




# Global Heart Hub

## Annual Review 2022



Building a united  
alliance that advocates  
for, supports, educates  
and empowers those  
living with or affected  
by cardiovascular  
disease.

# Contents

Welcome	4
Our Supporters	7
Our Growing Community	8
Global Heart Hub in Numbers	10
Social Media Presence	11
Heart Valve Disease Council HIGHLIGHTS	12
Heart Failure Council HIGHLIGHTS	16
Cardiomyopathy Council HIGHLIGHTS	20
Focus on ASCVD	24
Focus on Cardio-Diabetes	26
Capacity and Capability - Education & Training	28
Events and Collaborations	32
Contact	38

## Our mission

Our mission is to **ensure the best possible outcomes for people living with heart diseases** by creating a global cardiovascular disease community that advocates for, supports, educates and empowers patients and caregivers.

## Our vision

Our vision is to be the **leading voice for the needs of heart patients globally ensuring that they are equal stakeholders in cardiovascular healthcare.**

## Our goals

- To understand the global landscape of cardiovascular disease patient organisations and provide resources and support to strengthen their capacity and capability for patient advocacy.
- To represent the global cardiovascular disease community on global and regional platforms as an equal stakeholder along with clinical stakeholders and decision-makers in healthcare strategy.
- To identify pressing issues for the cardiovascular patient community and develop and advocate for innovative solutions at the global, regional, and national level.

### Global Heart Hub is a member of:



## Company Information

### Board of Directors:

Kevin O'Reilly, Chairman - IRELAND  
Susan Campbell - USA  
Pat O'Donnell - IRELAND  
Ellen Ross - CANADA

### Company Secretary:

Marie Gavin - IRELAND

### Executive Director:

Neil Johnson - IRELAND

### Registered office:

Ireland

The Global Heart Hub is a non-profit organisation, registered in Ireland as a company limited by guarantee and as a charitable organisation.

## Welcome

Over the past year, the challenges faced by the global heart patient community have become only more pressing, with many still feeling the impacts of the pandemic and struggling to gain timely access to diagnostics and treatment in healthcare systems around the world.

A central goal of Global Heart Hub is to unite, support, and elevate the patient voice, particularly when it comes to highlighting unmet patient and caregiver needs.

The involvement of patients in healthcare policy and practice not only provides accountability and legitimacy in health systems but also allows for the sharing of important insights and experiences which are otherwise unknown to healthcare professionals, researchers, and policymakers. Furthermore, patient organisations and advocates have unique access to a large patient and caregiver community. True progress in healthcare advancement will not be achieved without patient involvement, yet too often, crucial decisions on policy and practice are made without them. Global Heart Hub promotes the concept of patient engagement and involvement at every level of healthcare decision making.

Throughout 2022, we worked closely with our affiliates, who now number almost 100 patient organisations and operate in 30 countries. Together, we have made great strides in strengthening and supporting

**“We wish to acknowledge the contribution of the patient organisation leaders and individual advocates who provided the strength and experience of the patient community.”**

the patient voice and in advocating for the needs of those living with or affected by heart diseases.

In this annual review we are delighted to share with you the highlights from our many activities and initiatives over the past year. Our patient councils and working groups developed and led several international disease awareness campaigns; engaged in a number of capacity and capability training and development activities and implemented numerous advocacy initiatives at national and regional levels across the world.

We would like to thank all those who have supported and collaborated with us to achieve our mission and in particular we wish to acknowledge the contribution of the patient organisation leaders and individual advocates who provided the strength and experience of the patient community. We would like to especially acknowledge the support of our funding partners who share a common goal of improving the outcomes and quality of life for patients and their caregivers.



**Neil Johnson**  
Executive Director



**Kevin O'Reilly**  
Chairman





## Our Supporters

Our work throughout the past year has been funded through multi-industry support. 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

