

ANNUAL

REVIEW

2023



Contents

Company Information	2
Our Supporters	3
Welcome	4
Our Global Community	6
2023 Highlights in Numbers	8
Heart Valve Disease	10
Heart Failure	14
Cardiomyopathy	16
Events	18
Collaborations	19
Hub Highlights	20
Invisible Nation	22
Academy	24
Advocacy	27
Financial Overview	29

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 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 proud to collaborate with:



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.



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.

Global Heart Hub (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.

The organisation is funded primarily through multi-industry support - in 2023, from across 14 industry supporters. All industry support is received under contract which clearly and transparently specifies what the funding supports and confirms that GHH retains its independence, and editorial control in the context of any publications, at all times. No industry partner support exceeded 22% of total income in 2023.



Welcome

Dear Global Heart Hub Community,

It's a pleasure to share with you the highlights of our work together throughout 2023, a year that marks a significant milestone in our journey. During the year, we were delighted to welcome our [100th international patient organisation affiliate](#). Our growing network of patient organisations and individual advocates from across the globe is a testament to our collective dedication and unwavering commitment to strengthening the patient voice as an equal stakeholder in healthcare and advocating for the best possible outcomes for those living with or affected by heart disease and its connected conditions.

This year, we were delighted to host our first in-person [Unite Annual Summit](#) which was a resounding success, bringing together our diverse community for the first time in a shared space. This landmark event not only strengthened our bonds but also reinforced our resolve to continue our very important work. The energy and passion for engagement and the shared insights from the Summit propel us forward in our mission. Our [manifesto on early detection and early diagnosis](#), together with our other thought leadership publications highlight how important the patient perspective is in CVD healthcare.

We extend our heartfelt thanks to each of our affiliates and supporters. Your collaboration, partnership and collective commitment to our shared vision of an empowered, activated and engaged patient community is what drives us. Together, we have made significant strides in raising awareness of heart disease and its connected conditions, building a connected and strong patient voice and placing the patient at the centre of their healthcare.

Looking ahead, we are excited about the possibilities that the future holds for patient education, empowerment and engagement. With your continued and collective support, we are confident that together we can make a lasting difference in the lives of those affected by or living with cardiovascular disease.

Thank you for being an integral part of the Global Heart Hub community. Together, we are stronger, and together, we will continue to make a difference.

Sincerely,



Kevin O'Reilly
Chairman



Neil Johnson
Executive Director



Global Heart Hub





Our Global Community in 2023

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

2023 Highlights in Numbers



Heart Valve Disease Awareness Week campaign generated

126M

opportunities to see the campaign message

Heart Failure Awareness Week campaign generated

11M

opportunities to see the campaign message

Cardiomyopathy Awareness Week campaign generated

8.3M

opportunities to see the campaign message

3 new publications!



1st in-person Unite Summit

Unite Annual Summit



Developed the 1st patient-led global manifesto on early detection and diagnosis of CVD

125 participants from across 27 countries



100% of survey respondents were inspired to take action!

8,000+ followers across social media channels

130k page views on our website

Heart Valve Disease

Global Heart Hub and Global Coalition on Aging release healthy ageing position paper

Heart Valve Disease: Harnessing Innovation to Save Lives, Mitigate Costs, and Advance the Healthy Ageing Agenda

In March 2023, Global Heart Hub (GHH) and the Global Coalition on Aging (GCOA) released a global position paper “Heart Valve Disease: Harnessing Innovation to Save Lives, Mitigate Costs, and Advance the Healthy Aging Agenda”.

The report builds upon on a December 2022 GCOA-GHH roundtable of cross-sector experts and examines how behaviour and policy change can best address heart valve disease in our 21st century. Aligned with the UN Decade of Healthy Ageing, the experts at the roundtable called on policymakers; health system leaders; patients,

caregivers, and their advocates; healthcare providers; and other stakeholders to prioritize and strengthen responses to heart valve disease. Together, a multi-sector coalition of leaders and organizations can combat ageist stereotypes that constrain care, improve early detection and diagnosis, and ensure increased and widespread access to life-saving interventions.

“We need to transform the relationship between people with heart valve disease and their care teams,” said Susan Strong, Founding President, Director of Patient Engagement, Heart Valve Voice US and Heart Valve Disease Patient. “This should be a true partnership, empowering people to understand the disease, their treatment options, and long-term care plans.”

Read the position paper now: globalhearthub.org/hvdpositionpaper



Shared Decision-Making in Heart Valve Disease



AUGUST 2023

Global Heart Hub, in collaboration with The Health Policy Partnership, convened an in-person roundtable in August on facilitating successful implementation of shared decision-making in heart valve disease. The special event, held in Amsterdam, was co-chaired by Sandra McGonigle, heart valve disease patient, Ireland, and Dr Sandra Lauck, clinical nurse specialist, Canada. The event brought together 19 experts from around the world representing all heart team stakeholders, including patients and patient organisations, surgeons, cardiologists, researchers and nurses. The roundtable served as basis to develop a compelling, consensus-driven roadmap that can facilitate advocacy in different countries and settings.

