

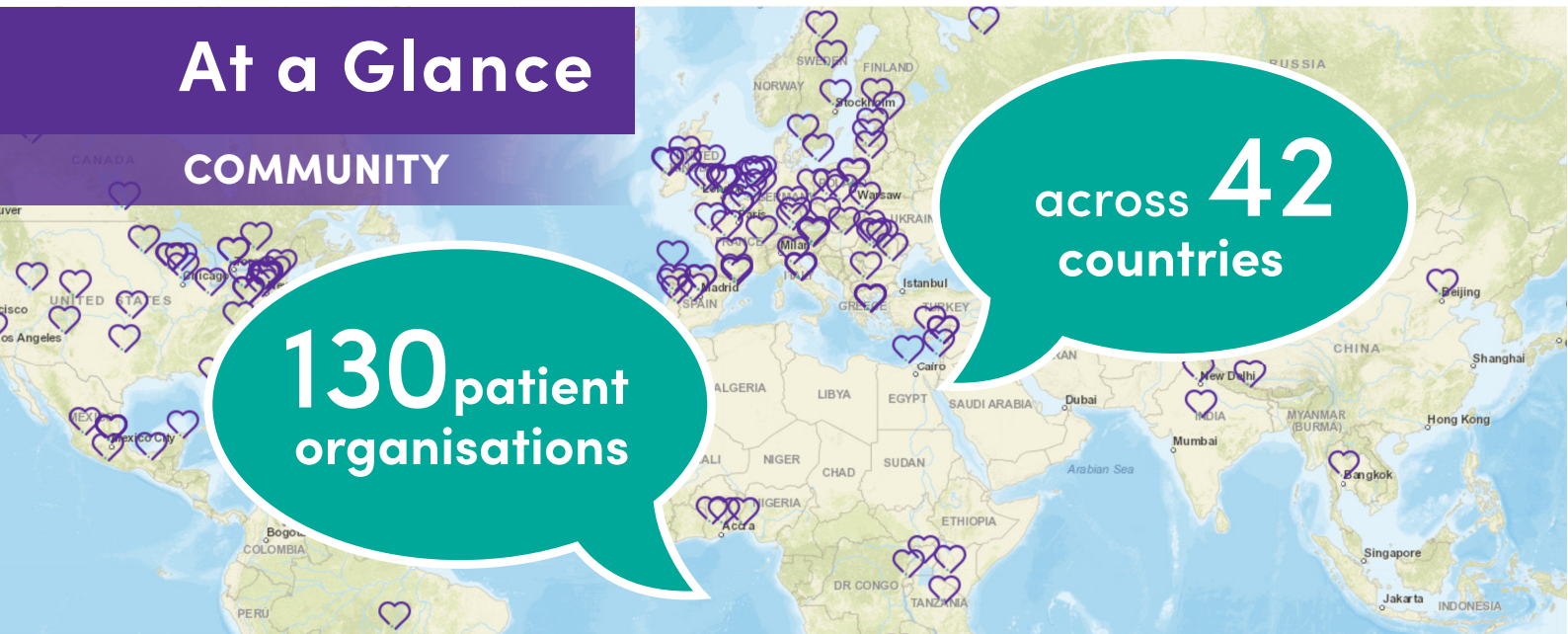


ANNUAL REVIEW

2024

At a Glance

COMMUNITY



OUR ANNUAL INTERNATIONAL PATIENT CONGRESS



165
international
delegates



from 34
countries



20
speakers



100%
of survey respondents
are inspired to act

AWARENESS CAMPAIGNS

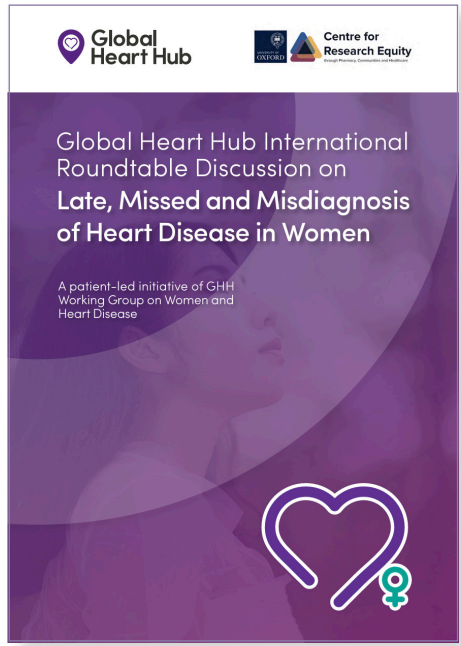
Our Heart Valve Disease, Heart Failure and Cardiomyopathy Awareness Campaigns reached +450M opportunities to see the campaign messages.



NEW PUBLICATIONS



Achieving early detection and diagnosis of cardiovascular disease: A manifesto for change.
Downloaded **630 times**, **113K** opportunities to see across social media channels.



Global Heart Hub International Roundtable Discussion on Late, Missed and Misdiagnosis of Heart Disease in Women.
Downloaded **670 times**, **395K** opportunities to see across social media channels.

CHANNELS



Website
www.globalhearthub.org



LinkedIn
Global Heart Hub



Instagram
@globalhearthub_org



Facebook
facebook.com/GlobalHeartHub



X
x.com/GlobalHeartHub



YouTube
@globalhearthub



Newsletters



Mailing List

2024 REACH

FOLLOWERS:
LinkedIn **4.7K**
Facebook **3K**
Instagram **1.1K**
X Followers **2.6K**

FINANCIALS

As a non-profit organisation, Global Heart Hub is committed to efficient and effective use of resources. The financial management of the organisation ensures all income is utilised for the purposes for which it was received.

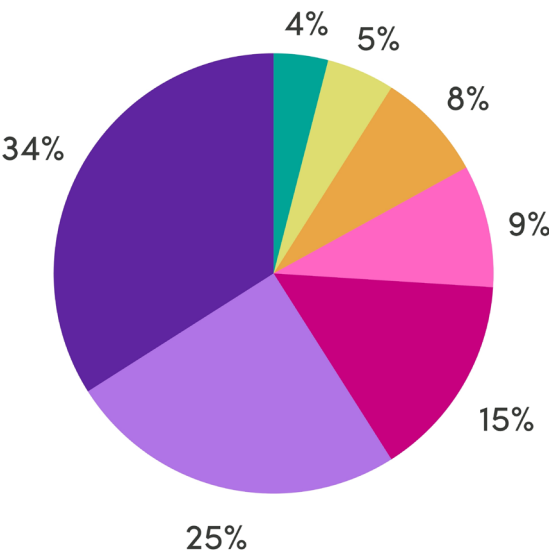
2024 INCOME

In 2024, Global Heart Hub received funding from 18 corporate supporters across the Pharma and MedTech industry sectors. We only engage with industry through ethical and transparent collaborations where, at all times, best patient awareness, education and/or outcomes are the sole objective. All corporate support is received under contracts which clearly and transparently specify what the funding supports. We maintain complete autonomy in the execution of all our activities and programs and retain full editorial control of all our content development, including publications. As a patient organisation promoting cardiovascular health, we do not accept any funding from companies producing products deemed harmful to health.