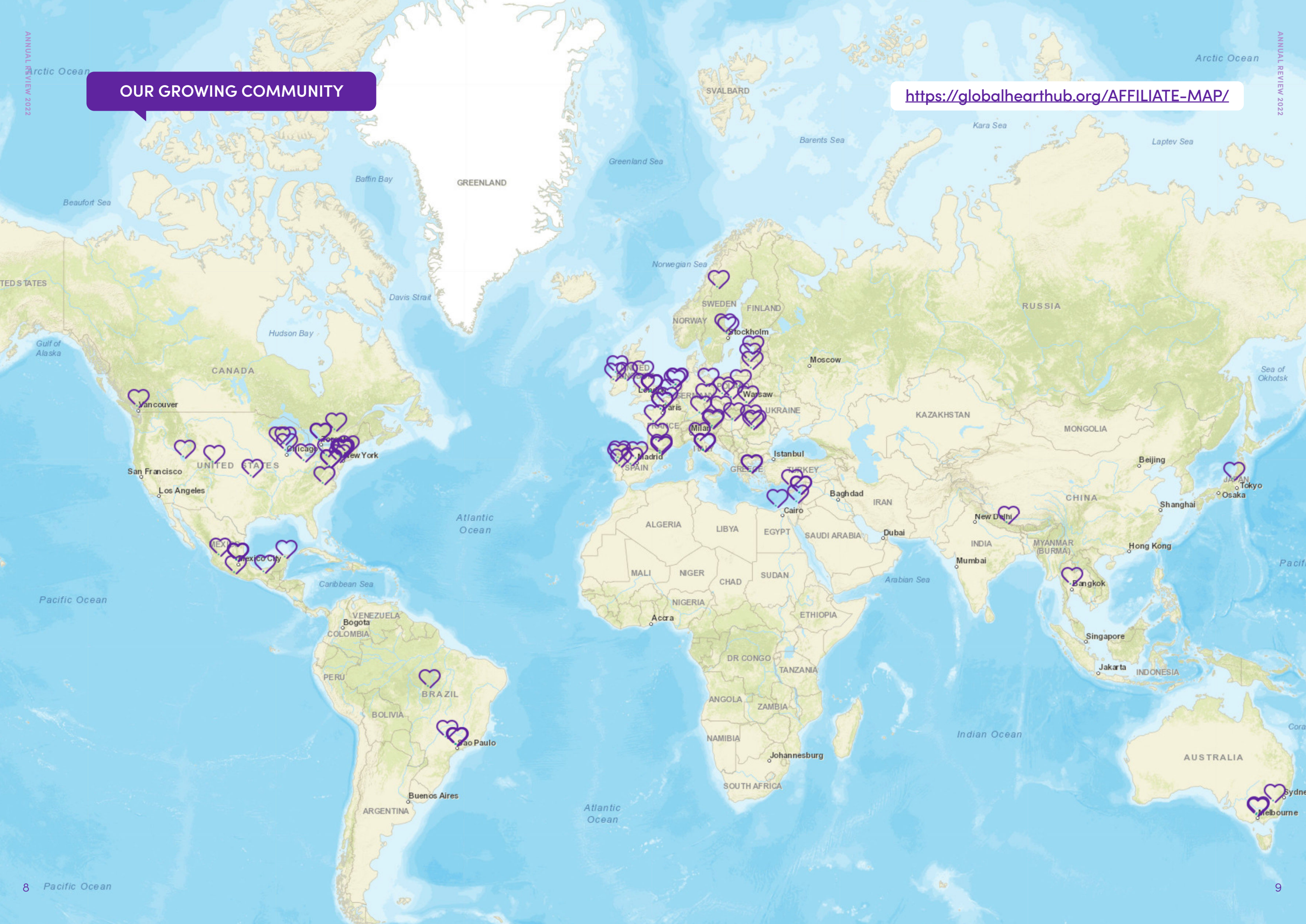
names of all our industry funders; seek support from multiple funders (to avoid real or perceived exclusive relationships); and only work with those companies who abide by our code of conduct on patient / industry engagement.





# OUR GROWING COMMUNITY

<https://globalhearthub.org/AFFILIATE-MAP/>





2022 HIGHLIGHTS IN NUMBERS



# 95

Patient Organisations are now affiliated with Global Heart Hub

The Global Heart Hub has a presence in

# 30 countries worldwide



SOCIAL MEDIA PRESENCE



**Unite Summit:**  
450+ registered delegates from across 55 countries with 100% of attendees reporting being inspired by the topics discussed

**Heart Valve Disease Awareness Week:**

# 94m

opportunities to see the campaign message



**Heart Failure Awareness Week:**

# 8m

opportunities to see the campaign message

**Cardiomyopathy Awareness Week:**

# 6.5m

opportunities to see the campaign messages

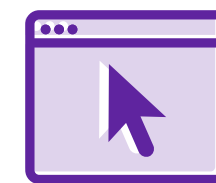
**Phase 3 Covid-19 Education Campaign:**

# 4.5m

opportunities to see the campaign messages

# 5,500+

followers across social media channels



# 92,000+

visits to the website

# 113m+

opportunities to see Global Heart Hub content across social media platforms

## HIGHLIGHTS FROM THE HEART VALVE DISEASE COUNCIL

## 2022 Heart Valve Disease Awareness Campaign

Global Heart Hub delivered its International Heart Valve Disease Awareness Campaign from September 12 to 18, with the goal of raising awareness of the need to improve early detection, early diagnosis and the timely treatment and management of heart valve disease across the world. As heart valve disease can be a significant barrier to active and healthy ageing, early detection and timely treatment can greatly increase longevity and quality of life.

This campaign highlighted that senior citizens are significant contributors to society and to the economy. Raising awareness of heart valve disease and encouraging early diagnosis promotes the importance of healthy and active ageing,



particularly in the context of the changing global age demographics.

Heart Valve Disease Awareness Week 2022 sought to highlight the common signs and symptoms that are often ignored or overlooked, resulting in delayed diagnosis and treatment. The campaign message was: As we age, symptoms

like breathlessness, fatigue and dizziness could be signs of heart valve disease, and sometimes go undetected. If you're experiencing these symptoms, ask your doctor for a stethoscope check, and if you're over 65 years old, an annual stethoscope check, could be the first step in the detection of the condition. Heart valve disease is common, serious, but treatable. Follow the campaign using #ListenToYourHeart.

*This campaign was developed and led by the Heart Valve Disease Patient Council whose affiliates included: Initiative Herzklappe, Germany; Meine Herzklappe, Austria; Instituto Lado A Lado Pela Vida, Brazil; Heart Valve Voice, UK; Heart Valve Voice, USA; Heart Valve Voice, Canada; Heart Valve Voice, Japan; AEPOVAC, Spain; EcoSerce, Poland; PACO, Mexico; Croí, Ireland; Mended Hearts, USA; the Israeli Heart Association, and Hearts4Heart, Australia.*



**Global Heart Hub**

**Heart Valve Disease Awareness Week**  
September 12 - 18, 2022

Delivered over 94 million opportunities to see the campaign messages across social, digital, print, TV, and radio channels

Social media posts by 115+ influencers, follower total of 1,840,000+ users

**#ListenToYourHeart**

Translated across 11 languages

Shared across 23 countries

Press pick-up - 80+ features across 6 countries, including: national TV, radio and print coverage

This year, the return of in-person events encouraged patients, family members, carers and the general public to meet and get involved.