Paving the way: a roadmap to the successful implementation of shared decision-making in heart valve disease

NOVEMBER 2023

To coincide with PCR London Valves in November 2023, Global Heart Hub published an implementation roadmap aimed at patient organisations, healthcare professionals and advocates. The roadmap provides the knowledge and guidance needed to make shared decision-making a reality for people living with heart valve disease in their countries.

Paving the way: a roadmap to the successful implementation of shared decision-making in heart valve disease was developed following a patient-led, consensus-driven roundtable collating insights from 19 international, multidisciplinary experts.

The roadmap, developed in partnership with The Health Policy Partnership, supports national patient organisations in their work with other key stakeholders, advocates and decision-makers to accelerate change.

People who are diagnosed with heart valve disease are often presented with a range of different treatment options, which can make it difficult to make decisions about which treatment to have. Currently, shared decision-making is rarely embedded in patient pathways despite being shown to greatly improve quality of life and patient satisfaction. This can lead to people feeling anxious and unsure of their options – sometimes even doubting they have made the right decision.

The roadmap was launched on November 20 at PCR London Valves with a special shared decision-making session with our project co-chairs Dr Sandra Lauck, cardiovascular nurse, and Sandra McGonigle, patient representative.

Download the Roadmap now: globalhearthub.org/SDM-Roadmap



Heart Valve Disease Awareness Week

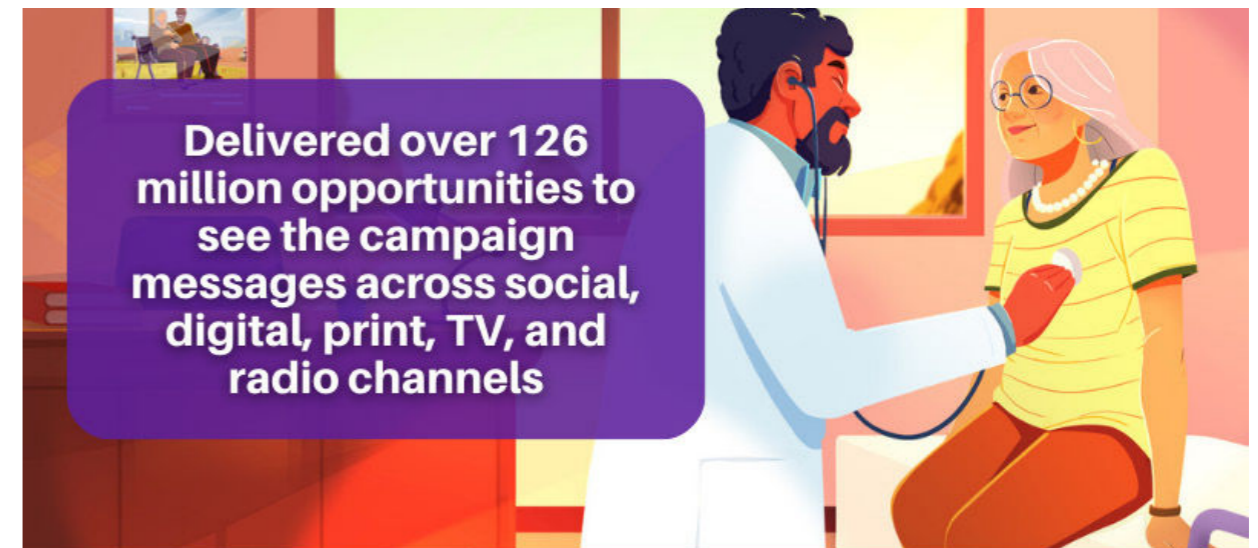
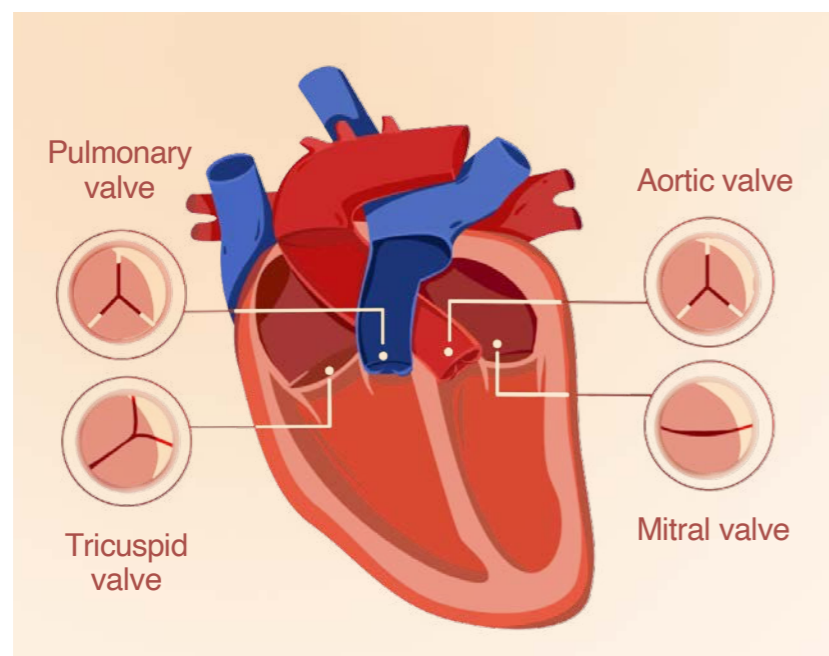
September 11 - 17, 2023



Heart Valve Disease Awareness Campaign

The 2023 Heart Valve Disease Awareness Week (11 - 17 September) aimed to raise awareness of symptoms and improve diagnosis, treatment and management of heart valve disease globally.

