



Mended Hearts  
Europe

# SUPPORT EDUCATE ADVOCATE

Annual Report 2025





# MESSAGE FROM OUR PRESIDENT

As we reflect on 2025, I am both proud and deeply encouraged by the progress the Mended Hearts Europe Association (MHE) has made in strengthening its role as a patient-centred organisation dedicated to supporting, educating, and advocating for people living with or affected by cardiovascular disease across Europe.

Throughout the year, we continued to shape a clear and purposeful model: developing practical educational resources patients can use in their everyday life, working hand in hand with local patient organisations to co-create and co-brand materials adapted to local needs, and gradually moving from beyond information-sharing toward more personal, human-centred support.

Education remained at the heart of our work – but always with people at the centre. Last year, we released 17 new educational resources, including Go-To Guides, Discussion Guides, Patient Journey infographics, and whiteboard animations covering cardiomyopathy, heart failure, amyloidosis, cholesterol, stroke and secondary prevention, as well as emerging areas such as chronic kidney disease and gene therapy. Available in six languages, these materials were disseminated both online – via our multilingual website and resource hub – and offline through hospitals, clinics, and community settings, with over 18,000 printed resources distributed across Europe. Behind each of these resources is a simple intention: to help someone better understand their condition, feel less alone, and take a more active role in their care.

This year also marked an important step as we began translating education into structured peer support through the Welcome Home™ model. In France, together with the Ligue Contre la Cardiomyopathie, we advanced the adaptation of Welcome Home Hypertrophic Cardiomyopathy™. In Northern Ireland, in partnership with Heart Failure Warriors Northern Ireland, we co-designed a version of Welcome Home Heart Failure™ tailored to the local context and identified the first pilot setting for implementation. These efforts reflect a shared belief that beyond information, people need connection, reassurance, and guidance from others who truly understand their journey.

Our ability to reach patients and communities also grew significantly. Through targeted awareness campaigns and digital engagement, we generated nearly 15 million campaign impressions, demonstrating the strong demand for clear, trustworthy patient information.

None of this would be possible without the trust, collaboration and commitment of our partners, supporters, and donors – including our Corporate Roundtable members – as well as the dedication of our Executive Committee, volunteers and staff. It is through this collective effort that we continue to build something meaningful.

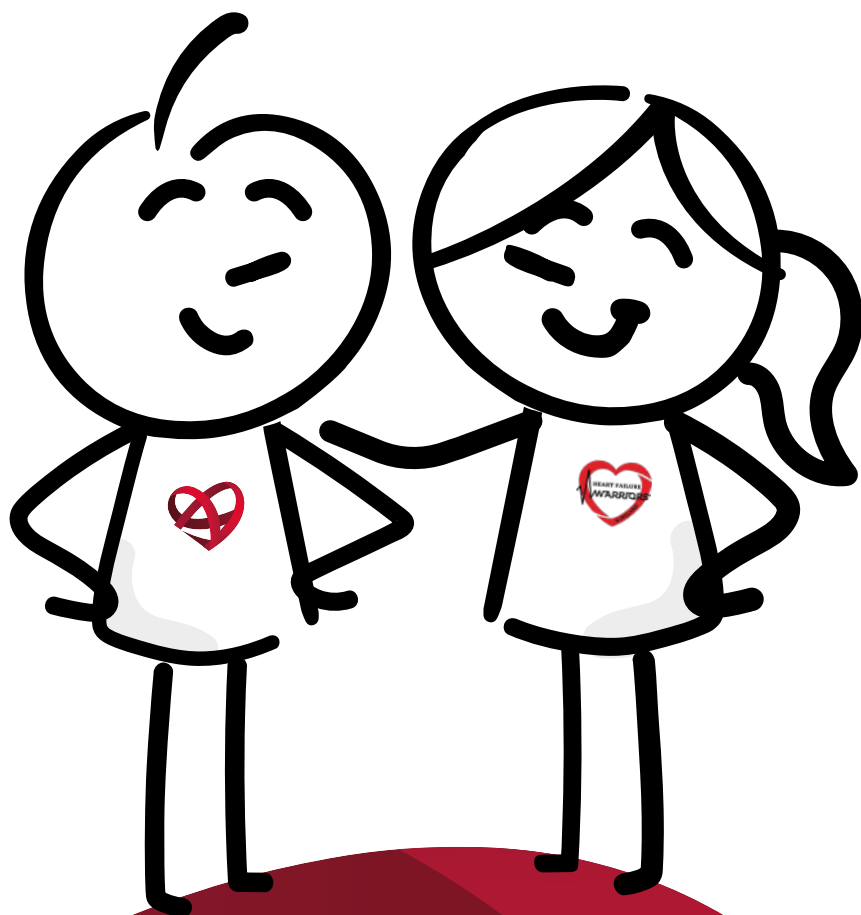
Together, we are working toward a simple but powerful goal: to ensure that no person affected by cardiovascular disease has to navigate their journey alone.