2024 EXPENDITURE

Total Expenditure: €2.7M

| | | |
|-------------|--|-----|
| <div></div> | Governance & Management – HR, Finance, Communications & IT | 34% |
| <div></div> | Capacity & Capability Building | 25% |
| <div></div> | Evidence Generation – Patient led Research | 15% |
| <div></div> | Advocacy Training | 9% |
| <div></div> | Thought Leadership & Activation | 8% |
| <div></div> | Disease Awareness | 5% |
| <div></div> | Patient Stakeholder Engagement | 4% |



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Who is Global Heart Hub

Global Heart Hub (GHH) is the first global non-profit organisation established to provide a voice for those living with, or affected by, cardiovascular disease (CVD). We are an alliance of heart patient organisations, endeavouring to create a unified global voice for those living with or affected by heart disease.

Our Mission

Our mission is to create and unite a global cardiovascular patient community to advocate for the best possible outcomes for people living with heart disease.

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 CVD patient organisations and provide resources and support to strengthen their capacity and capability for patient advocacy.
- To represent the global CVD 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 global, regional, and national levels.

Our Purpose

Because at the heart of every decision, there should be the people it impacts the most. Our purpose is to amplify the voices of patients through collaboration, education, and collective action to drive real change in heart healthcare. We believe that policies and practices are stronger, fairer, and more effective when patients are truly heard and involved.

Our Strategic Plan 2024 – 2027

Aligned with our mission, the new GHH strategic plan for 2024 – 2027 outlines six key imperatives aimed at enhancing our collective global impact:

1. Programs & Capacity Building
2. Research & Publications
3. Brand & Reputation
4. Sustainability
5. Organisation Capability
6. Governance & Oversight

Learn more: globalhearthub.org/about.

Global Heart Hub Collaborations

GHH is proud to collaborate with:



Company Information

Board of Trustees:

Kevin O'Reilly, Chairman - Ireland
Susan Campbell - USA
Pat O'Donnell - Ireland
Ellen Ross - Canada
Susan Hennessy - USA

Company Secretary:

Marie Gavin - Ireland (Resigned Oct 2024)
FCS Corporate Services

Executive Director:

Neil Johnson - Ireland

Registered office:

Ireland

GHH is a non-profit organisation,
registered in Ireland as a company
limited by guarantee and as a charitable
organisation.



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 always 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.

GHH is a non-profit organisation registered in Ireland as a company limited by guarantee and having charitable status. The organisation is governed by a board of voluntary non-executive directors. The board oversees the governance of the organisation and each year GHH undergoes an independent audit and files reports and accounts with the Irish companies' registration office and the Irish charity regulator.



Welcome

Dear Community,

This year, GHH celebrates five years of uniting and amplifying the voice of the global cardiovascular patient community. To date, we have grown our international affiliate network to 130 patient organisations across 42 countries, working together to strengthen the patient voice, raise awareness of the burden of CVD and advocate for optimal cardiovascular care worldwide. As we grow, we better understand the patient landscape across the globe. As we unite our patient community, we have identified differing capacity and capability challenges across patient organisations; upskilling and training needs in patient advocacy and unmet patient needs across the CVD landscape from detection through to treatment and recovery. As we reflect on our work to date, and in particular over the past year, we reaffirm our core mission to ensure that the patient voice remains central to all issues in cardiovascular healthcare.

In the past year, we launched significant publications, including a Manifesto for Early Detection and Diagnosis of Cardiovascular Disease and an insight report on Late, Missed and Misdiagnosis of Heart Disease in Women. The Manifesto was driven by the lived experience of our patient community, whose evidence on the impact of delayed, missed and misdiagnosis on their health outcomes and multiple other areas of their lives, confirms the critical importance of this issue. Equally, the lived experience of women with CVD from within our international network served as the catalyst for a multi-disciplinary roundtable discussion. The output from this event now serves to guide our urgent and future work to address the cardiovascular healthcare gap between men and women.

In November, we were delighted to welcome 165 delegates from 34 countries across the globe to Dublin, Ireland, for the 4th Annual GHH Unite Patient Summit. The focus of the meeting was on CVD and its interconnected conditions. Uniquely, the event brought together for the first time the patient communities across heart, stroke, diabetes, obesity, kidney and liver disease to explore the challenges of living with lifelong connected conditions. The summit report identified key healthcare policy asks essential to integrated and holistic care.

Our annual disease awareness campaigns were once again co-created and activated by our patient councils in Heart Valve Disease, Cardiomyopathy and Heart Failure. Together, these initiatives delivered a combined 450 million opportunities internationally to see the campaign messages.

Importantly, over the past year, we have had increased opportunities for patient engagement in research and patient insight advisory initiatives. Our collaborations with international organisations such as the EACH alliance continue to contribute to amplifying the patient voice in cardiovascular healthcare policy. We are encouraged and motivated by the prospect of an imminent EU Cardiovascular Health Plan.

GHH is only as strong as its affiliates and supporters. We extend our heartfelt gratitude to our incredible community of affiliates and supporters. Your unwavering commitment, collaboration, and generosity have been instrumental in advancing our mission to improve the lives of those living with and affected by CVD. Together, we continue to achieve significant milestones, raise awareness on a global scale, and empower patient advocates and patient organisations.

Thank you for your sustained support and commitment and we look forward to continuing our journey together in the years to come.

Sincerely,



Kevin O'Reilly
Chairman



Neil Johnson
Executive Director



Our Global
Community
in 2024

30

patient
organisation
affiliates
in North America

5

patient
organisation
affiliates
in Latin America

73

patient
organisation
affiliates
in Europe

11

patient
organisation
affiliates
in Africa
& Middle East

11

patient
organisation
affiliates
in Asia
& Australasia

<https://globalhearthub.org/affiliate-map/>

Our Work

Disease Awareness Campaigns

HEART FAILURE

HEART FAILURE AWARENESS MONTH - MAY

Led by GHH’s Heart Failure Patient Council, the [2024 Heart Failure Awareness Campaign](#) focused on heart failure comorbidities and the importance of managing heart failure and connected conditions.

An impactful campaign that delivered an educational message highlighting the role of comorbidities. Heart failure and comorbidities are closely linked, with heart failure often contributing to the development of other health conditions, and in turn, those conditions can accelerate the progression of heart failure.

Heart Failure patients often suffer from multiple comorbidities (cardiovascular and non-cardiovascular), such as an irregular heart rate or rhythm, high blood pressure, kidney disease, Type 2 diabetes, obesity, iron deficiency, and mental health conditions like anxiety and depression.