**#ValveWeek22**

Global Heart Hub  
info@globalhearhub.org | www.globalhearhub.org



## HIGHLIGHTS FROM THE HEART VALVE DISEASE COUNCIL

## Creating a Better Patient Journey Launch event

Global Heart Hub convened key stakeholders and policymakers in Brussels on April 27, 2022, to advocate for improvements in the care pathway across detection, diagnosis, and treatment of heart valve disease. This event marked the launch of the Global Heart Hub Patient Pathway Report, published in December 2020 which offered a European perspective on what the optimal care pathway should look like for people with heart valve disease.

A seminar on Creating a Better Patient Journey, was co-hosted by a member of the European Parliament, Mr Brando Benifei, MEP and the event leveraged the findings and recommendations of the report to raise stakeholder awareness, highlight the calls to action, and bring a patient advocacy focus to heart valve disease.

Attendees included members of the European Parliament; heart valve disease patients from across Europe, the USA, Canada, Brazil and Australia, a heart valve disease specialist, researchers and representatives of civil society.

MEP Brando Benifei commented: "In my work as co-chair of the MEP Heart Group, I have seen the positive efforts being made

to address cardiovascular diseases at EU level, but people living with heart valve disease can often get left behind, and we need to remedy this. Global Heart Hub has developed a clear plan for the heart valve disease patient care pathway. The patient journey report provides a brilliant map for patients from detection to diagnosis and treatment. The political world needs to draw on this example, to help empower patients and the people treating them."

Throughout the year, Global Heart Hub supported numerous individual national advocacy and implementation efforts and by year-end, the report had been localised and launched in Germany, Austria, Spain, Ireland, Brazil, Mexico, and Canada.

Speakers at the event included MEP Brando Benifei, Co-Chair of the MEP Heart Group; Vytenis Andriukaitis, former European Commissioner for Health and Food Safety; Dr Marta Sitges, Cardiovascular Institute, Hospital Clinic and University of Barcelona, Spain; Prof Ruggero De Paulis, European Hospital and UniCamillus University, Italy; Dr Suzanne Wait, Managing Director, Health Policy Partnership; and Jens Näumann, heart valve patient, Germany.



## HIGHLIGHTS FROM THE HEART VALVE DISEASE COUNCIL

## Shared Decision-Making A Patient Guide

Shared decision-making  
for people with  
heart valve disease:  
**A patient guide**



The importance of shared-decision making is often overlooked by healthcare professionals. In recognition of this fact, and that it has proven benefits across patient satisfaction, quality of life and other areas of care meaningful to patients and their carers, encouraging shared decision-making is a priority for the Heart Valve Disease Patient Council. This lack of recognition has begun to change however and recent European Society of Cardiology (ESC) and European Association for Cardio-Thoracic Surgery (EACTS) Guidelines for the management of valvular heart disease calls for patients to be involved in the decision making about their treatment. There is still much progress to be made however in encouraging both clinicians and patients to engage in this process. This guide aims to help empower patients to be an active and informed participant in their treatment decisions, especially those who feel overwhelmed by their options or struggle to voice their concerns.

In February 2022, Global Heart Hub launched *A Patient's Guide to Shared Decision-Making*, which aimed to support people with heart valve disease in participating in decision-making about their care. Created in collaboration with The Health Policy Partnership and an advisory board including both clinicians and patients, this guide walks patients through the process of working with their clinicians to develop a care plan.

The guide includes a patient-friendly background to the clinical guidelines, outlines a shared decision-making checklist, and provides a summary one-pager for people living with heart valve disease. The materials have been translated into French, German, Spanish and Italian. The guide was launched across social media channels and is being promoted at in-person events internationally.



## HIGHLIGHTS FROM HEART FAILURE COUNCIL

## 2022 Heart Failure Awareness Campaign

The Global Heart Hub Annual Heart Failure Awareness Campaign took place between May 9 to 15 and it aimed to raise awareness of heart failure by sharing patient and carer stories to illustrate the reality of living with the condition.

This campaign targeted the identified need to highlight that an estimated 1 in 5 people are at risk of heart failure and that it is the most frequent cause of hospitalisation in people over the age of 65 across the world. Heart failure is estimated to affect over 65 million people worldwide and with the global population of over 60's set to rise rapidly in the coming decades, many more people are expected to develop heart failure. The positive news is that, with the correct medication and lifestyle, heart failure can be controlled.



The Heart Failure Patient Council is united in the view that heart failure is poorly recognised and not well understood by the general public.



Disease awareness is therefore essential to timely diagnosis and treatment. The campaign call to action was to understand heart failure and connect with a person living with heart failure for a #HearttoHeart conversation. Each patient organisation participating in the campaign received a toolkit to support and help drive the key messages while also customising the campaign to their local culture and contexts.

*This campaign was developed and led by the Heart Failure Patient Council whose affiliates included: AISC, Italy; AVEC, France; Croí, Ireland; Egyptian Association for Care of Heart Failure Patients, Egypt; HeartLife Foundation, Canada; Slovenian Heart Foundation, Slovenia; Focus Patient, Sweden; Lithuanian Heart Failure Association, Lithuania; Her Heart, Australia; Israeli Heart Association, Israel; EcoHeart Association National Association of Patients with Heart&Vascular Conditions, Poland; Heart Support Australia, Australia; Mended Hearts, USA; PACO, Mexico.*

**Global Heart Hub**

**Global Heart Failure Awareness Week**

May 9 - 15, 2022

The hardest part of heart failure is behind me.

Have a #HearttoHeart with a person living with Heart Failure.

**Delivered over 8 million opportunities to see the Heart Failure message!**

Even with heart failure, you can still be you.

Have a #HearttoHeart with a person living with Heart Failure.

