by ensuring that they receive the treatments that will transform their quality of life and lower their vulnerability to future pandemics and other significant infections.”

Many people living with heart valve disease do not experience severe or noticeable symptoms, or simply put their symptoms down to ageing, which makes diagnosis of the disease challenging. This new Survey worryingly revealed how only a low percentage of older Europeans would seek an appointment with their GP if they experienced key heart valve disease symptoms such as fatigue (26.2%), reduced physical activity (19.9%) and ‘feeling older than your age’ (12.5%). Such hesitancy could potentially be harmful, as it prevents early detection opportunities.

The 2020 campaign message was: **Listen to Your Heart. If you are over 65, ask your doctor for a stethoscope check at least once a year. Heart valve disease is common, serious, but treatable.**



Over 47,225,000 opportunities to see the Valve Week message across print, TV, radio and digital channels

Shared across 17 countries

Social media posts by 140+ influencers, follower total of 2,000,000+ users

## #ListenToYourHeart

Translated across 7 languages

**#HöraufdeinHerz**  
**#Ascoltailtuocuore**  
**#EcoutezVotreCoeur**  
**#あなたの心臓の声を聴こう**  
**#EscuchaATuCorazón**  
**#sigaseucoracao**

Press pick-up across 185 outlets - national TV, radio and print coverage

## Cherish life.

Heart Valve Disease Awareness week was led by members of the Heart Valve Disease Patient Council, including; AEPOVAC, Spain; Alliance du Cœur, France; Croí, the heart and stroke charity, Ireland; Cuore Italia, Italy; Heart Valve Voice, Canada; Heart Valve Voice, Japan; Heart Valve Voice, UK; Initiative Herzkloppe, Germany; Instituto Lado A Lado Pela Vida, Brazil; Meine Herzkloppe, Austria; PACO, Mexico; Street Doctor, Netherlands.



## HIGHLIGHTS FROM THE HEART VALVE DISEASE COUNCIL

### 2021 Heart Valve Disease Awareness Week

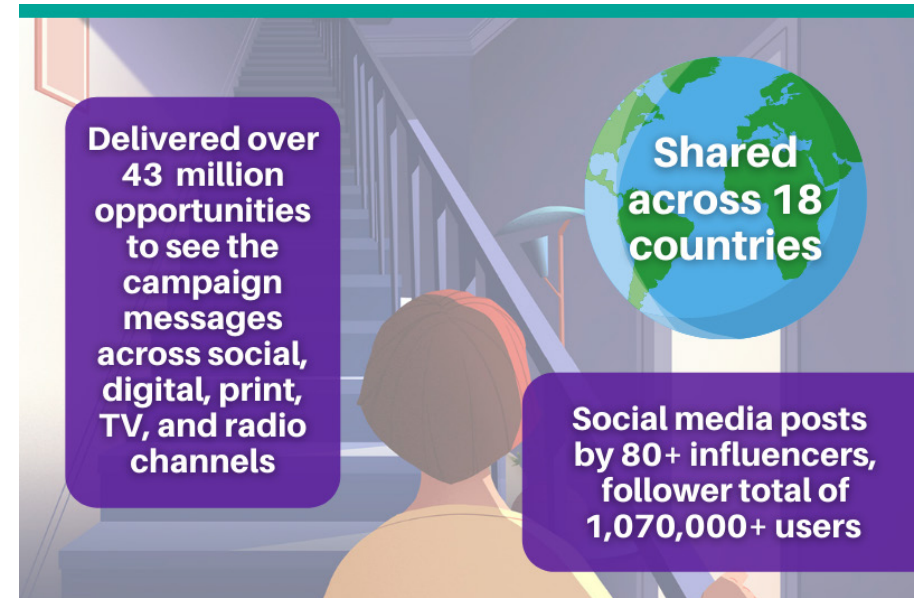
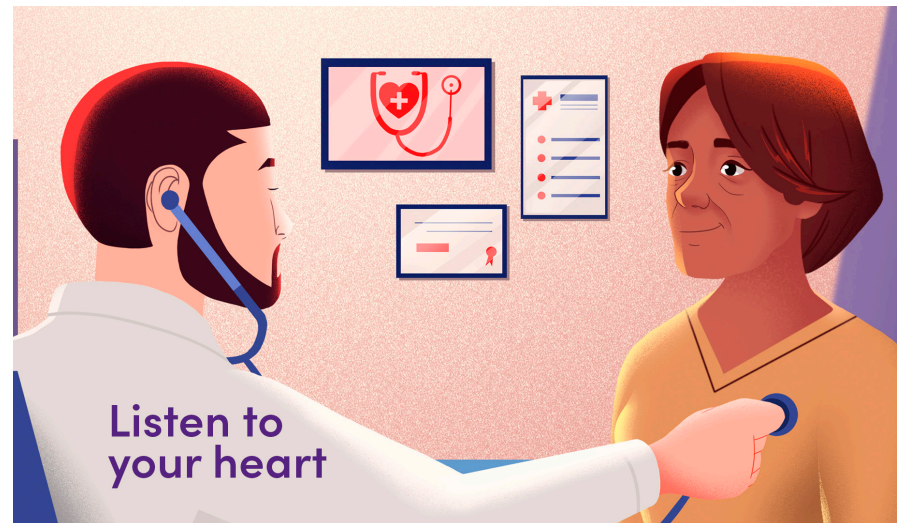
Global Heart Hub's 2021 Heart Valve Disease Awareness Week (13 - 19 September) aimed to improve diagnosis, treatment and management of heart valve disease globally.