The campaign generated 26M opportunities to see, was translated into 15 languages and shared by 21 organisations across 18 countries. We thank our Affiliates and cardiovascular community for supporting the campaign and raising awareness of heart failure comorbidities. *See our campaign’s impact on the next page.*



HEART FAILURE PATIENT COUNCIL MEETING, MILAN

HEART FAILURE PATIENT COUNCIL MEETING

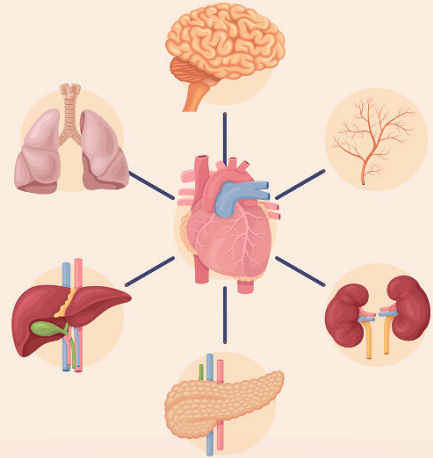
In September, the Heart Failure Patient Council Meeting took place in Milan, Italy, bringing together 19 Patient Organisation leaders from across 16 countries for an opportunity to connect, share experiences, and discuss advancements in heart failure advocacy.

HEART FAILURE AND HYPERTENSION THINK TANK


GHH hosted a Heart Failure & Hypertension Think Tank, bringing together 21 patient organisations and leaders, 6 patient advocates, 19 participants with lived experience and/or hypertension and 7 industry representatives. The event, which took place in Milan, invited those in attendance to discuss the current care landscape, share personal insights, and contribute to a discussion on clinical trials and unmet needs.

OUR IMPACT


HEART FAILURE AWARENESS CAMPAIGN 2024



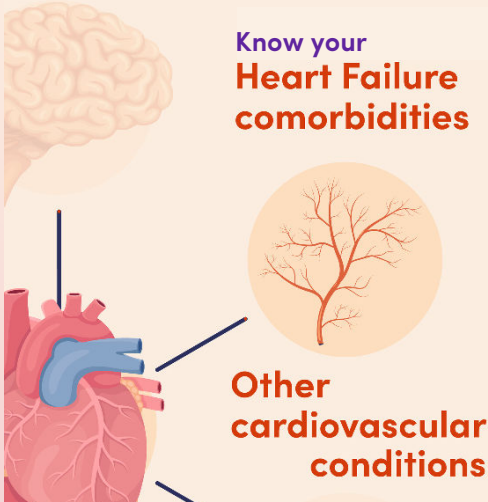
Delivered over **26M** opportunities to see Heart Failure Campaign messages across print, social and digital coverage.



Campaign video and social media assets translated across **15 languages**




Know your **Heart Failure comorbidities**



Other cardiovascular conditions

Campaign messages shared by **21 organisations & influencers across 18 countries**



Press pick-up across **84 media outlets, including national radio, press and TV coverage.**

HEART VALVE DISEASE

GLOBAL HEART HUB ATTENDS THE HEART VALVE SOCIETY ANNUAL MEETING

GHH kicked off 2024 by attending the Heart Valve Society’s Annual Meeting in Boston with a special session representing the patient voice and highlighting the important role of shared decision-making in heart valve disease treatment.

Ellen Ross (Chair, GHH Heart Valve Disease Council) presented the outcomes and recommendations of GHH’s Paving the way: a roadmap to the successful implementation of shared decision-making in heart valve disease; while in conversation with the Heart Valve Society President, Dr Ismail El Hamamsy, GHH Operations Manager, David Kelly discussed his own patient journey with congenital heart valve disease and the importance of true shared decision making in the healthcare system.



GLOBAL HEART HUB PATIENT ADVOCATE TRAINING ON HEART VALVE DISEASE

In June, GHH held a patient advocate training workshop on heart valve disease, in collaboration with the Heart Team Academy, bringing together thirty-nine participants across eighteen countries, including patient organisation leaders, advocates and clinicians from the heart team. This event provided attendees with the tools to better support their heart valve communities.

The patient-led training day was designed to broaden the attendees’ knowledge of heart anatomy; the nature and types of Heart Valve Disease; treatment options and innovations, as well as an insight into treatment guidelines; shared decision-making; and post-procedure expectations.

Speakers included:

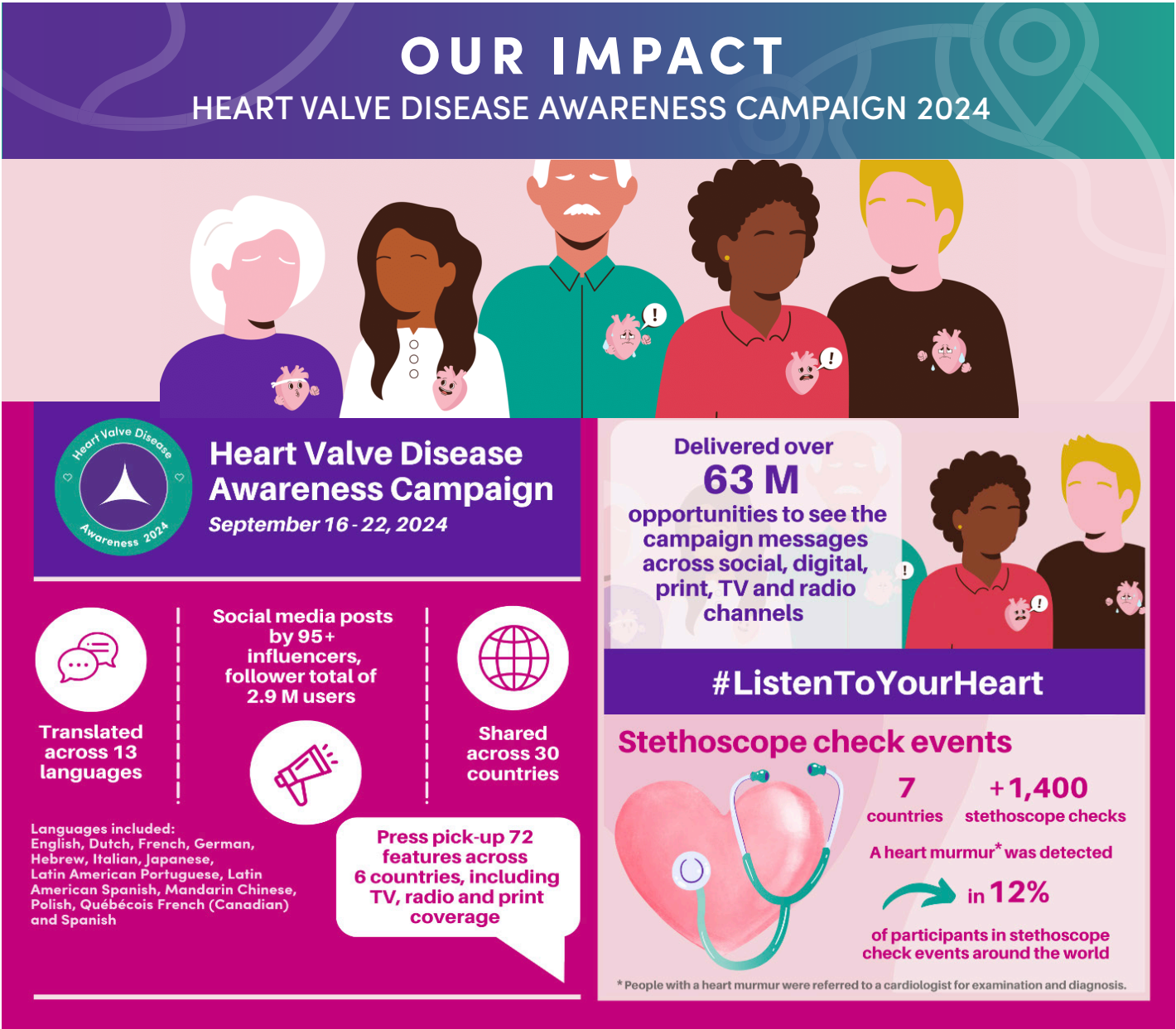
- **Dr Peyman Sardari Nia**, MD, PhD – a Senior Consultant Cardiothoracic Surgeon at Maastricht University Medical Center and associate professor at Maastricht University in the Netherlands, with a specialised focus on minimally invasive cardiothoracic procedures.
- **Dr Nabila Laskar** – a specialist in Cardiac Imaging at Barts Heart Centre in London, with a focus on heart valve disease.
- **Dr Konstantinos Spargias** – an Interventional Cardiologist and the Director of the Transcatheter Heart Valves Department at the Hygeia Hospital in Athens, Greece.