WITH HEARTFELT THANKS,

*A.R. Voss*

MHE PRESIDENT





## *Vision:*

We believe in a world where every cardiovascular disease patient has the resources and support needed to live a healthy life.



## *Mission:*

**SUPPORT – EDUCATE – ADVOCATE.**



## *Strategic Objective:*

To expand The Mended Hearts Inc. (MHI) services and provide support to cardiovascular disease patients, their families and caregivers, across Europe.



## *Our Approach:*

- ♡ adapting and translating educational materials to ensure accessibility across countries;
- ♡ developing new practical, patient-centred materials for real-life use;
- ♡ partnering with local organisations to build and strengthen peer support;
- ♡ empowering patients to become champion advocates.

# 2025 HIGHLIGHTS

## REACHING PATIENTS AND COMMUNITIES

14.8 million

Impressions across five major awareness campaigns

Cardiomyopathy, Heart Failure, Secondary Prevention of Stroke, Amyloidosis

18,400

Printed resources distributed across Europe

## EDUCATION AND PROGRAMMES

59

Versions of educational resources produced across 6 languages



## BUILDING SUPPORT AND PARTNERSHIPS

5

New programmes launched

Lp(a), CKD & CVD,  
AL Amyloidosis,  
ATTR-CM, Gene Therapy

9 total programmes

9

Corporate Roundtable Members

13

Total donors supporting our work

# 250,000+

YouTube views

# 64,332

Website visits

+84.3% compared  
with 2024 (34,909)

# 17

New educational resources released

- 4 Go-to-Guides
- 7 Discussion Guides
- 3 Patient Journeys
- 3 Whiteboard animations

# 12

Condition-specific  
educational pages  
available online

# 6

Languages available  
on our website: English,  
French, German, Italian,  
Spanish and Flemish



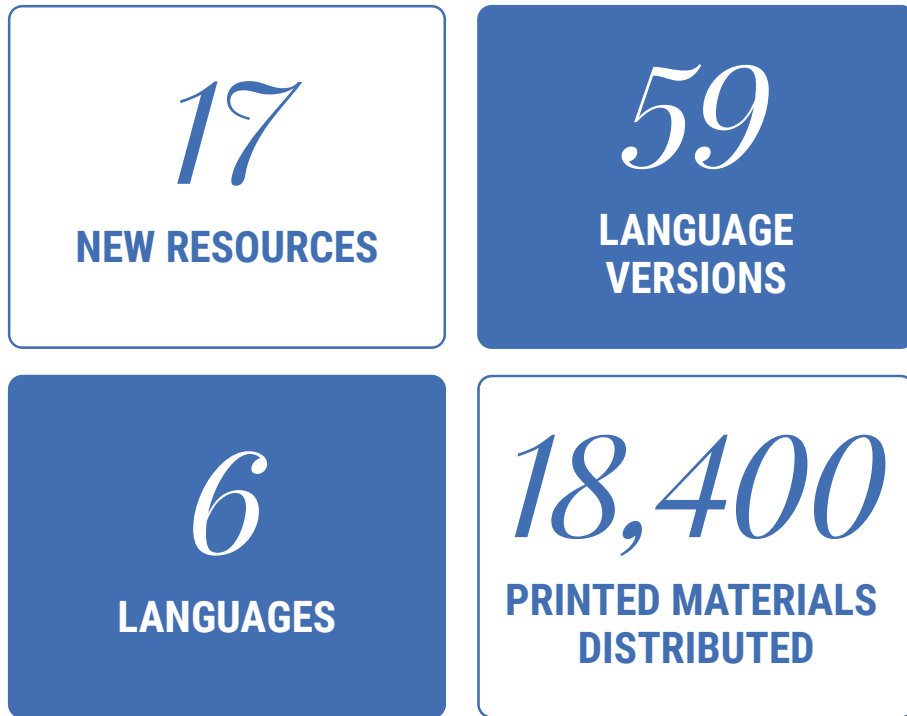
# 2

Peer-support programmes launched

- Welcome Home HCM (France)
- Welcome Home Heart Failure (N. Ireland)



# EDUCATE



Education remains a cornerstone of our mission, empowering people living with cardiovascular disease and their families. In 2025, we significantly expanded our portfolio of patient-centred resources, reinforcing our commitment to providing clear, practical, and medically aligned information that supports understanding, shared decision-making, and patient engagement.