**Special 'Heart to Heart' videos created with people living with heart failure**

**Driven by patient organisations and supporters across 15 countries**

**5.6 million impressions achieved across Global Heart Hub social media channels with over 4k clicks to 'learn more' on the campaign webpage!**

Global Heart Hub, Croí House, Moyola Lane, Newcastle, Galway, Ireland  
info@globalhearhub.org | www.globalhearhub.org



## HIGHLIGHTS FROM HEART FAILURE COUNCIL

## International Heart Failure Patient & Caregiver Charter



In collaboration with and supported by our affiliate patient organisation Heart Life Canada, Global Heart Hub launched its International Heart Failure Patient & Caregiver Charter on June 15, 2022. Recognising that the treatment of heart failure varies widely around the world and that many are unable to access high quality care, the charter seeks to lay the foundation for patient and carer expectations and responsibilities. Our aim is that the charter can be used by advocates as a tool for engagement with all stakeholders and decision-makers in heart failure, including policymakers, healthcare providers, insurance companies, patients and carers.

The International Patient and Caregiver Charter has been endorsed by 31 Heart Failure Patient Council affiliate organisations in 23 countries and has been translated into 16 languages across the Americas, Europe, Middle East and Australia. Global Heart Hub further encouraged the use of the charter through the creation of 'Patient and Caregiver Charter User Recommendations' and 'Statement of Support' letter templates, to assist in focusing on local issues and to provide guidance on how to use the document to implement change.

The charter has already generated important conversations and advocacy efforts around the world, which led to National Charter localisations. The Heart Failure Patient Foundation has launched the US version of the Charter, which was endorsed by the American Association of Heart Failure Nurses.

Global Heart Hub was delighted to see the launch of the Brazilian Patient & Caregiver Charter in September 2022 with a live event involving the President of the Department of Heart Failure at the Brazilian Society of Cardiology and the Brazilian Heart Failure Network. Both these organizations have endorsed the charter. In Poland, the Patient and Caregiver Charter was presented at a conference in Warsaw in October 2022 attended by national clinical specialists in cardiology, the Office of the Patient Ombudsman, the Ministry of Health, the Senate and patient organisation representatives.

The Lithuanian Patient and Caregiver Charter was launched on World Heart Day in September 2022, followed by a roundtable discussion with relevant stakeholders. The document has been endorsed by the Lithuanian Society of Cardiology and the Lithuanian Heart Association.



# Heart Failure Patient & Caregiver Charter



An International collaboration of heart failure patient organisations and patients





## HIGHLIGHTS FROM CARDIOMYOPATHY COUNCIL

## 2022 Cardiomyopathy Awareness Campaign

Global Heart Hub delivered its first International Cardiomyopathy Awareness Week Campaign from June 20 to 26. The awareness campaign aimed to highlight the barriers to proper diagnosis and treatment by calling attention to the signs, symptoms, and risks of cardiomyopathy. The aim was to encourage and empower those with symptoms to consult with their clinicians and ask important questions.

The campaign message was: speak to your doctor if you're feeling exhausted, out of breath, dizzy or have palpitations, chest pain, or swelling in the ankles, feet, legs or abdomen; and tell your doctor about your family's history of heart disease or sudden unexplained death, because cardiomyopathy often runs in families and it's important to protect loved ones who may not have any symptoms. If you think that something is not right, seek help and #GetToTheHeartofit.

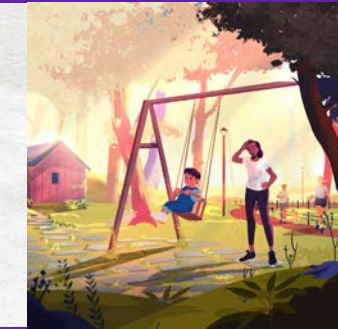


*This campaign was developed and led by the Cardiomyopathy Patient Council: AICARM ONLUS, Italy; ARVC-Selbsthilfe, Germany; Cardiomyopathy Association of Australia Ltd, CMAA, Australia; Cardiomyopathy Research The Netherlands; Cardiomyopathy UK; Children's Cardiomyopathy Foundation, USA; Croí Heart & Stroke, Ireland; DCM Foundation, USA; HCMA, Hypertrophic Cardiomyopathy Association, USA; LMNA Cardiac Foundation, The Netherlands; Sudden Arrhythmia Death Syndromes, SADS Foundation, USA; and Asociación SAMS, Síndromes Arrítmicos Relacionados con la Muerte Súbita, Spain.*



### Cardiomyopathy Awareness Week

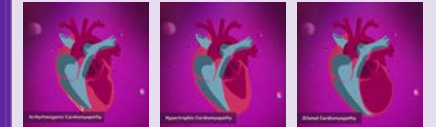
June 20 - 26, 2022



**Delivered over 6.5 million opportunities to see the Cardiomyopathy messages!**

**Campaign materials translated across 5 languages!**

**x3 educational cardiomyopathy videos created - HCM, DCM and ACM**



**Get to the heart of it**

**Driven by GHH, patient orgs and supporters across 9 countries**



**6 million impressions achieved across Global Heart Hub social media channels with over 1.3k clicks to 'learn more' on the campaign webpage!**

Global Heart Hub, Croí House, Moyola Lane, Newcastle, Galway, Ireland  
info@globalhearhub.org | www.globalhearhub.org



## Guiding Principles For Cardiomyopathy Research

Global Heart Hub supports the principle of patient involvement and patient engagement in cardiomyopathy research. The Cardiomyopathy Patient Council believes that the perspective of individuals with personal experience of Cardiomyopathy could inform all stages of the research process to lead to better outcomes for those affected by this condition.

In October, the Cardiomyopathy Patient Council launched the Guiding Principles for Patient Involvement in and engagement in Cardiomyopathy Research. This document highlights six principles essential to a patient-centric research plan, namely: inclusivity & empowerment, accountability, transparency, collaboration, communication, and impact. By incorporating all these elements, the council believes researchers will best be able to plan and execute research projects that engage patients responsibly. Cardiomyopathy Patient Council affiliates have agreed to support research projects where the researchers agree to follow the established guiding principles.