HEART VALVE DISEASE AWARENESS WEEK - SEPTEMBER

September was GHH’s International [Heart Valve Disease Awareness Week](#), which took place from September 16-22, 2024. The awareness campaign was led by the Heart Valve Disease Patient Council of GHH, where the message was driven by supporters across 30 countries including: Austria, Brazil, Canada, China, France, Germany, Ireland, Israel, Italy, Japan, Mexico, Poland, Spain, The Netherlands, UK, US, and more.

The campaign achieved over 63 million opportunities to see the message across online media, TV, radio and print. Translated across 13 languages, the campaign was shared across 30 countries and press pick-up included 72 features across 6 countries. In addition, over 1,400 stethoscope checks were carried out across 7 different countries, highlighting the significance of performing stethoscope examinations to detect a heart murmur.

A collective effort with our affiliates, we thank everyone who supported this awareness campaign.



CARDIOMYOPATHY

CARDIOMYOPATHY AWARENESS MONTH - JUNE

Led by GHH's Cardiomyopathy Patient Council, which has 24 patient organisation affiliates across 15 countries, the 2024 campaign, titled [Think Cardiomyopathy!](#) focused on patient and advocate stories, the impact of cardiomyopathy and the importance of recognising symptoms and knowing your family history.

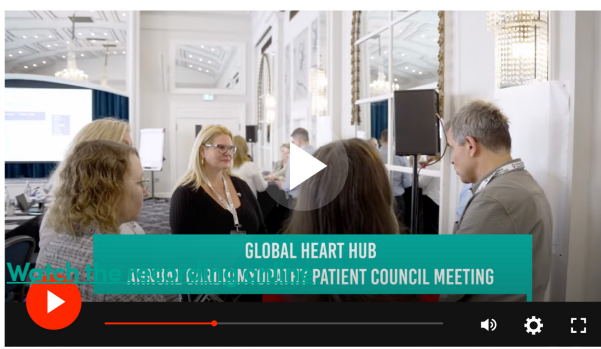
With a succinct key message to 'Think Cardiomyopathy', the campaign delivered a combined 364.2M opportunities to see the campaign messaging across social, digital, and press release media outlets, reaching a large-scale global audience. The campaign messages were translated into 11 different languages and shared across 17 countries. A collective effort with our affiliates, we thank everyone who supported this initiative.

CARDIOMYOPATHY PATIENT COUNCIL IN-PERSON MEETING

In August, GHH held its in-person Cardiomyopathy Patient Council meeting in Windsor, UK. This event brought together 17 patient organisations from 12 different countries over 3 days, where we examined common challenges and synergies, and explored opportunities for collaboration to improve awareness, diagnosis and management of cardiomyopathy.

The Cardiomyopathy Patient Council discussed the relationship between Cardiomyopathy, Cardiac Amyloidosis and Heart Failure at this year's Patient Council meeting in Windsor, UK. We were honoured to welcome keynote speakers Professor Hugh Watkins of the University of Oxford and Professor Perry Elliott of University College London. They explored a wide range of topics, from the most pressing challenges and unmet needs to the evolving cardiomyopathy landscape, with a particular focus on advances in genetic therapies.

In addition to the Patient Council meeting, GHH hosted a session with key stakeholders to discuss synergies, challenges and opportunities in Cardiac Amyloidosis, Cardiomyopathy and Heart Failure. This subsequent meeting explored collaborative approaches for those affected by these connected conditions, providing a unique opportunity to connect, share experiences, and map our course for the future.



GLOBAL HEART HUB JOINS WORLD HEART FEDERATION CALLS FOR NATIONAL CARDIOVASCULAR ACTION PLANS

On World Heart Day, GHH joined the World Heart Federation's 'Use Heart for Action' campaign to help send a powerful and united message to our leaders and governments, to encourage all nations to implement comprehensive cardiovascular health plans and make cardiovascular health a priority.

CVD remains the world's leading cause of death, claiming more than 20.5 million lives each year. Yet in many countries, heart health is still not a priority, and national policies to address CVD are either inadequate or non-existent.

To address this urgent gap, GHH and its partner patient organisations worldwide joined forces to deliver a united message, urging people everywhere to support the World Heart Federation petition campaign to help save lives and reduce the global toll of cardiac deaths.