In life, there are many important events. None more important than a regular stethoscope check, as it's the first step in detecting Heart Valve Disease. Symptoms can include breathlessness, dizziness and fatigue but sometimes there can be no symptoms at all. Heart valve disease is common, serious, but treatable. Ask your doctor for a stethoscope check regularly and keep making the most of every day – this simple check can save your life.



Delivered over 126 million opportunities to see the campaign messages across social, digital, print, TV, and radio channels



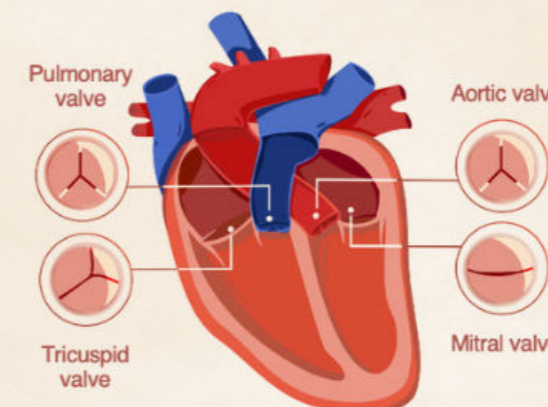
Translated across 12 languages

Social media posts by 100+ influencers, follower total of 2,000,000+ users



Shared across 18 countries

#ListenToYourHeart



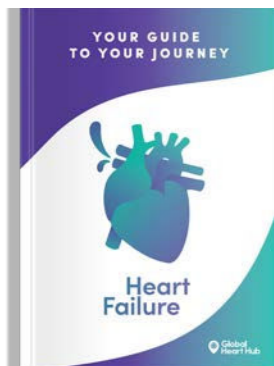
Press pick-up 80 features across 9 countries, including: TV, radio and print coverage

Languages included English, Dutch, French, Québécois French (Canadian), German, Italian, Hebrew, Japanese, Latin American Spanish, Latin American Portuguese, Polish and Spanish

Heart Failure

Heart Failure Friendly Guide

Based on the most recent ESC and AHA Heart Failure clinical guidelines, the Global Heart Hub Heart Failure Patient Council developed a 'friendly' guide and eight summaries in 2023, designed to support individuals who have been newly diagnosed with heart failure, those who are living with the condition, and their caregivers.



By providing clear and concise information that is tailored to the patient's needs, this guide can help individuals to understand the optimal care pathway for heart failure, inform their expectations, and encourage a more informed patient-doctor shared decision making. This will enable people with heart failure and their carers to better manage the condition, improve

outcomes, and enhance the overall quality of life for those affected by heart failure.

The aim of this guide is to empower people affected by heart failure to take an active role in their care and make informed decisions about their treatment. It provides clear information that may help people with heart failure and their caregivers to understand better the causes and symptoms of heart failure, how it is diagnosed and managed, and the importance of lifestyle changes such as diet and exercise.

The Guide is available now in Lithuanian, Spanish and Romanian, with more translations in progress.

Learn more: globalhearthub.org/hf-patient-guide

Heart Failure Awareness Month

This awareness campaign is led by the Heart Failure Patient Council of the Global Heart Hub.

The 2023 Heart Failure Awareness Month in May aimed to raise awareness of the signs, symptoms, and risk factors associated with heart failure, as well as the importance of early detection and effective management. The 2023 campaign focused on bringing attention to heart failure using the slogan #HighlightHeartFailure and save lives.

Aistė Štaraitė, Chair of the GHH Heart Failure Patient Council and President of the Lithuanian Heart Failure Association said: "As someone with lived experience and who works at the local level to support people living with heart failure and their families, I understand the importance of having global initiatives like the GHH Heart Failure Awareness Month campaign. These efforts help to increase public awareness, provide access to resources, and improve the quality of care for people around the world. By working together, we can amplify our voices and drive positive change that will make a significant impact."

An evergreen toolkit of materials was also developed for our Heart Failure Patient Council to continue the #HighlightHeartFailure message throughout the year.

Learn more: globalhearthub.org/heart-failure-awareness-2023

Heart Failure Awareness Month

May, 2023

Campaign Highlights



Delivered over **11m** opportunities to see #HighlightHeartFailure campaign messages across print, TV, radio, social and digital channels.

Campaign video and social media assets translated across **18 languages.**



Campaign activated by Patient Organisations in **18 countries** utilizing all media channels & live events.

Regional activation in LATAM, USA, Canada, Europe, Middle East & Australia.

HEART FAILURE AWARENESS MONTH 2023

Cardiomyopathy

Why genetics matter in Cardiomyopathy?

On 21 March, Global Heart Hub's Cardiomyopathy Patient Council presented a webinar 'Why genetics matter in Cardiomyopathy?', where Prof James Ware, an expert in the field of genetics, talked about why genetics, genetic testing and genetic counselling are important in cardiomyopathies.