*The guiding principles were developed by council affiliates – AICARM ONLUS, Italy; ARVC-Selbsthilfe, Germany; Asociación SAMS, Síndromes Arrítmicos Relacionados con la Muerte Súbita, Spain; LMNA Cardiac Foundation, The Netherlands; Cardiomyopathy Research, The Netherlands; Cardiomyopathy Association of Australia, Ltd, CMAA, Australia and the US organisations – Children’s Cardiomyopathy Foundation, Hypertrophic Cardiomyopathy Association, HCMA and the DCM Foundation. When new affiliates join the Council they are encouraged to endorse these principles. In 2022, they were endorsed by 17 associations across 12 countries.*



### Guiding Principles

#### For patient involvement and engagement in cardiomyopathy research

The Global Heart Hub (GHH) supports the principle of patient involvement and patient engagement in cardiomyopathy research. The GHH Cardiomyopathy Patient Council believe that the perspective of individuals with personal experience of cardiomyopathy and the impact it can have should inform all stages of the research process to lead to better outcomes for people affected by this condition.

**The Cardiomyopathy Patient community will support research projects only where researchers agree to the following guiding principles:**



#### 1. INCLUSIVITY & EMPOWERMENT

Researchers must ensure that at all times patients are at the centre of their work and that the focus is on improving patient outcomes. Patients from all communities must be able to access opportunities to be involved in the research process, and the voice of patients must be respected.



#### 2. ACCOUNTABILITY

Researchers must recognise the need for patient confidentiality and meet all the necessary legal and ethical requirements for conducting research in the country in which the research will take place.



#### 3. TRANSPARENCY

Researchers must be clear and transparent in all communications pertaining to the research project and the research processes should be open to adjustments to meet the needs of patients.



#### 4. COLLABORATION

Researchers must involve and engage patients in all stages of the research project, from concept through to dissemination.



#### 5. COMMUNICATION

Researchers must ensure that all public-facing literature is patient friendly and excludes scientific speak and jargon, using lay summaries which have been reviewed by patients. Researchers must also respond to all requests for clarifications and provide feedback on comments and alterations.



#### 6. IMPACT

Researchers must report the findings of their work to the patients with whom they have engaged and also disseminate findings to the wider cardiomyopathy community. Where applicable, researchers should provide a plan for the translation of their research into clinical practice.

**Bringing the patient to the heart of cardiomyopathy research.**

[globalhearthub.org/patient-councils/cardiomyopathy](https://globalhearthub.org/patient-councils/cardiomyopathy)





## FOCUS ON ASCVD

## Launch of Global Cholesterol Action Plan

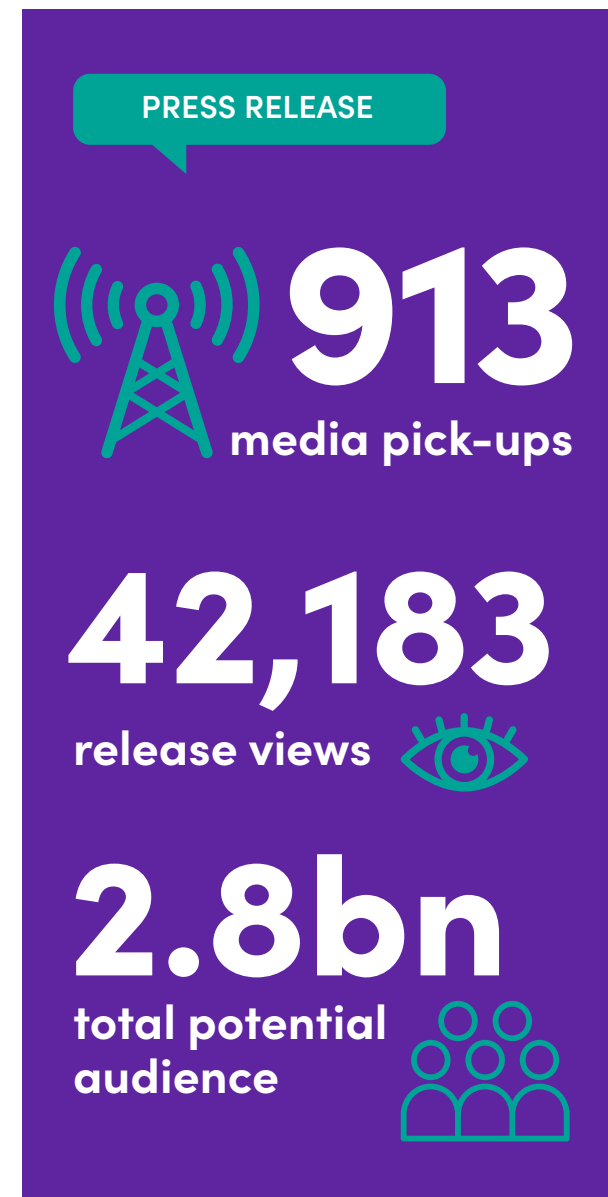
Atherosclerotic cardiovascular disease (ASCVD) accounts for 85% of all cardiovascular-related deaths and is the leading cause of mortality worldwide, responsible for more than 15 million deaths each year. A main risk factor of ASCVD is low-density lipoprotein (LDL-C) – also known as ‘bad cholesterol’.

While 80% of premature cardiovascular events are preventable, many people with elevated LDL-C levels go undiagnosed until they experience a major cardiovascular event such as a heart attack or a stroke. While the onset of cardiovascular disease is often associated with lifestyle factors such as smoking, physical inactivity and diet, almost 40% of the adult population is at risk of elevated LDL-C levels due to an inherited genetic condition.