[Watch the recording online.](#)

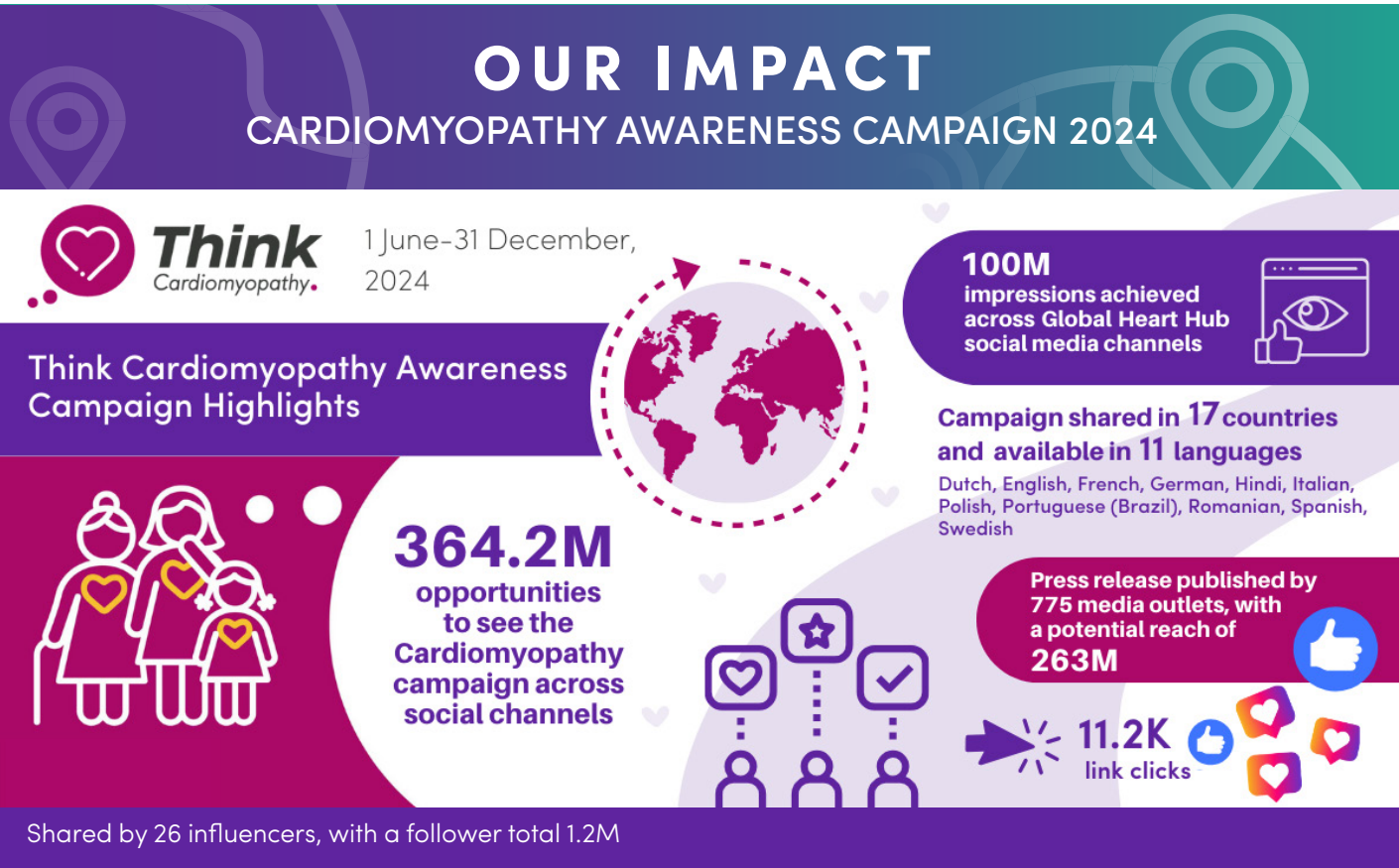
WORLD DIABETES DAY



GHH team member Dr Konstantina Boumaki sharing her lived experience story on World Diabetes Day

As we continued our focus on comorbidities, in November on World Diabetes Day, we celebrated the collective strength of our global connected conditions community as we worked toward the same goals – equitable healthcare, earlier and accurate diagnoses, better education, and access to the latest treatments and technologies.

Diabetes and CVD are closely linked, with cardiovascular complications being a leading cause of mortality for people with diabetes. This connection underscores the urgency of our work in the cardiovascular space to raise awareness, support prevention, and improve care options.



Roundtable Meetings

ROUNDTABLE MEETING ON LATE, MISSED AND MISDIAGNOSIS OF HEART DISEASE IN WOMEN

On April 22, GHH was delighted to host a roundtable meeting in Madrid, Spain, bringing together 27 participants from across 15 countries, including women with lived experience, patient organisation leaders, public health experts, researchers and clinicians to focus on late, missed and misdiagnosis of heart disease in women.

This event was hosted with support from the Centre for Research Equity at Oxford University, London, represented by Dr Paula Wray, who collaborated to prepare a consensus paper to drive impactful change and foster practical solutions to this pressing issue.



The challenges experienced by women across the globe in relation to the diagnosis and treatment of heart disease are well documented. Heart disease is the leading cause of death in women, yet there are enormous sex inequities – heart disease in women is under-studied, under-detected, under-diagnosed and under-treated. GHH together with our affiliate network across the globe is committed to tackling the health care gap between women and men in CVD.

ROUNDTABLE DISCUSSION ON INTEGRATING PATIENT PERSPECTIVES INTO FUTURE CARDIOVASCULAR HEALTH POLICIES - BRAZIL



On June 18, GHH partnered with our affiliate in Brazil Instituto Lado a Lado pela Vida in convening a national multistakeholder roundtable discussion on integrating patient perspectives into future cardiovascular health policies.

The meeting was hosted by Instituto Lado a Lado pela Vida who brought together key stakeholders – policymakers, healthcare professionals and civil

society leaders, all of whom are committed to reducing the burden of CVD which is a leading cause of death in Brazil.

GHH's Executive Director, Neil Johnson together with Fernanda de Carvalho, Public & International Affairs, Instituto Lado a Lado pela Vida, presented findings from the GHH IPEC Study (Insights from Patients living with Elevated Cholesterol), a multi-national patient-led research initiative that collected insights on the lived experiences of individuals from Brazil, USA & Australia who are living with high cholesterol levels.

The IPEC findings provided valuable insights for the stakeholders who are all united in the need for a national cardiovascular health strategy for Brazil. Instituto Lado a Lado pela Vida was instrumental in securing the national cancer plan for Brazil and they are now hoping to achieve similar success in the area of cardiovascular health.