People are living longer and senior people are crucial contributors to society and the economy. Untreated valve disease is a barrier to active aging but conversely, early detection and timely treatment will increase longevity and quality of life.

The awareness week was driven by the Heart Valve Disease Patient Council of the Global Heart Hub which included; Initiative Herzklappe in Germany, Meine

Herzklappe from Austria, Instituto Lado A Lado Pela Vida in Brazil, Alliance du Cœur in France, Cuore Italia in Italy, Heart Valve Voice in the UK, US, Canada and Japan, AEPOVAC in Spain, EcoSerce in Poland, PACO in Mexico, Croí, the heart and stroke charity in Ireland, Mended Hearts in the US, The Israeli Heart Association, and hearts4heart in Australia.

The 2021 campaign message was: **If small, everyday tasks feel more like a big ordeal, listen to your heart - ask your doctor for a stethoscope check. Heart valve disease is a common, serious, but treatable condition. Follow the campaign using #ListenToYourHeart.**



## #ListenToYourHeart

Translated across 11 languages

#KontrollieredeinHerz  
#Ascoltailtuocuore  
#EcoutezVotreCœur  
#あなたの心臓の声を聴こう  
#EscuchaATuCorazón  
#SigaseuCoração  
#Ouçaseucoração  
#Wysłuchajsięwsojserce  
#מוגשכשירותלציבורע"

Press pick-up - 170+ features across 6 countries, including: national TV, radio and print coverage



## HEART VALVE DISEASE COUNCIL

### Heart Valve Disease: Working Together to Create a Better Patient Journey

Heart valve disease is a serious cardiovascular condition which can be fatal if left untreated, but it has received little attention compared to other cardiovascular disease.

That's why the Global Heart Hub's Heart Valve Disease Patient Council partnered with The Health Policy Partnership, an independent health policy research organisation, to develop a report aiming to raise stakeholder awareness of heart valve disease across Europe. The Report launched in December 2020, with work continuing into 2021 to raise awareness.

*Heart valve disease: Working together to create a better patient journey* takes a European

perspective on what an optimal care pathway should look like for people with heart valve disease, from awareness to follow-up care, what gaps exist, and how we can best address them. Addressing gaps in heart valve care is important, and urgent. Heart valve disease affects millions of people in Europe and cases are on the rise with the ageing of the population.

The report was developed under the guidance of a multidisciplinary advisory group, whose members included patient representatives and different healthcare professionals engaged in heart valve disease care from around Europe.

#### HEART VALVE DISEASE

### Working together to create a better patient journey

Report out now



#ValvesAtHeart



### Creating a better journey of care for patients with heart valve disease

In November 2021, the European Heart Journal Open published the article *Creating a better patient journey for patients with heart valve disease*, written by a multidisciplinary group of experts including Chair of the Global Heart Hub Heart Valve Disease Patient Council, Wil Woan. The peer-reviewed paper sets out recommendations for an improved patient pathway for heart valve disease.

The ideal patient pathway set out in the article comprises: early detection and diagnosis, timely intervention using the most appropriate approach, person-centred follow-up care, and

patient engagement, education and empowerment. This final step includes addressing the psychological dimension of receiving a heart valve disease diagnosis.