Prof James Ware is a Professor of Cardiovascular and Genomic Medicine at Imperial College London and has a visiting position at the Broad Institute of MIT and Harvard. At the event, Prof Ware explained the role that genes play in cardiomyopathy and the importance of family history. After his presentation, Prof Ware was joined by a specialist in genetic counselling for cardiomyopathy for a discussion session.

Genetic Cardiomyopathy Awareness Consortium

Led by the DCM Foundation, the Genetic Cardiomyopathy Awareness Campaign was launched in the US in early 2023 by eight US-based cardiomyopathy patient groups to raise awareness about the need for genetic testing for cardiomyopathy patients and family members. The purpose of the campaign is to raise awareness and to get more cardiomyopathy patients and family members genetically tested, which will help save lives and advance genetic research and therapies.

Global Heart Hub fully supports this initiative and thanks the DCM Foundation and the Genetic Cardiomyopathy Awareness Consortium for their support in developing the International Cardiomyopathy Awareness Week 2023.



The Cardiomyopathy Patient Council meets in Florence

On World Heart Day, the Cardiomyopathy Patient Council came together for our first in-person council meeting since it was established in 2021. Over the 3 days, the meeting was an opportunity for 22 patient advocates from 11 countries to advance knowledge in the cardiomyopathy space by learning from each other, networking, aligning on what can be achieved together.

The group had an opportunity to welcome Professor Iacopo Olivetto and MDs Francesca Girolami, Mattia Zampieri, Alessandra Milazzo and Sara Giovani to learn the best practices for care in Florence and updates to the 2023 ESC Guidelines for Treatment of Cardiomyopathy. We were also joined by Professor Cecchi, president of AICARM and Denis Costello to learn best practices from the Rare Disease Community.

It was an important opportunity to support our collective goal to amplify the patient voice and positively impact the trajectory of cardiomyopathy and its impact on patients, families and healthcare systems. Thank you to all who joined us!

Cardiomyopathy Awareness Week

June 26 to July 2 marked Global Heart Hub's second Cardiomyopathy Awareness week. Led by the Cardiomyopathy Patient Council, the objective of the MYCardiomyopathy campaign was to raise awareness of cardiomyopathy, bring to light the importance that genetics play in cardiomyopathy and encourage affected family members to get genetically tested to help protect other loved ones.

Social media assets, videos and webpages were created in ten languages - English, French, German, Italian, Dutch, Polish, Portuguese, Romanian, Spanish, Swedish, and driven by the 19 associations across 13 countries that make up the Cardiomyopathy Patient Council. Learn more: globalhearthub.org/cardiomyopathy-awareness-2023



8.3+ million opportunities to see the Cardiomyopathy campaign across social channels

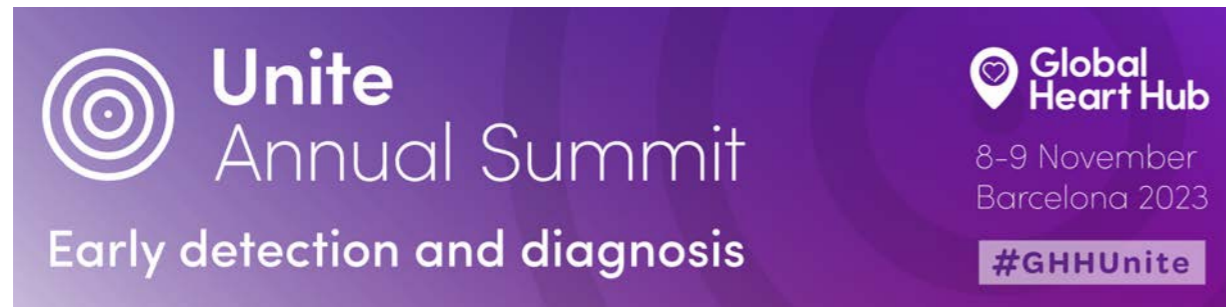
Campaign available in 10 languages and shared in 12 countries

6.6 million impressions achieved across Global Heart Hub social media channels



10,000+ clicks to 'learn more' on the Global Heart Hub website

Events



Global Heart Hub’s 3rd Unite Annual Summit a huge success

Global Heart Hub brought the cardiovascular disease patient community together from 8-9 November for the 3rd Annual Unite Summit, held in Barcelona, Spain. Participants united to develop the first patient-led global Manifesto calling for action on early detection and timely diagnosis of cardiovascular disease. **Learn more and watch back recordings here: globalhearthub.org/unite-annual-summit**



125 DELEGATES

23 SPEAKERS

27 COUNTRIES

100% of attendees now feel motivated & inspired to take action!

100% of attendees rated the event as excellent or good!

Unite Annual Summit

Global Heart Hub

PARTICIPANTS DEVELOPED THE FIRST PATIENT-LED GLOBAL MANIFESTO CALLING FOR ACTION ON EARLY DETECTION AND TIMELY DIAGNOSIS OF CVD – LAUNCHING IN EARLY 2024!