[Watch the recording online.](#)

Reports

ACHIEVING EARLY DETECTION AND DIAGNOSIS OF CARDIOVASCULAR DISEASE: A MANIFESTO FOR CHANGE

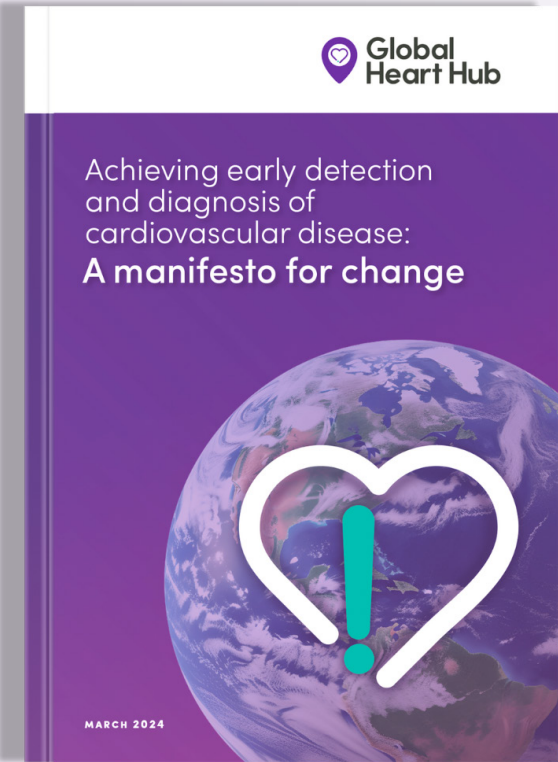
GHH united the cardiovascular patient community to create the first global manifesto calling for early detection and early diagnosis of CVD.

This manifesto, an output of the Unite Summit 2023, was developed in response to the concerns of those with lived experience of missed or delayed diagnosis.

In March 2024 GHH launched this first global manifesto calling for greater attention to early detection and diagnosis of CVD. This first-of-its-kind manifesto was developed through a multi-stakeholder approach, bringing together 125 patient advocates including 40 CVD patient organisations, key opinion leaders and multidisciplinary experts from leading organisations including World Heart Federation and the European Society of Cardiology.

Urgent action to improve the early detection and diagnosis of CVD is essential. Globally, CVD places considerable pressure on health systems, and this burden is predicted to continue to increase as populations age, affecting not only population health but also workforce productivity and the economic sustainability of health systems and wider society. Delayed or missed detection and diagnosis of CVD significantly increases mortality and healthcare costs. GHH's landmark manifesto focuses on eight practical evidence-based actions which are critical for the implementation of early detection and diagnosis of CVD.

This manifesto is a much-needed call to action, to focus attention on the importance of early detection and diagnosis of CVD and outlines clear, tangible actions required to address this situation.



Tackling CVD requires a cohesive, global approach. It requires the concerted efforts of governments, healthcare providers and professionals, patient groups and industry representatives. To make early detection and diagnosis of CVD universally accessible, we are calling on policymakers to lead on these efforts, driving change that integrates best practices into national healthcare strategies.

An article summarising the key actions suggested in the manifesto was published in the European Heart Journal, authored by Prof Fausto J. Pinto, Department of Cardiology, Santa Maria University Hospital and Faculty of Medicine, University of Lisbon, Portugal; Ed Harding, The Health Policy Partnership; and Olive Fenton, GHH.

The full report is available [online](#).

WOMEN AND HEART REPORT

GHH International Roundtable Discussion on Late, Missed and Misdiagnosis of Heart Disease in Women

The roundtable meeting, held in Madrid in April 2024, and the resulting report, titled 'Global Heart Hub International Roundtable Discussion on Late, Missed and Misdiagnosis of Heart Disease in Women', reflect on the environment around diagnosis, treatment and management of CVD in women. In addressing women's cardiovascular health, recognition of unique challenges and disparities experienced by women who face gender related barriers in accessing healthcare is necessary.

Urgent global action is required to improve equity in early detection, early diagnosis and the treatment journey for women with CVD. GHH hosted a one-day international roundtable discussion, in collaboration with the GHH Women & Heart Disease Working Group. The meeting focused primarily on the issues of under-representation of women in clinical research;

late, missed and misdiagnosis of heart disease in women and under-research of female-specific risk factors and heart conditions.

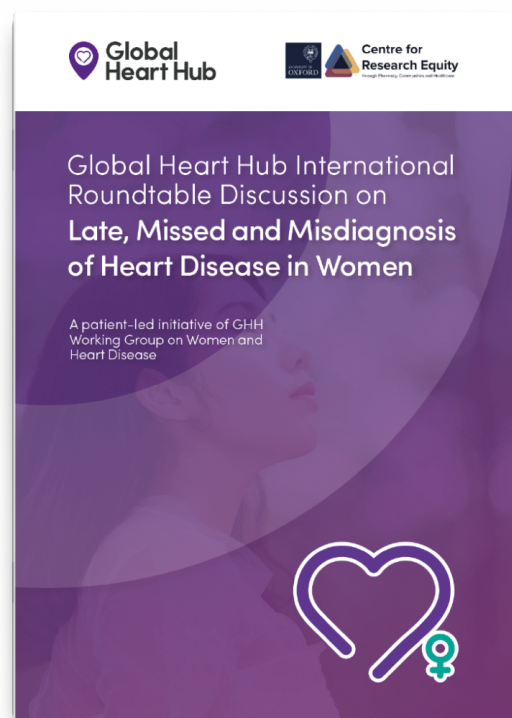
The resulting report focuses on four priority areas:

- Healthcare system and medical education;
- Research;
- Patient & public engagement and awareness;
- Policy change and public health.

These priority areas provide a roadmap for GHH as it embarks on a journey to engage with relevant stakeholders in addressing the sex equity gaps for women with CVD.

This roundtable meeting took place in Madrid, Spain on April 22nd 2024, for more information on the meeting see page 16 of report.

The report can be viewed [online](#)



Priority areas identified by the roundtable meeting participants



HEALTHCARE SYSTEM AND MEDICAL EDUCATION



PATIENT AND PUBLIC ENGAGEMENT AND AWARENESS



RESEARCH



POLICY CHANGE AND PUBLIC HEALTH

Patient Engagement

UNITE SUMMIT

OUR IMPACT

UNITE ANNUAL SUMMIT 2024





165
international delegates



from
34
countries



20
speakers



100%
of survey
respondents are
inspired to act

4TH ANNUAL UNITE SUMMIT -
CARDIOVASCULAR DISEASE; LIVING
WITH MULTIPLE CONDITIONS AND ITS
CONNECTED CONDITIONS

In November, GHH welcomed 165 delegates from 34 countries across the globe to Dublin, Ireland, for its 4th Annual International Patient Congress. This meeting brought together patient organisation leaders, patient advocates & carers, together with clinical experts, researchers, policy makers, and a range of key healthcare stakeholders from around the world to discuss the challenges of living with heart disease and its interconnected conditions such as stroke, diabetes, chronic kidney disease, liver disease and obesity.

The two-day event focused on the challenges of the lived experience and heard from several individuals living with multiple long-term connected conditions. Those attending also discussed and heard about innovations in treatment and care for multiple long-term CVD-related conditions. A key aspiration of the Summit was to explore solutions and actionable priorities to improve patient care and quality of life.

For the first time, the patient communities across heart, stroke, diabetes, obesity, kidney and liver disease came together to explore the challenges of living with lifelong connected conditions.