Launched at Global Heart Hub’s annual Unite Summit in November 2022, the Global Cholesterol Action Plan aims to implement change in the way unhealthy cholesterol levels are detected and managed. The plan follows and builds on the World Heart Federation Cholesterol Roadmap which was launched in October 2022.

Until now, global action on ASCVD has been limited, despite the publication of international prevention and management guidelines. The Global Heart Hub Action Plan aims to shine a light on unhealthy cholesterol and unmanaged ASCVD and highlight the burden it places on individuals and health systems around the world. The action plan has four clear goals to ensure

unhealthy cholesterol levels are addressed as a public health priority, namely: build alliances, raise public awareness, activate alliances, and improve high cholesterol detection and management. The four-point plan proposes measures that can be taken to meet these goals and activate change in the way ASCVD is prevented and treated.



# A GLOBAL CHOLESTEROL ACTION PLAN

## ACTIVATING CHANGE TO REDUCE THE IMPACT OF UNHEALTHY CHOLESTEROL LEVELS

A main risk factor for atherosclerotic cardiovascular disease (ASCVD) which leads to heart attacks and stroke is elevated LDL-Cholesterol, known as bad cholesterol – it is a critical modifiable risk factor. For some, elevated LDL-C is a result of an inherited genetic condition called familial hypercholesterolemia or FH.

Working with patient community partners across the globe, the Global Heart Hub has set goals and actions to ensure unhealthy cholesterol levels are addressed as a public health priority.

<b>GOAL #</b>		<b>BUILD ALLIANCES</b> Create country or regional intersectoral alliances to address the urgent need to reduce cholesterol-related ASCVD risk	
<b>ACTIONS:</b>	<ul style="list-style-type: none"> <li>Identify a lead organization to champion the creation of regional or country multistakeholder alliances to move the needle on unhealthy cholesterol levels, the underlying cause of 85% of heart attack or stroke-related death</li> <li>Create country-level or regional alliances or movements that bring together patient organizations, healthcare professionals and other non-traditional</li> </ul>	<ul style="list-style-type: none"> <li>stakeholders who are motivated to mobilize streamlined, integrated action</li> <li>Develop strategies to secure resources from various sources to support the multistakeholder alliances to implement advocacy and awareness activities to advance alliance goals</li> </ul>	
<b>GOAL #</b>		<b>RAISE PUBLIC AWARENESS</b> Improve public understanding of the serious risks of unhealthy cholesterol levels	
<b>ACTIONS:</b>	<ul style="list-style-type: none"> <li>Collect regional/country data to frame the scale of the unhealthy cholesterol problem and the burden on health care systems</li> <li>Develop powerful messages to explain how unhealthy cholesterol levels present a significant health threat that unknowingly puts people at risk of heart attack, stroke or premature death and are a major driver of ASCVD</li> </ul>	<ul style="list-style-type: none"> <li>Disseminate evidence-based messages to create public awareness of this growing health issue, the serious risks and urgent need to address unhealthy cholesterol levels and to give a voice to the people who are at risk</li> </ul>	
<b>GOAL #</b>		<b>ACTIVATE ALLIANCES</b> Mobilize alliances to roll out integrated advocacy	
<b>ACTIONS:</b>	<ul style="list-style-type: none"> <li>Implement training sessions to build advocacy skills for alliance members</li> <li>Package global and regional evidence to demonstrate the relevance of cholesterol to the burden of ASCVD and the urgent need to improve unhealthy cholesterol levels</li> </ul>	<ul style="list-style-type: none"> <li>Present a call to action to governments and other stakeholders to prioritize and address unhealthy cholesterol levels as a public health priority</li> <li>Urge governments and other stakeholders to collaborate with the alliance and cardiovascular communities to address this large-scale health care system challenge and improve health outcomes</li> </ul>	
<b>GOAL #</b>		<b>IMPROVE HIGH CHOLESTEROL DETECTION AND MANAGEMENT</b> Encourage implementation of approaches to reduce gaps in cholesterol testing and treatment	
<b>ACTIONS:</b>	<ul style="list-style-type: none"> <li>Identify regional/country level barriers to reducing modifiable cholesterol-related ASCVD-risk</li> <li>Activate governments and policy makers to develop, build on or support existing strategies to improve high cholesterol detection and treatment</li> </ul>	<ul style="list-style-type: none"> <li>Enable best practice-sharing to optimize regional / country level cholesterol testing and treatment approaches</li> </ul>	

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

Invisible Nation is a collaboration between Global Heart Hub and Novartis.



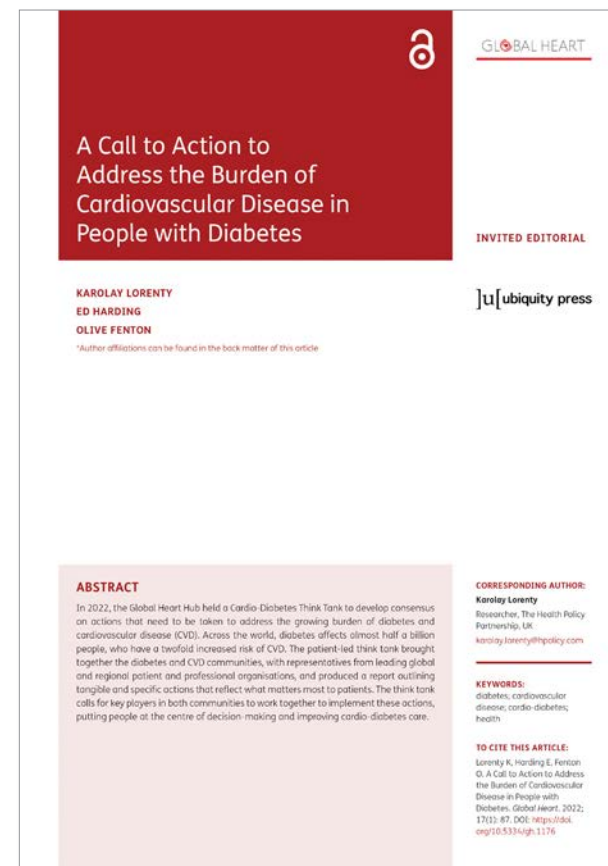
## FOCUS ON CARDIO-DIABETES

## Publication Of Report A Call To Action to address the burden of Cardiovascular Disease in people with Diabetes

In 2022, Global Heart Hub hosted an International Cardio-Diabetes Think Tank to develop consensus on actions that need to be taken to address the growing burden of diabetes and cardiovascular disease (CVD). Across the world, diabetes affects almost half a billion people, who have a twofold increased risk of CVD.