“The summit was a great opportunity to listen to **experts** in the field, to hear the voice of **patients**, to contribute to the **manifesto** and to **network** with many attendees.**”**

“It was such an **amazing conference** and am truly grateful. The sessions were very informative and it was wonderful to be able to connect with other patient organisations across the globe!**”**

Collaborations

Global Heart Hub part of new coalition formed to fight heart disease in Asia

Announcing the Asia-Pacific Cardiovascular Disease Alliance

In June 2023, patient organisations including Global Heart Hub, allied health professionals, academia, corporate partners and a global health think-tank came together to launch the Asia-Pacific Cardiovascular Disease Alliance (APAC CVD Alliance), a multisectoral coalition committed to improving heart health and reducing the CVD burden across nine health systems in Asia.

The APAC CVD Alliance will engage policymakers, patients, professionals, academia, non-profits, and implementation partners to champion increased attention and innovations for CVD.

CVD is the leading cause of death in the Asia-Pacific, with the largest increase in premature deaths occurring in East Asia, South Asia, and Southeast Asia over the last 20 years. In 2019 alone, over 10 million people died of heart disease in Asia, making up 35% of all deaths in the region.

The APAC CVD Alliance will adopt a patient-centered approach across the entire CVD care continuum – prevention; early detection; treatment, cardiac rehabilitation, and step-down care.

“We are excited to join the APAC CVD Alliance to provide a global voice for those affected by CVD in Asia,” said Neil Johnson, Executive Director, GHH. “As a long-time heart patient advocate, I believe we can make a real difference for patients and their families by partnering professionals and policymakers in Asia.”

Learn more here: apac-cvd.org

Global Heart Hub joins EUPATI partnership – supporting shared goal of enhancing patient engagement through education

In November, Global Heart Hub and EUPATI, the European Patients’ Academy of Therapeutic Innovation, were both delighted to enter into a partnership.

By joining forces, the voices of those living with or affected by cardiovascular disease in the area of medicines research and development can be enhanced. EUPATI is a non-profit Foundation with a multi-stakeholder structure representing patient organisations, pharmaceutical industry and academic institutions. EUPATI provides education and training to patients and patient representatives in medicines research and development with the EUPATI Open Classroom and its EUPATI Toolbox.

Both Global Heart Hub and EUPATI aim to ensure patients are in the best position possible to be equal stakeholders and ultimately improve their health outcomes and quality of life.

Hub Highlights

New Clinical and Specialist Advisory Panel

In 2023, Global Heart Hub established a new Clinical and Specialist Advisory Panel (CSAP) to support us in helping to ensure that evidence-based knowledge underlies our efforts to achieve the best possible outcomes for those living with heart diseases.

We are extremely proud that nine leading global experts, representing interdisciplinary fields of cardiovascular disease, have agreed to join the CSAP and to provide guidance to the Global Heart Hub on medical, scientific, and professional matters.

The establishment of the CSAP is yet another significant milestone in the rapid development and growing impact of the Global Heart Hub.

Learn more: globalhearthub.org/about/advisory-panel



Global Heart Hub celebrates reaching 100 Affiliates!

Our patient community has come together in the fight against cardiovascular disease.

In 2023, Global Heart Hub was thrilled to welcome our 100th Patient Organisation Affiliate. Since our launch in 2019, Global Heart Hub has remained committed to uniting, supporting and elevating the patient voice through our alliance of heart patient organisations, and reaching 100 organisational affiliates represents a milestone in our journey.

We are so proud to work with over 100 patient organisations across the globe. This is a huge milestone for our organisation – over 100 Affiliates are now part of Global Heart Hub, joining us on our mission to advocate for the best possible outcomes for people living with heart disease. Our Affiliate reach is now 33 countries – Austria, Australia, Brazil, Belgium, Canada, Cyprus, Egypt, France, Germany, Ghana, Greece, Hungary, Ireland, Israel, Italy, Japan, Latvia, Lebanon, Lithuania, Mexico, Nepal, Netherlands, Nigeria, Northern Ireland, Poland, Portugal, Romania, Rwanda, Slovenia, Spain, Sweden, USA, United Kingdom.

“Our work is only beginning – We are so proud to work with patient advocates from across 33 countries in our mission to advocate for the best possible outcomes for people living with heart disease,” says Neil Johnson, Executive Director, GHH.

Watch a special celebratory video: globalhearthub.org/global-heart-hub-celebrates-reaching-100-affiliates



Invisible Nation

Global Heart Hub launches new patient-led research to bring attention to unhealthy cholesterol levels

Cardiovascular patient community calls for change urging unhealthy cholesterol levels to be addressed as a global health priority.

To reinforce the call to action on the Global Cholesterol Action Plan, Global Heart Hub began collecting patient insights in 2023 from individuals whose cholesterol levels are not at target or those who have suffered a cardiovascular event to better understand patient experiences that can help impact care and improve outcomes. The first-of-its-kind cholesterol patient insights generation by the cardiovascular patient community is needed to help support the local implementation of the Global Cholesterol Action Plan and to drive strategies to manage unhealthy cholesterol, a critical modifiable risk factor for the world's biggest killer, atherosclerotic cardiovascular disease (ASCVD)¹.

Neil Johnson, Executive Director, Global Heart Hub said: "While we've advanced with science and treatment, ASCVD remains the world's number one killer, with unhealthy cholesterol levels as the main culprit. We need to continue our work from the Invisible Nation program to better understand why this continues to be a global challenge and would like to gain a deeper understanding of the patient perspective and journey. Collecting patient insights will give us what we need to mobilise stakeholders to have much needed discussions around better detection and better management of high cholesterol. We must act now to reduce the tremendous burden of atherosclerotic cardiovascular disease on individuals, society and healthcare systems."