A key issue identified by those living with connected conditions is having to navigate healthcare systems which were designed to provide care in silos. The meeting heard of the frustrations and challenges experienced by those living with co-existing CVD conditions. It highlighted the opportunities and benefits of patient-centred, integrated, holistic care. By bringing the related patient communities together, we can create a stronger voice for policy change, which can deliver better patient outcomes.

This year's GHH Patient Summit welcomed 20 international speakers from across the fields of patient advocacy, clinical practice, research, policy and public health. The patient perspective was integrated throughout the programme, anchoring the Unite Summit as the only global, patient-led, international cardiovascular patient congress.

PATIENT-LED QUALITATIVE RESEARCH: INSIGHTS FROM PATIENTS LIVING WITH ELEVATED CHOLESTEROL (IPEC)

A Year of Impact – Amplifying the Patient Voice in Cardiovascular Research

New qualitative research explores patient experiences with high cholesterol and ASCVD events.

Insights from Patients Living with Elevated Cholesterol (IPEC) was led by GHH, with the support of WomenHeart, USA; Lado A Lado Pela Vida, Brazil; hearts4heart, Australia and the cardiovascular patient community. Findings from IPEC were submitted to key congresses around the world for visibility among decision makers, policy makers and physicians. Supported by the findings from IPEC, the global cardiovascular patient community is positioning itself to take part in future conversations around LDL-C management strategies.

In 2024, IPEC highlighted the growing recognition of the patient perspective in cardiovascular research, with abstracts successfully presented at leading scientific congresses. It has become clear that patient-led insights are no longer optional—they are essential to driving meaningful change.



A GLOBAL PLATFORM FOR PATIENT VOICE

Throughout 2024, IPEC was featured at major international congresses, including the European Atherosclerosis Society (EAS), the European Society of Cardiology (ESC), and the American Heart Association (AHA). Local findings were presented at key events such as the Sociedade Brasileira de Cardiologia (SBC) meeting in Brazil, the Cardiac Society of Australia and New Zealand (CSANZ) in Australia, and the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) in the U.S.

These platforms provided invaluable opportunities to highlight the real-world experiences, needs, priorities, and perspectives of the participants, and underscore critical insights, such as the concerning finding that one-third of participants were unaware of the risks associated with elevated cholesterol.

View posters [here](#).

LEADERSHIP, DEDICATION AND POLICY CHANGE

The success of IPEC is rooted in the guidance of its multidisciplinary Steering Committee and the dedication of the patient organisations – Women Heart (USA), Lado A Lado pela Vida (Brazil), and hearts4heart (Australia).

We are deeply grateful to the Steering Committee for their exceptional guidance and leadership from the very inception of this research initiative. Our three patient organisation affiliates rose to the challenge, demonstrating unwavering commitment and dedication throughout the process. Their efforts transformed data into actionable insights, furthering patient advocacy. One standout example was Lado A Lado’s multi-stakeholder roundtable in Brazil, which brought together 20 experts to discuss findings from IPEC and set the stage for meaningful policy shifts. The meeting amplified critical insights that have opened doors to deeper conversations with stakeholders, especially clinicians and policymakers, ensuring the patient perspective takes centre stage in cardiovascular care.

A SHARED COMMITMENT TO ONGOING PATIENT EXPERIENCE RESEARCH IN 2025

GHH takes immense pride in the successes achieved through the IPEC study. This initiative has demonstrated the strength of collaboration and the transformative impact of patient-led research. IPEC has laid a strong foundation for advancing the role of the patient voice in research, clinical practice and healthcare policy—and we’re just getting started.

2025 holds exciting opportunities to build on these milestones, and GHH remains steadfast in its commitment to empowering patients, deepening understanding of lived experiences, and championing patient-led research. Guided by the voices and perspectives of patients worldwide, we look forward to driving even greater impact and contributing to meaningful improvements in cardiovascular health.



PATIENT VOICE INCORPORATED

Improving patient engagement is not just a strategic imperative but also a necessary step towards more effective, efficient and equitable healthcare. Fostering better patient engagement can drive innovation, enhance patient satisfaction and ultimately improve global cardiovascular health outcomes. GHH is committed to ensuring that our patient engagement activities, in partnership with key stakeholders, are not only effective but also ethical and transparent.

In September 2024, GHH launched Patient Voice Incorporated (PVI), a set of best practice guidelines to foster trust and collaboration, drive innovation, influence both industry and healthcare practice and policies, ultimately delivering better outcomes for heart patients globally.



The guidelines offer an agreed set of fundamental principles which help to standardise patient engagement practice, evaluate the quality of engagement and set a standard for best practice.

GHH recommends using the guidelines as a practical planning tool for future patient engagement projects.

Patient Voice Incorporated – learn more at globalhearthub.org/patientvoiceinc.

EU COLLABORATIVE PROJECTS

GHH recognises the importance of engaging in EU-funded projects to advance research, improve healthcare policies, and promote patient-centred care.

EUROPEAN CONSORTIUM TO DEVELOP A “HARMONIZED APPROACH TO EARLY FEASIBILITY STUDIES FOR MEDICAL DEVICES IN THE EUROPEAN UNION” (HEU-EFS)

Improving patient access to innovative medical technologies in the European Union

In January 2024, the HEU-EFS project addresses the need for a unified approach to Early Feasibility Studies for medical devices in Europe by creating a harmonised framework. This initiative aims to accelerate patient access to innovative technologies while boosting clinical trial efficiency and attracting global investment in European healthcare innovation.

GHH joined the HEU-EFS project consortium, teaming up with the European Patients' Forum (EPF) to advance patient centricity in the project. GHH's contribution centres on ensuring the patient voice is heard, represented and meaningfully engaged early on, benefitting everyone involved in the development and use of medical devices.

Together, GHH and EPF, lead efforts to integrate patient input into all stages of the project via a dedicated Patient Advisory Group, ensuring that patient perspectives are integrated throughout the project, contributing to more patient-focused medical device development.

This four-year project is funded by the Innovative Health Initiative under the Horizon Europe Framework Programme and involves 22 public and private organisations across Europe (including EEA and Switzerland).

Learn more [here](#).

RESILIENCE TOOL FOR ENHANCED CRISIS PREPAREDNESS IN CVD ACROSS EU MEMBER STATES (RESIL-CARD)

RESIL-Card is an EU4Health funded project managed by a consortium of four partners dedicated to enhancing the resilience of European healthcare systems in providing cardiovascular care. The project aims to develop and implement a protocol-based tool enabling cardiovascular stakeholders to assess and address the gaps in care systems, ensuring continuity during crises. GHH is delighted to support the work of the consortium, representing the patient voice throughout the planning process and at their Year 1 General Assembly Meeting in Paris in November 2024. Following the tool pilot phase taking place in 2025, GHH will play a key role in communication and dissemination within the patient community planned for 2026.