The think tank brought together leading representatives of key international CVD and diabetes patient, nursing, primary and secondary care organisations, including the World Heart Federation, International Diabetes Federation, International and European Primary Care Cardiovascular Societies, Worldwide Cardiometabolic, the Preventative Cardiovascular Nurses Association, the Federation of European Nurses in Diabetes; Diabetes Sisters, Croí, ParSirdi.lv, Diabetes UK and Pacientes de Corazón. Together they produced a consensus report outlining specific, tangible actions needed to improve care for individuals with these concomitant diseases. It calls for key players in both communities to work together to implement these actions, putting patients at the centre of decision-making to enhance cardio-diabetes outcomes.

The key findings from the think tank were published in The World Heart Federation's Global Heart Journal in December 2022.



The  
**Health Policy**  
Partnership

## Cardio-Diabetes Think Tank: Call To Action

Advancing action through patient  
collaboration



JULY 2022



## CAPACITY AND CAPABILITY – EDUCATION AND TRAINING



## Global Heart Hub Academy

In 2020, Global Heart Hub launched the Global Heart Hub Academy, which is an advocacy development programme to support patient organisations, patient advocates and their carers in their advocacy activities. Throughout 2022, the Academy developed and delivered a webinar series (Inspire Speaker Series) aimed at the global patient advocacy community; a comprehensive two-day

virtual conference (Unite Annual Summit) that provided a skills-building and disease updates agenda, and a three-day, in-person training course on Health Technology Assessment Frameworks which took place at SDA Bocconi in Milan which is the leading School of Management in Italy and stands among the top-ranked educational institutions world-wide.



## Inspire Speaker Series

The Inspire Speaker Series featured conversations with key experts and members of the patient community sharing insights and knowledge to inspire patient & carer involvement in advocacy. Some of the topics included:

- What can CVD patient advocates learn from the rare diseases community?
- Nurturing patient advocacy and building sustainable patient organisations.
- Inspiring lived experiences, mobilising adversity for good.

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

- **Dr Durhane Wong-Rieger**, President & CEO at Canadian Organization for Rare Disorders.
- **Jon Barrick**, past President of Stroke Alliance for Europe (SAFE) and current SAFE Patient Voice Ambassador.
- **Susan Strong**, Founding President and current Director of Patient Engagement with Heart Valve Voice US.

## CAPACITY AND CAPABILITY – EDUCATION AND TRAINING



## Unite Annual Summit

On November 29 and 30, the Global Heart Hub brought together 450+ patients, advocates, and patient representatives from across 55 countries for its second 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.

decision-making in heart valve disease and women & heart disease.

The Unite Summit 2022 inaugural remarks were delivered by Professor Fausto Pinto, President of the World Heart Federation, who highlighted that cardiovascular health advocates can convey vital messages to the public and policymakers, helping to improve outcomes at a global level. 'Your mission is our mission,' he said. 'Together we can tackle cardiovascular disease and promote health in the most efficient and successful way.'

Delegate evaluations were overwhelmingly positive, with 100% of those responding saying that they were inspired by what was discussed, and 95% saying that they got ideas which they or their organisation could immediately act upon.



41 excellent speakers explored a variety of topics ranging from 'How To' sessions on fundraising or achieving political impact; to 'Hot Topic' explorations of the links between heart disease and mental health, personalised medicine, or prevention; and 'Focus' sessions on specific aspects of cardiovascular health, such as shared





## CAPACITY AND CAPABILITY – EDUCATION AND TRAINING

## SDA Bocconi Health Technology Assessment Training

From December 12 to 14, 2022, Global Heart Hub brought together 40 global CVD and Cardiometabolic patient advocates from 17 different countries to Milan, Italy for a three-day programme on Health Technology Assessment (HTA) Frameworks.

This Global Heart Hub Academy custom-designed training programme was developed in partnership with the SDA Bocconi School of Management and was a 'first' for the CVD patient community. The programme was designed to contribute to strengthening the patient voice as equal stakeholders in healthcare decision-making.

'Engaging patients in a more inclusive approach can improve the quality of the HTA recommendations' said Prof. Monica Otto, lecturer at the Department of Policy Analysis and Public Management.

The programme not only increased participant understanding of the role of patients in Health Technology Assessment but was also a great networking opportunity for the global CVD patient advocacy community. In the post-course evaluation, 100% of respondents wanted to remain in touch with the other participants, and everyone indicated an interest in or openness to attending future trainings organised by Global Heart Hub.