The paper was developed following the launch of the Global Heart Hub patient pathway report, *Heart Valve Disease: Working Together to Create a Better Patient Journey*.

*Article authors: Marta Sitges, Britt Borregaard, Ruggero De Paulis, Paul Nolan, Wil Woan, Keith Pearce, Jens Näumann, Neil Johnson, Suzanne Wait*

**Everyone over the age of 65** should have their heart checked with a stethoscope at least once a year



#ValvesAtHeart

## HIGHLIGHTS FROM THE HEART FAILURE COUNCIL

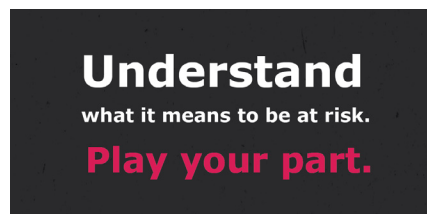
### 2020 Heart Failure Awareness Week

The 2020 Heart Failure Awareness Campaign ran from October 12 - 26, led by the Heart Failure Patient Council. Living with Heart Failure is challenging, more so now than ever. This campaign aimed to raise awareness of heart failure, and highlight the importance of understanding the needs of those most vulnerable to the coronavirus.

The 2020 campaign message was: **26 million people worldwide are living with Heart Failure. Few know what it is... most don't. Living with Heart Failure is challenging. Understand what it means to be at risk. Play your part. #HFAwareness**

Patient organisations and supporters from across 17 countries shared stories from people living with heart failure to help raise awareness.

Heart failure is a serious chronic condition where the heart cannot pump enough blood to support the needs of other organs in the body. The most common causes of heart failure include coronary heart disease, myocardial infarction (heart attack), congenital heart defects, or damaged heart valves. Symptoms include breathlessness, fatigue and swollen limbs. It is estimated that 1 in 5 people are at risk of heart failure.



## Global Heart Failure Awareness Week

October 12 - 26, 2020



**7,063,800+**  
opportunities to see  
heart failure campaign



**Developed video series  
on people living with  
heart failure**



**4,137,200+**  
opportunities to see  
campaign video  
across 13 languages



Shared by 53 influencers, with a combined follower total of 860,600 users

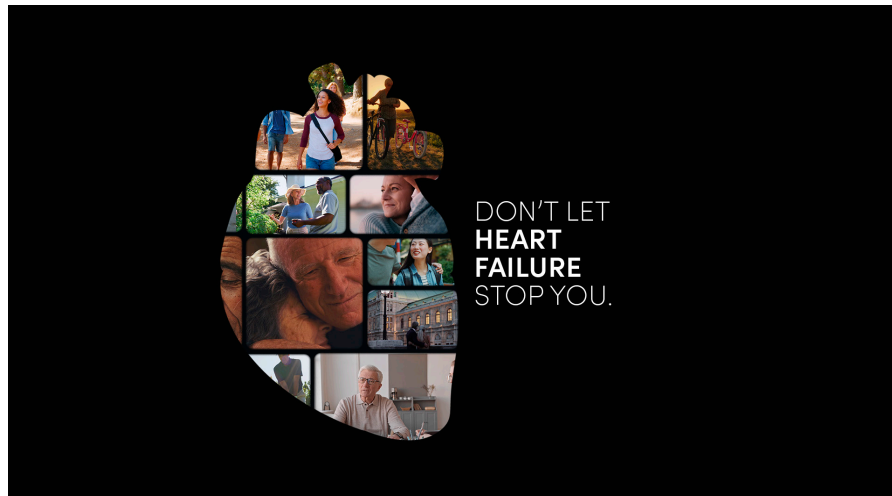
## HIGHLIGHTS FROM THE HEART FAILURE COUNCIL

### 2021 Heart Failure Awareness Week

The 2021 Heart Failure Awareness Campaign ran from October 4 - 10, led by the Heart Failure Patient Council.

The 2021 Heart Failure Awareness campaign aimed to raise awareness of heart failure and highlight what it is like to be living with heart failure. Heart failure is a serious chronic condition where the heart cannot pump enough blood to support the needs of other organs in the body.