HEALTH TECHNOLOGY ASSESSMENT (HTA) STAKEHOLDER NETWORK

GHH appointed a member of the Health Technology Assessment (HTA) Stakeholder Network.

The HTA Stakeholder Network aims to facilitate dialogue between stakeholder organisations and the HTA Coordination Group. It plays a crucial role in implementing the EU Health Technology Assessment Regulation (EU) 2021/2282, which seeks to ensure that health technologies are evaluated comprehensively based on their medical, economic, social, and ethical implications. By bringing together diverse perspectives, the network supports the development of policies that enhance access to safe and effective health technologies across Europe.

Being part of the HTA Stakeholder Network allows GHH to contribute our expertise and insights towards shaping health technology assessments that directly impact patients' lives. Our participation will enable us to advocate for patient-centred approaches in health technology evaluations, ensuring that innovations are not only effective but also accessible and equitable. This collaboration is vital for fostering a transparent and inclusive decision-making process that

prioritises patients' needs and enhances healthcare delivery across Europe.

We look forward to actively engaging with other members of the HTA Stakeholder Network to promote meaningful advancements in health technology assessments.

EUROPEAN CARDIOVASCULAR HEALTH PLAN

As a proud member of the European Alliance for Cardiovascular Health (EACH), GHH welcomed the announcement by the European Commissioner for Health Olivér Várhelyi, that the European Commission will develop a new European Cardiovascular Health Plan.

The announcement by the Health Commissioner in December 2024 reflected the key objectives of the EACH Roadmap (call to action), which includes strengthening primary and secondary prevention, early detection and screening, and optimising the management and rehabilitative care of those with CVD.

It is vitally important now that the European Commission ensures the availability of adequate funding to drive cardiovascular health actions in an integrated way, across primary, secondary and tertiary care. GHH is committed to empowering its patient organisation affiliates to collectively advocate, engage and ensure that the patient voice is at the heart of policy making.



Capacity

ACADEMY

The GHH Academy supports the development needs of the global heart patient community by providing a range of capacity and capability activities throughout the year.

MASTER CLASS WITH BOCCONI UNIVERSITY

GHH partnered with the SDA Bocconi School of Management to present a three-day training course in Milan, Italy from September 11 – 13, 2024, focusing on practical steps to patient engagement in health technology assessment, advocacy and strategic communications.

32 advocates from across 18 countries took part in patient impact training, which was designed to allow for in-depth exploration of key topics, hands-on learning and collaborative problem-solving; empowering participants to implement advocacy strategies that drive meaningful change in their organisations and communities.

SDA Bocconi is a leading institute, making it an ideal partner for patient advocacy empowerment by developing the strategic and leadership skills necessary to drive impactful change in global cardiovascular health.

In the post-event evaluation survey, participants rated the course and experience between 93–100%. A sample of attendees’ comments includes:



“This experience has been incredibly positive and impactful. Gaining a deeper understanding of effective communication with regulator s, advocacy groups, ministers and HCPs is truly priceless”.



EMPOWER WEBINAR SERIES

The EMPOWER series of patient-focused webinars presents up-to-date information, answers burning questions, and communicates in patient-friendly language. The webinars are co-hosted with patient organisations within the GHH affiliate community.

In 2024 GHH hosted the following webinars:

- **March:** *Mental Health and Wellness While Living With CVD*, in partnership with Serce na Banacha, Poland
- **June:** *Understanding the Link Between Obesity and CVD*, in partnership with the Irish Coalition for People Living with Obesity & European Coalition for People Living with Obesity
- **September:** *A Patient’s Guide to SDM for HVD*, in partnership with Heart Valve Voice Canada

In all three webinars, 100% of respondents rated the webinar positively, with ‘excellent’ being the most common response and feedback provided.

Watch back our webinars [online](#).

GROW WORKSHOPS

GROW virtual workshops are online webinars offering regular networking and skill-building opportunities to enhance key skills in advocacy, communications, and organisational growth.

In 2024, GHH’s Grow series delivered a total of nine virtual workshops, structured into four key topics. These sessions provided patient advocates with valuable insights, skills, and strategies to deliver impact. The series covered the following topics: Social Media, Advocacy, Patient Data and Fundraising.

Across all four topics, 100% of respondents rated the webinar positively, with ‘excellent’ being the most common response. Attendees commented:



“Thoroughly enjoyed the session and loved the opportunity to discuss in the breakout room. This also was a special way to continue relationships and feel part of this worldwide heart family”.



“It was an excellent session, well-structured and well-delivered. I loved the opportunity to meet other patient leaders”.

PUBLICATIONS

➔ Fausto J Pinto, Ed Harding, Olive Fenton, **A Manifesto from Global Heart Hub for early detection and diagnosis of cardiovascular disease**, *European Heart Journal*, Volume 46, Issue 4, 21 January 2025, Pages 339–340, <https://doi.org/10.1093/eurheartj/ehae45>

This publication shines a spotlight on GHH’s ‘Achieving early detection and diagnosis of cardiovascular disease: A manifesto for change’, a global, patient-led manifesto. [Learn more](#)

➔ Damien Gruson, Chiara Peranio, Sergio Bernardini, Aistė Štaraitė, Mikki Koo, Mike Coyle, Bryan Shannon, David Luu, Ed Harding, Tuğba Kemaloğlu Öz, **Light After Armageddon: Enhancing Cardiovascular Care through Emerging Technologies and Patient-Centric Approaches**, *Journal of the International Federation of Clinical Chemistry* (ejlFCC), <https://ifccfiles.com/2025/01/ejlfcc2024vol35No4pp212-215.pdf>


➔ M Camafort, A Dzudie, B Ivanovic, N Johnson, J Magne, J M Mostaza Prieto, I Pecin, A Postadzhiyan, T Shaburishvili, D Vinereanu, **Blood pressure control and cardiovascular risk assessment in patients with hypertension: a pooled analysis of 6 countries in Eastern and Southern Europe (SNAPSHOT study)**, *European Heart Journal*, Volume 45, Issue Supplement_1, October 2024, ehae666.2549, <https://doi.org/10.1093/eurheartj/ehae666.2549>

In addition, GHH was delighted to contribute to the following articles:


- [“Heart Failure in the face of the Healthcare System”](#)
- [“How to make treatment plans work”](#)
- [“A patient-community-led qualitative study to understand the patient experience with high cholesterol in the United States”](#)

In 2024, GHH was thrilled to present six scientific abstracts on Insights from Patients Living with Elevated Cholesterol (IPEC), a patient-led research initiative, at leading scientific congresses around the world. [Learn more.](#)


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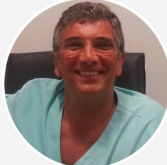
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