Fernanda de Carvalho, Instituto Lado A Lado Pela Vida, Brazil said: "We need to put even more focus on ASCVD. In Brazil, there are 300,000 premature deaths per year, and we know that 80% of these are related to ASCVD. Considering these numbers and reality, it is important to sign the Global Cholesterol Action Plan and to participate in a task force to reduce cardiovascular deaths."



Patient Experience Data & Patient-Led Research Training Workshop

From December 5-6, Global Heart Hub was delighted to convene representatives from 10 global patient organisations at a dynamic two-day Patient Experience Data (PED) & Patient-Led Research Training workshop in Boston, USA.

The Workshop explored how patient organisations can collect and employ high-quality patient experience data, in support of our mission to elevate the patient voice. "This training will help to build patient community capacity and amplify the importance of patient experience data and how we can use this to drive change," says Neil Johnson, Global Heart Hub Chief Executive.

As part of the Invisible Nation project, Global Heart Hub is working with Affiliates to collect

patient insights from individuals whose cholesterol levels are not at target or those who have suffered a cardiovascular event to better understand patient experiences that can help impact care and improve outcomes.

"The recent sessions in Boston on Patient Experience Data and Patient Reported Outcomes were a tremendous source of knowledge and inspiration. The insightful speakers brought a wealth of information, offering new perspectives and fueling our determination to elevate patient care. HeartLife is enthusiastic about applying these learnings to move our work forward, ensuring that the patient experience remains at the forefront of our endeavors." – Marc Bains, HeartLife Foundation, Canada.

Invisible Nation LinkedIn Live Event

Global Heart Hub hosted a LinkedIn live event on February 1st to raise awareness of the Global Cholesterol Action Plan. The speaker line-up included Dr Shaun Goodman, Associate Head of Cardiology, St Michael's Hospital, Toronto, Canada; Fernanda Carvalho, Director of Public & International Affairs, Instituto Lado a lado pe la vida, Brazil; Magdalena Daccord, Chief Executive, FH Europe Foundation; Neil Johnson, Executive Director, Global Heart Hub; and Prof Urh Groselj, Associate Professor, UMC - University Children's Hospital Ljubljana and University of Ljubljana Faculty of Medicine, Slovenia.

ASCVD Think Tank meeting in London

On 2 February, Global Heart Hub hosted a think tank meeting in London with a group of patient organisations to discuss ways to build alliances to tackle the burden of unhealthy cholesterol and its role in ASCVD. At the meeting, the participants

endorsed Global Heart Hub's Cholesterol Action Plan. The event brought together representatives from FH Europe Foundation, Fokus Patient, Initiative Herzklappe e.V., CardioAlianza, Alliance du Coeur and Associazione Italiana Scompensati Cardiacci.

European Atherosclerosis Society becomes the 100th signatory on Global Cholesterol Action Plan

In November, Global Heart Hub was delighted to announce that the European Atherosclerosis Society (EAS) signed support for the Global Cholesterol Action Plan, bringing the number of signatories to 100!

"This 100 signatories milestone on our Cholesterol Action Plan underlines the commitment to address ASCVD, responsible for more than 15 million deaths globally each year. The endorsement from EAS, a leading voice on ASCVD in Europe, will help drive forward our four-point plan to ensure unhealthy cholesterol levels are addressed as a public health priority," says Neil Johnson, GHH Executive Director.

The 100 supporters, from across 41 countries, will receive specially developed training materials to help them activate change in the way ASCVD is prevented and treated in their country. **Learn more and support the plan – invisiblenation.com**

Rallying policymakers and health systems to prioritise ASCVD

Global Heart Hub was featured in a *Health Europa* in January 2023 with Neil Johnson emphasising the need to take stronger action when it comes to preventing and managing Atherosclerotic Cardiovascular Disease.

Academy

Global Heart Hub's Academy supports the global heart patient community to develop their advocacy capacity and capability. 2023 activities included:

Empower Webinars for Patients

- How Patients Can Advocate for Themselves with Clinicians
- Living with Congenital Heart Disease
- Heart Failure – Your Guide to Your Journey

In all three webinars, 100% of respondents rated the webinar positively, with 'excellent' being the most common response. A sample of the comments across the three webinars:

- Enjoyed the format – a strong opening leading into the discussion, the global participants sharing their stories of diagnosis treatment and ongoing care. Their tips for advocating for oneself were very useful.
- Great mix of speakers with real-world insights on how to manage difficult interactions.
- Inspiring speakers and great perspective by all relating to shared decision-making between patients and clinicians based on the patient's lifestyle.

GROW Workshops for Patient Organisations and Advocates

- Patient Storytelling
- The Fundamentals of Community Building
- Social Media for Non-Profits

Again, in all three sessions, 100% of respondents rated the webinar positively, with 'excellent' being the most common response. Attendees commented:

- The discussion with accompanying slides was so helpful. [...] Many of the techniques described will become part of my storytelling in future.

- [This] was exactly what I needed to gain momentum with Her Heart Sounds. I was able to immediately begin making plans for more community involvement and create timelines. I very much appreciate your knowledge!
- The opportunity to share experiences in the breakout session was a powerful moment and although from different charities, didn't feel like we were competitors, more like collaborators helping and sharing. I enjoyed this event.