The 2021 campaign message was: **Heart failure is a serious chronic condition, but it doesn't have to stop you from living. 26 million people worldwide are living with heart failure, and with the right medication and lifestyle, it can be controlled. Let's focus on living, because even with heart failure, you can still be you. Don't let heart failure stop you. #HeartFailureAwareness**



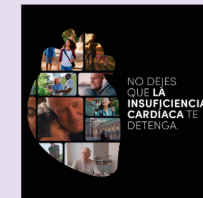
## Global Heart Failure Awareness Week

October 4 - 10, 2021



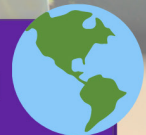
**4,088,600+**  
opportunities to  
see heart failure  
campaign

**Video and Toolkit  
translated into  
16 languages**



**DON'T LET  
HEART  
FAILURE  
STOP YOU.**

**Driven by patient  
organisations and  
supporters across  
28 countries**



**Shared by 120 influencers, with a  
combined follower total of 1,621,100 users**



## FOCUS ON ASCVD

### Global Heart Hub launches program to put the spotlight on an 'Invisible Nation' living with ASCVD – the world's #1 killer

In October 2021, The Global Heart Hub launched Invisible Nation, a program aimed to expose and respond to the realities of atherosclerotic cardiovascular disease (ASCVD) – a silent, chronic disease which affects 300 million people across the world. Working with a global network of heart patient organisations and heart patient advocates, and created in partnership with Novartis, Invisible Nation aims to engage with all the stakeholders in cardiovascular diseases.

Invisible Nation will advocate for policy-shaping efforts to rewrite how governments, health systems and all stakeholders can work together to change the trajectory of ASCVD and begin a generational decline in CV death. This program will help reduce the 15 million ASCVD deaths per year and the enormous financial costs of continued inaction by shedding light on this undeniable global public health issue, hidden in plain sight.

Even though the great majority of ASCVD-related deaths are preventable, most countries are nowhere near attaining the World Health Organization (WHO) goal of a 25% reduction in CV mortality by 2025. By putting a spotlight on the number 1 cause of heart attacks, strokes, and death, Invisible Nation

intends to ignite discourse, inspire action, and activate systemic change to make the burden of undiagnosed and unmanaged ASCVD un-ignorable.

"Many will be surprised to learn that millions and millions of people die each year from ASCVD, and they will be even more surprised when they realize that this terrible loss of life is roughly 60% higher than the number of deaths attributed to cancer," says Neil Johnson, Executive Director of the Global Heart Hub. "This is a shocking fact, when you consider that up to 80% of CV events could be prevented. Patient organizations have a responsibility and now the opportunity to highlight the realities of ASCVD and expose the barriers for people living with it to reach better health outcomes."

In 2021, the Global Heart Hub began working with its affiliates to engage stakeholders to develop an action plan to tackle the burden of ASCVD. Novartis will assist this community-driven movement by helping coalition members access the information and evidence needed to engage with local health systems, health authorities and policymakers.

To learn more, visit:  
[www.InvisibleNation.com](http://www.InvisibleNation.com).

**INVISIBLE NATION™**  
EXPOSING THE REALITIES OF ASCVD

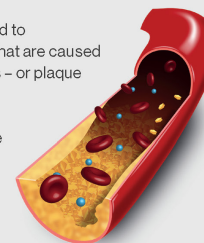


## WHAT IS ASCVD?

**ATHEROSCLEROTIC CARDIOVASCULAR DISEASE**

ASCVD is an umbrella term used to describe a variety of diseases that are caused by the build-up of fatty deposits – or plaque – in arteries.<sup>1</sup>

Many people do not experience any symptoms until the plaque in the arteries unexpectedly ruptures.<sup>1</sup> This may lead to a heart attack or stroke.<sup>1</sup>



*My heart attack came out of the blue for me. It's an invisible illness, one that you can't smell, can't feel. I had never felt any symptoms - at least none that I would have identified as warning signs, or of a heart attack.*

**Jean-Daniel,**  
living with ASCVD



**85%**  
of all CVD deaths caused by ASCVD<sup>2</sup>

**300 MILLION**  
people living with ASCVD<sup>3</sup>

**15 MILLION**  
deaths per year<sup>3</sup>

**2 BILLION**  
people at risk<sup>4</sup>

**27%**  
of world population has plaque build up in their arteries<sup>5</sup>

### KEY RISK FACTORS



**80%** of premature cardiovascular events **CAN BE PREVENTED**<sup>6</sup>

By knowing the risk factors we can modify, including our cholesterol level, we can significantly lower the risk of developing ASCVD.



### REGULAR CHECK-UPS

Visit your doctor and get your blood pressure and cholesterol levels checked. Everyone should have their first cholesterol screening test by age 35 for men, and age 45 for women.<sup>7</sup> Blood pressure should be checked every 2 years.<sup>8</sup> Those who are at higher risk should consider more frequent assessment.