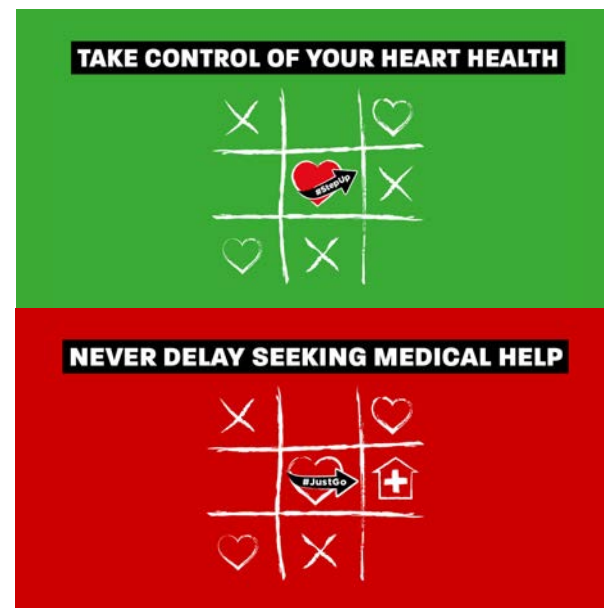
## EVENTS AND COLLABORATIONS

## Phase 3 Covid-19 Education Campaign



Global Heart Hub initiated a patient-led COVID response campaign, shortly after the onset of Covid-19 where patients were encouraged to put their fear of Covid aside and prioritise their heart health. The final phase of the campaign was delivered in Q1 2022. Working with industry partners, Global Heart Hub created a series of posters sharing the key messages of 'Just Go' and 'Step Up' – to encourage heart patients not to delay seeking help and to step up and take control of their own health. The posters were distributed both in print and online, backed by a social media campaign which created over 4.5 million opportunities to see these messages. Global Heart Hub also delivered a webinar on 'Prioritising your Heart Health', which emphasised the necessity to put heart health first, and discussed how to detect and communicate new or changing

symptoms of cardiovascular conditions. The webinar was promoted and made available across digital channels and was also available on the Global Heart Hub website, achieving over one million views.



## EVENTS AND COLLABORATIONS

## World Heart Federation Campaign

Global Heart Hub proudly continued its support of the annual World Heart Day campaign which takes place each year on September 29. Created by the World Heart Federation (WHF), World Heart Day seeks to spread the message around the world 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 equip individuals with the

knowledge they need to take control of their health, including education on the risk factors such as tobacco use, unhealthy diet, and physical inactivity. By raising awareness and encouraging action, lives can be saved – at least 80% of premature deaths from heart disease and stroke could be avoided.

As part of this year's campaign, Neil Johnson, Executive Director of Global Heart Hub, was nominated as a WHF Heart Hero.





## EVENTS AND COLLABORATIONS

## Fokus Patient Event

On October 4, 2022, the Global Heart Hub was delighted to co-organise a CVD Forum in collaboration with Fokus Patient, a Swedish patient organisation, in Stockholm, Sweden. This event was aimed at CVD patients, patient organisation advocates and stakeholders including policymakers, government officials and industry leaders, with the aim of starting important conversations about the future of CVD healthcare.

Topics discussed included: how to create a better patient journey for heart valve patients; the development of optimal high-quality care for patients living with heart failure and its adoption internationally; the urgent need to raise awareness of the realities of atherosclerotic cardiovascular disease (ASCVD); the outstanding barriers to the implementing FH paediatric screening across Europe; and the need for the strategic plans to tackle the burden of CVD at different levels, involving policymakers, patient associations, and industry.



## EVENTS AND COLLABORATIONS

## Roundtable on Heart Valve Disease & Ageing

In December 2022, Global Heart Hub in collaboration with the Global Coalition on Ageing organised an in-person roundtable event in New York where an invited group of 22 international key opinion leaders across the ageing, clinical, policy, economic, and academic fields came together to discuss heart valve disease and ageing. The output of this meeting is a consensus paper calling for key actions on heart valve disease as a barrier to optimal ageing.

The conclusions of the meeting were the base for the global position paper *Heart Valve Disease: Harnessing Innovation to Save Lives, Mitigate Costs, and Advance the Healthy Aging Agenda*, launched in March 2023. The report examines how behaviour and policy change can best address heart valve disease in the ageing population.





## EVENTS AND COLLABORATIONS

## From the Heart Series



Global Heart Hub was invited to contribute to a series of conversations with Marie-France Tschudin, a senior executive with Novartis who narrated a video series 'From the Heart' which is a collection of life experiences told by those living with and those committed to tackling the global reality of CVD. In the series of conversations with leading voices advocating for CVD awareness and change, the series provides an honest look into global healthcare systems, personal anecdotes, patient

journeys and an insight into the non-clinical barriers that prevent people from receiving the care and treatment they need.

In episode 3, released on World Heart Day in 2022, Global Heart Hub's Executive Director, Neil Johnson talked about health preservation and the importance of national health strategies for preventing CVD. He also highlighted the need to reframe the discussion on CVD to wake people up to the significant societal burden of ASCVD.

## EVENTS AND COLLABORATIONS

## European Medtech Forum

The Global Heart Hub was invited to participate at a breakout session at the Medtech Forum in Barcelona on May 5, 2022, to discuss 'Empowering Independent Patient Advocacy'.

This session provided Global Heart Hub with the opportunity to engage directly with Medtech industry representatives and to provide insights into the strength and expertise of the patient community. Furthermore, this was an opportunity to highlight the importance of: patient involvement in CVD treatment and care advancement, supporting patient advocacy and discussing the importance of safeguards to protect independence and transparency.



## Global Heart Hub Endorsed The Prague Declaration

On September 6, 2022, Global Heart Hub was proud to sign the Prague Declaration calling for FH Paediatric Screening across Europe, as part of European and national strategies to prevent cardiovascular disease and to promote cardiovascular health.

The Prague Declaration is a call to action for national and European Union policymakers and decision-makers. It is a policy brief which is the outcome of

the Czech EU Presidency meeting on FH Paediatric Screening (early detection of inherited high cholesterol) which took place at the Czech Senate in Prague.

The Prague event addressed the outstanding barriers to systematic implementation of FH paediatric screening across Europe and highlighted the concrete actions needed to move forward.



## Contact

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