Master Classes for Advanced Training

PATIENT IMPACT TRAINING: ADVOCACY AND COMMUNICATIONS FOR PATIENT ORGS & ADVOCATES

Global Heart Hub partnered with the SDA Bocconi School of Management to present a three-day training course in Rome, Italy from September 18 – 20, 2023. Over 30 advocates from across 16 countries took part in the patient impact training, which covered key topics on advocacy and communications including understanding the health policy landscape, stakeholder engagement, building partnerships and how to elevate the patient voice in the health technology assessment process.

PATIENT EXPERIENCE DATA TRAINING

In both Master Classes, the average rating given by survey respondents on the success of the event was over 97%. Likewise, in both events, 100% of respondents were interested in taking part in further events and 100% of respondents were interested in remaining in touch with the other members of the course. A sample of attendees' comments:

- The quality of the SDA Bocconi School of Management instructors and presentation of information regarding its applicability to all affiliates was outstanding.
- Superb compilation and selection of professionally experienced experts. Super!

EU-Funded Projects

Harmonized Approach to Early Feasibility Studies for Medical Devices in the European Union (HEU-EFS)

Harmonized Approach to Early Feasibility Studies for Medical Devices in the European Union (HEU-EFS) is a four-year IHI research project which aims to develop a shared and innovative program entirely dedicated to conducting Early Feasibility Studies (EFS) in the European Union for medical devices.

Global Heart Hub is delighted to be part of the consortium and is teaming up with the European Patients' Forum (EPF) to advance patient centricity in the project.

Learn more: globalhearthub.org/projects

Publications

Britt Borregaard, Sandra B Lauck, **Improving the heart valve disease journey of care: a new action plan for better partnerships with patients, clinicians, and policymakers**, *European Journal of Cardiovascular Nursing*, Volume 22, Issue 8, November 2023, Pages e118–e119, <https://doi.org/10.1093/eurjcn/zvad042>

Faye Forsyth, Cynthia A Lamendola, **Cardiovascular disease and diabetes care: patient and healthcare professional advocacy priorities from the Global Heart Hub Cardio-Diabetes Think Tank**, *European Journal of Cardiovascular Nursing*, 2023;, zvad100, <https://doi.org/10.1093/eurjcn/zvad100>

Learn more: globalhearthub.org/journal-publications

Awards

Heart Failure Patient & Caregiver Charter Wins 2023 Think Global Award

The Heart Failure Patient & Caregiver Charter won the sixth edition of the Think Global Awards for the category of Life Sciences. The Think Global Awards recognise the global success of individuals and organizations, supported by Think Global Forum, an international hub to generate creative, insightful, and inspiring strategic thinking across global topics.

This win comes from the dedication and hard work of the Heart Failure Patient Council, who created this document to support the development of optimal high-quality care and to promote its adoption internationally across all healthcare systems.

'Hall of Fame' Award

Global Heart Hub's Executive Director, Neil Johnson, was announced as the inaugural winner of a prestigious international 'Hall of Fame' award for his work in patient advocacy and engagement.

The award was presented at the Patient Engagement Open Forum Annual Conference in Milan, Italy recently – an annual meeting of global patient organisations, industry, and other stakeholders across multiple disease areas. The awards programme is a collaboration between the European Patients' Forum (EPF); the European Patients' Academy on Therapeutic Innovation (EUPATI) the Patient Focused Medicines Development Initiative (PFMD).

Neil received his award in recognition of his leadership of the Irish heart and stroke charity Croí for the past 30 years, founding the National Institute for Prevention and Cardiovascular Health (Ireland) in 2014 and establishing the Global Heart Hub in 2019.

Aistė Štaraitė Heart Hero

Aistė Štaraitė, Global Heart Hub's Heart Failure Development Executive and President of the Lithuanian Heart Failure Association, was named a "Heart Hero" as part of World Heart Federation's World Heart Day celebrations. "It isn't difficult to share my story of heart failure since I want to erase the stigma that young people, especially young females, cannot be sick. I see that sharing the patient experience makes a positive impact in other people's lives."



Honorary Degree (Doctor of Laws LLD) for Global Heart Hub Executive Director

Congratulations to our Executive Director, Neil Johnson, who received an Honorary Degree (Doctor of Laws LLD) from the University of Galway in November, in recognition of his 30+ year career to the fore in the fight against heart disease and stroke.

Neil has overseen foundation, growth and development of significant projects in cardiovascular health promotion across several non-profit organisations including Croí Heart & Stroke Charity in Galway, Ireland, and the Irish National Institute for Prevention and Cardiovascular Health (NIPC). His advocacy work continues in international patient engagement through the Global Heart Hub, which has a focus on strengthening the patient voice.



Urging a cardiovascular health plan for Europe's biggest killer

Global Heart Hub and the European Alliance for Cardiovascular Health met with EU MEPs, calling for a comprehensive EU policy response to improve the cardiovascular health of European citizens.