### CHOLESTEROL

A high level of cholesterol (dyslipidemia) is a **leading cause of ASCVD**.<sup>1</sup> Cholesterol is an essential part of cells and nerves, but too much bad cholesterol (also called LDL-Cholesterol) in your blood can be problematic. Bad cholesterol is one of the most common factors of ASCVD.

Cholesterol levels can be measured by taking a simple blood test which shows the amount of "good" and "bad" cholesterol present in the blood. Maintaining healthy levels of cholesterol is one way to minimize the risk of developing ASCVD.

**People taking medicines to lower cholesterol levels should be offered a cholesterol test every year.<sup>9</sup>**

**By exposing the realities of ASCVD, we can change the course of this disease. Share this information to help an Invisible Nation be seen. To learn more, visit [www.InvisibleNation.com](http://www.InvisibleNation.com)**



## CAPABILITY BUILDING UPDATE - EDUCATION AND TRAINING

### Inspire Speaker Series

#### Advocacy Development Programme: Inspire Speaker Series

In 2020, the Global Heart Hub launched the Global Heart Hub Academy, which is an Advocacy Development programme to support patients, carers and patient organisations with their advocacy needs. In 2020 and 2021, topics addressed included:

- Introduction to Advocacy for Patient Organisations
- Having a Voice
- Evolution of Patient Leadership
- Advocating for Yourself
- Empowering Patients as Advocates
- Digital Media
- Patients of the Future

- Prof. Derek Stewart, OBE
- Julie Drury, patient advocacy leader
- Amy Friedrich-Karnik, VP Advocacy and Communications, WomenHeart
- Cecily Foster, Postpartum Cardiomyopathy patient and WomenHeart Champion
- Dave deBronkart, Leading advocate for patient engagement
- Krista Neher, Bootcamp Digital

**Recordings are available on our website: [globalhearthub.org/resources/videos/](https://globalhearthub.org/resources/videos/)**

The Inspire Speaker Series included excellent presentations from world-leading patient advocates, such as:

- Avril Easton, Alzheimer Society of Ireland
- Gay Mitchell, Former MEP, EU Parliament
- Craig Dwyer, Digital Campaigns
- Susan Campbell, WomenHeart

## Unite Annual Summit

#### Advocacy Development Programme: Unite Summit

On 22<sup>nd</sup> and 23<sup>rd</sup> November 2021, the Global Heart Hub brought together patient representatives from all over the world for its first annual Unite Summit. This virtual conference took place over two half days, with the aim of uniting and empowering cardiovascular patients and patient advocates on matters of importance to the community.

The sessions delved into:

- The impact of the COVID-19 pandemic on the cardiovascular patient community and how the lessons learned can catalyse change.

- How policymaking works, and how patients can use their understanding to advocate effectively.
- What policies and guidelines in specific cardiovascular disease areas mean for patients, and what are the associated advocacy issues.
- The benefits and drawbacks of digital innovation from a cardiovascular disease patient perspective.

**Recordings are available on our website: [globalhearthub.org/unite](https://globalhearthub.org/unite)**

**400+** Delegates  
from **51** Countries





**"This Summit has given me hope and inspiration about the prospect of a better patient journey going forward."**

Global Heart Hub Summit Delegate

## UPDATES ON WORKING GROUPS

### Cardiomyopathy and Related Conditions:

After months of engaging as a Working Group, The Cardiomyopathy Patient Council was launched in November 2021 and brings together patient organisations from around the world focused on improving awareness and understanding of cardiomyopathy.

The newly formed Cardiomyopathy Patient Council aims to raise awareness and improve understanding of cardiomyopathy, with a view to enabling people to live well with this condition.

To learn more, visit:  
[globalhearthub.org/patient-councils/cardiomyopathy/](https://globalhearthub.org/patient-councils/cardiomyopathy/)

### Cardio-Diabetes Working Group

Throughout 2020, over 30 international patient organisations representing the heart and diabetes communities participated in a series of round-table discussions on the interface between diabetes and heart disease.

The outputs from this collective engagement will result in a Cardio-Diabetes 'Think Tank' in May 2022.



## AWARDS

### Global Heart Hub's 2021 COVID-19 Response Campaign awarded 'Best Digital Campaign' by the World Heart Federation!

The Global Heart Hub is delighted to announce that our 2021 COVID-19 Response Campaign was awarded 'Best Digital Campaign 2021' by the World Heart Federation!