Members of the European Parliament (MEPs) at 2023's ending plenary session from 11-14 December in Strasbourg, France, were being urged to prioritise health and help defeat the continent's most pervasive health threat: cardiovascular disease (CVD). Leading the call was a grouping of 18 partners, including Global Heart Hub, making up the European Alliance for Cardiovascular Health (EACH). They emphasise an EU-wide Cardiovascular Health Plan and 27 National Action Plans as the way forward.

CVD cost the EU an estimated €282 billion in 2021, topping the leaderboard as the cause of more than one-third of all deaths and impacting the lives of some 60 million people. Misperceptions plague CVD: it is often still regarded as a "man's disease" although women are more than twice as likely to die after a heart attack than men. Cardiovascular conditions also affect children and young adults.

In Strasbourg, EACH unveiled the "Vote Cardiovascular Health 2024" exhibition, hosted by MEP Elżbieta Łukacijewska (Poland) and MEP Radka Maxová (Czech Republic), long-standing supporters of cardiovascular health. The exhibition highlights CVD's toll on the EU, country by country, while the online media campaign is calling on leaders to #VoteHealth2024.

At the event, Global Heart Hub's David Kelly shared his experience of living with heart valve disease.

GHH Engagement Highlights

In 2023, the Global Heart Hub team participated in 58 external speaker and project engagements. Here are some highlights from our 2023 engagements:

- Aistė Štaraitė, Heart Failure Development Executive, participated in the British Society of Heart Failure's 25in25 Summit in London on 9 March, to highlight issues and needs to reduce the burden of HF by 25% in 25 years.
- In March, Aistė Štaraitė participated in Boehringer Ingelheim's Annual Conference, sharing her story as a heart failure patient and advocate and participating in a panel session.
- Karen Padilla, Heart Valve Disease Development Executive, and Teresa Glynn, Development Executive, were delighted to represent Global Heart Hub at the Heart Valve Society's 2023 meeting in Malaga, Spain, engaging with international stakeholders in the treatment of people impacted by heart valve disease. At the event, Dr Marta Stiges, President of the Heart Valve Society, introduced the Global Heart Hub's session, and discussed the importance of having the patient voice at medical congresses. As part of the session, Ellen Ross, Managing Director of Heart Valve Voice Canada, presented Global Heart Hub's "Heart Valve Disease: working together to create a better patient journey" report and the new position paper on Heart Valve Disease and the Healthy Aging Agenda.
- David Kelly, Operations and Special Projects Lead, participated in Edward Lifescience's Patient Advisory Board meeting in London in April.
- In April, David Kelly represented Global Heart Hub at the European Patients Forum 20 Year Anniversary Meeting in Brussels.
- In May, Aistė Štaraitė attended World Heart Federation's 2023 Summit in Geneva and took part in a panel discussion on the importance of the early diagnosis in Heart Failure.
- In May, David Kelly and Aistė Štaraitė represented Global Heart Hub at the Boehringer Ingelheim Global Patient Partnership Summit 2023 in Vienna, collaborating on finding the solutions for the current issues in healthcare.
- Neil Johnson, Executive Director, attended a workshop, Cardiomyopathies Matter in Brussels and spoke as part of a panel.
- In June, Aistė Štaraitė took part in a Roche LinkedIn Live virtual roundtable on healthy ageing.
- In August, Neil Johnson took part in World Heart Federation's Heart Café at ESC 2023 on the topic of cholesterol management in cardiovascular health policies.
- In September, Karen Padilla, attended a 2-day capacity building training session with Boehringer Ingelheim in Dubai as part of the Patient Union for Learning & Support Engagement (PULSE) with patient organisations from India, the Middle East, Turkey and Africa.
- Global Heart Hub Executive Director, Neil Johnson, spoke at the European Society of Cardiology's Council of Cardio-Oncology RESILIENCE meeting on 19 October at the European Heart House in Nice. The multi-stakeholder event gave a voice to the patient community to discuss the progress of the Cardio-Oncology study and the field of cardio-toxicity.
- On 25 October, The Heart Failure Policy Network launched the European Heart Failure Mission statement at the European Parliament. This was the largest gathering of the heart failure community at the European Parliament since 2016 and will provide firm foundations for the multi-year campaign to drive political urgency on heart failure. Aistė Štaraitė, Global Heart Hub's Heart Failure Development Executive, presented our Heart Failure Patient and Caregiver Charter to the parliament and emphasised the important role of patients and caregivers in research opportunities.
- Global Heart Hub was delighted to attend the kick-off meeting for the Harmonized Approach to Early Feasibility Studies for Medical Devices in the European Union (HEU-EFS) project in Milan. This project is led by Bocconi's Center for Research on Health and Social Care Management (CERGAS) and Edwards Lifesciences.
- David Kelly attended the 1st FH Europe Foundation Annual Network Meeting in Amsterdam from November 10-12.
- Global Heart Hub was delighted to be at PCR London Valves 2023 in November to launch our new implementation roadmap, Paving the way: a roadmap to the successful implementation of shared decision-making in heart valve disease. A special shared decision-making session, "Navigating the crossroads of care: challenges in shared decision-making for doctors and patients", took place with our project co-chairs Dr Sandra Lauck, cardiovascular nurse, and Sandra McGonigle, patient representative.
- Global Heart Hub took part in the European Federation of Pharmaceutical Industries and Associations (EFPIA) Patient Think Tank session in November.





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