This campaign was an international collaboration between heart patient organisations aimed at saving lives and reducing disability during the coronavirus pandemic. There were three aspects to this campaign – "Just Go", "Step Up" and "Just Treat". The campaign highlighted that cardiac emergencies are medical emergencies; heart patients need to be proactive in seeking care; and healthcare providers and systems need to

prioritise the treatment of heart patients. This campaign was first launched in 2020 and, with the ongoing pandemic across the world, we continue to share these important messages today.

The Global Heart Hub is delighted to receive this award and we thank our Affiliates, Supporters and fellow Advocates for their support and collaboration in ensuring the success of this initiative. #JustGo #StepUp

See the award-winning campaign: [globalhearthub.org/covid-response-21/](https://globalhearthub.org/covid-response-21/)

## 2021 AWARDS

### Global Heart Hub receives Spanish Award

In September 2021, The Global Heart Hub was honoured to be recognised at the annual award ceremony of the Spanish Patient Organisation, Corazón Sin Fronteras, for bringing international patient organisations together, strengthening the patient voice and raising the visibility of cardiovascular disease.



The award was presented by the President of Corazón Sin Fronteras, Maite San Saturnino to GHH Executive Director, Neil Johnson, at a ceremony in the Basque Capital, Vitoria-Gasteiz.



**Winner of Best Digital Campaign 2021!**

## EVENTS AND COLLABORATIONS

### World Heart Day

The Global Heart Hub proudly supports the annual World Heart Day campaign which takes place each year on September 29<sup>th</sup>. Created by the World Heart Federation, World Heart Day informs people around the globe that CVD, including heart disease and stroke, is the world's leading cause of death claiming 17.9 million lives each year, and highlights the actions that individuals can take to prevent and control CVD. It aims

to drive action to educate people that by controlling risk factors such as tobacco use, unhealthy diet and physical inactivity, at least 80% of premature deaths from heart disease and stroke could be avoided.



### Global Heart Hub supports the Global Coalition for Circulatory Health - Call To Action

The Global Coalition for Circulatory Health (GCCCH) – a consortium of international, regional and national stakeholders in circulatory health, including Global Heart Hub, – has called on governments to pay sufficient attention to the huge burden of CVDs and to do more to address the growing concern. The urgent need to address CVDs has become even more pressing as a result of the disproportionate impact the COVID-19 pandemic is having on people living with circulatory conditions such as diabetes, kidney disease or stroke.

On Universal Health Coverage (UHC) Day on December 12, the Global Coalition for Circulatory Health asked governments not to leave people living with CVDs behind.

We urged Member States to:

- Prioritise the inclusion of co-morbidity and multi-morbidity among NCDs in the design and implementation of policies aimed at the prevention, early detection and treatment of all NCDs and their common risk factors;
- Recognise multi-morbidity and co-morbidity as a growing worldwide public health concern that may affect over 1.7 billion people living with life-threatening NCDs;
- Include NCD prevention, early diagnosis, screening and appropriate treatment in essential public healthcare services and UHC benefit packages;
- Use the WHO HEARTS technical package to implement primary healthcare interventions for hypertension as part of UHC;
- Recognise the impact COVID-19 is having on people with circulatory conditions and address interruptions in access to life-saving treatments such as dialysis and transplantation;
- Protect and support the wellbeing of the health workforce: the most precious resource to tackle COVID-19 and to prevent, treat and manage CVDs;
- Collect standardised data on COVID-19 infection and death rates among health workers to understand the true magnitude of the pandemic and identify the most appropriate evidence-based measures to prevent and control the threat;
- Maximise common efforts to deliver an affordable, people-centered, integrated response to multiple morbidities, to leave no disease behind during and after the COVID-19 pandemic.

## EVENTS AND COLLABORATIONS

### World Heart Federation and Global Heart Hub supports “Use Heart to Act Now on Angina”, a public campaign to raise awareness on angina

In April 2021, Servier, an international pharmaceutical group, with World Heart Federation (WHF) and Global Heart Hub (GHH) launched “Use Heart to Act Now on Angina”. This worldwide campaign aims to raise public awareness about the symptoms of angina, which are often underestimated.

More than 100 million people globally are affected and the huge impact of angina on the quality of life of patients includes consequences such as disability, job loss, and depression. As angina manifests in a variety of ways, the symptoms may be hard to recognize, and risk being attributed to stress, menopause or digestive issues.

The incidence and prevalence of patients with angina is expected to increase in the coming decade as a result of an aging population, the obesity epidemic, the greater use of life-prolonging therapies, and better management of acute coronary syndromes.

Angina patients often remain under-diagnosed and under-treated. It is essential for early warning signs to be recognized in time by both health professionals and patients alike.

Therefore Servier, the World Heart Federation, and WHF’s Member organization, the Global Heart Hub are forging a path in the fight to address the urgency of angina symptoms, its potential consequences, and necessary care. “Use Heart to Act Now on Angina” is a new joint initiative that brings together the latest medical perspectives and patient views in order to ensure that we take angina seriously.

Neil Johnson, Executive Director, Global Heart Hub said: “Angina is a clear symptom of an underlying heart problem, and that’s why the Global Heart Hub wants to empower patients to Use Heart, connect with their health care provider and Act Now on Angina. We need to increase public awareness of angina, and encourage early detection and diagnosis, so that optimal management can be achieved and the impact on quality of life can be minimized.”

**Find the angina toolkit here:**  
[world-heart-federation.org/resource](https://world-heart-federation.org/resource)

### Global Heart Hub joins forces with key European organisations to shine spotlight on cardiovascular health

In September 2021, The European Alliance for Cardiovascular Health was launched to raise awareness of the burden of cardiovascular disease (CVD) and to call for action from European decision-makers.

The Alliance brings together, for the first time ever, 15 leading European and international organisations, including the Global Heart Hub, representing the full range of health actors. Together they offer an extraordinary wealth of knowledge in cardiovascular health.

Collectively, the Alliance represents:

- Tens of millions of patients.
- More than 200,000 health professionals.
- Over 400 health technology companies.
- Health insurers covering the medical costs of more than 200 million people.
- Millions of people living with genetic CVD risk factors but who have not been diagnosed yet.

The Alliance’s partners are committed to joining forces and sharing expertise to:

- Raise awareness of the burden of CVD on society.
- Call for a European CVD Plan to improve cardiovascular health, optimise quality of life in patients and undiagnosed citizens with CVD, and prevent first and subsequent heart events and strokes.
- Advise policymakers on actions to improve cardiovascular health and to prevent CVD in Europe, thereby making the population more resilient to future pandemics and other health threats.
- Mobilise investment for CVD research and promote public-private partnerships in CVD innovation.
- Ensure swift and equitable access to new medical technologies and medicines that add value to patients and society.



*Partners include: AIM; COCIR; EAS; ECDA; ECHDO; EFPIA; EHN; EKHA; ESC; ESO; EUCOPE; FH Europe; Global Heart Hub; MedTech Europe; SAFE; and World Heart Federation. Learn more: [www.cardiovascular-alliance.eu](https://www.cardiovascular-alliance.eu)*



## OUR FUNDERS

Our work is largely funded through grants from industry, which are either unrestricted or by way of sponsorship of specific activity initiated by the Global Heart Hub in support of our mission. We believe that ethical and transparent collaboration between industry and patient organisations contributes to valuable and important healthcare discussions, which ultimately lead to improved outcomes for patients. We undertake to, at all times, disclose the names of all our industry funders; seek support from multiple funders (to avoid real or perceived exclusive relationships); and only work with those companies who abide by our code of conduct on working with industry.

We wish to acknowledge the support we have received from the following (in alphabetical order) in 2020 and 2021:



## CONTACTING GLOBAL HEART HUB

**Executive Director:**

Neil Johnson

*neil@globalhearthub.org*

**To contact Global Heart Hub Patient Councils, please email:**

*info@globalhearthub.org*

**Chair, Heart Valve Disease Patient Council**

Wil Woan, *CEO, Heart Valve Voice*

**Chair, Heart Failure Patient Council**

Aistė Štaraitė, *President, Lithuanian Heart Failure Organisation*

**Chair, Cardiomyopathy Patient Council**

Joel Rose, *Chief Executive, Cardiomyopathy UK*



Global Heart Hub,  
Galway, H91 FF68,  
Ireland



+353 (0)91 544310



[info@globalhearthub.org](mailto:info@globalhearthub.org)



[www.globalhearthub.org](http://www.globalhearthub.org)



[@GlobalHeartHub](https://www.instagram.com/GlobalHeartHub)