Over the year, 17 resources were developed, including 4 Go-To Guides, 7 Discussion Guides, 3 Patient Journey Infographics, and 3 whiteboard animations designed to explain complex medical topics in accessible and engaging ways. These tools cover a wide range of cardiovascular conditions and related risk factors, including cardiomyopathy, heart failure, AL amyloidosis, ATTR-CM, cholesterol, stroke and secondary prevention, as well as emerging areas such as chronic kidney disease and gene therapy.

To ensure accessibility across Europe, materials were produced in six languages – English, French, Flemish, German, Italian, and Spanish – resulting in a total of 59 language versions. Country-specific adaptations were developed for France, Belgium, Switzerland, Italy, Northern Ireland, and Ireland, tailored to local healthcare systems and patient needs.

These resources were disseminated through hospitals, clinics, patient organisations, and community settings, with 18,400 printed copies distributed directly to patients and caregivers. In parallel, our multilingual website and resource hub continued to grow, now hosting 12 condition-specific educational pages that provide reliable, non-promotional information to support patients throughout their care journey.

By combining medically reviewed content, multilingual access, and strong partnerships with local patient organisations, Mended Hearts Europe continues to strengthen its role as a trusted source of cardiovascular education for patients across Europe.

## Our Programmes



**AL AMYLOIDOSIS**



**CARDIOMYOPATHY**



**CHOLESTEROL**



**CKD & CVD**



**GENE THERAPY**



**HEART FAILURE**



**LP(A)**



**RECURRENT AND SECONDARY  
PREVENTION OF STROKE**



**TRANSTHYRETIN AMYLOID  
CARDIOMYOPATHY**



### Understanding *Chronic Kidney Disease and Cardiovascular Disease*

A DISCUSSION GUIDE FOR PATIENTS AND CAREGIVERS

Whether you have just been diagnosed with kidney disease or have been living with it for some time, you may not know that it can increase your risk of developing cardiovascular disease (CVD), particularly heart disease. The reverse is also true — having heart disease can raise your risk of kidney disease. This happens because the heart and kidneys are closely connected when one is affected, the other is often impacted too.

**WHAT IS CARDIOVASCULAR DISEASE?**

Cardiovascular disease (CVD) is a general term for conditions affecting the heart and blood vessels. It often develops when fatty deposits, called plaque, build up inside the arteries — a process known as atherosclerosis. This buildup can reduce or block blood flow, leading to various health problems.

The main types of CVD include:

- CORONARY HEART DISEASE**  
When the arteries that supply blood to the heart become narrowed or blocked, which can lead to a heart attack.
- CEREBROVASCULAR DISEASE**  
Affecting the blood vessels in the brain, which can lead to stroke.
- PERIPHERAL ARTERY DISEASE**  
When blood flow to the limbs, especially the legs, is reduced.

**WHAT IS CHRONIC KIDNEY DISEASE?**

Chronic kidney disease (CKD) is a condition in which your kidneys gradually lose their ability to work properly over time. The kidneys' tiny filters, called nephrons, become damaged, making it harder for your body to remove waste and extra water from your blood.

CKD is usually progressive, meaning kidney function declines slowly and cannot be fully restored, but early detection and treatment can help slow the disease.

When your kidneys are not working well, waste products can build up in your body. CKD can also affect your blood pressure, red blood cells (which carry oxygen throughout your body), and the balance of important minerals such as phosphorus, sodium, and potassium. These changes can impact your overall health and wellbeing.

WORLDWIDE, AROUND **85.00** million people LIVE WITH CKD

**HEART DISEASE IS THE leading cause of death AMONG PEOPLE WITH KIDNEY FAILURE**

### A Patient's Journey Through *AL amyloidosis*

NAVIGATING YOUR DIAGNOSIS WITH CONFIDENCE

Being diagnosed with AL amyloidosis can be overwhelming. Here is a roadmap to help you gain the knowledge and confidence you need to adjust to your new diagnosis.

**1 SYMPTOMS**

AL amyloidosis can affect many organs in the body. It may affect the heart and kidneys, but it can also affect the liver, spleen, stomach, and nerves. Your symptoms will depend on which organs are involved and may include symptoms that may indicate heart problems.

Other signs and symptoms include:

- Swelling, light-colored stools, or dark stools
- Weight loss or gain
- Shortness of breath
- Unexplained weight loss
- Loss of appetite
- Easy bruising, bleeding, or purple-colored skin (purpura) around the eyes or on the legs
- Unexplained tingling, numbness, or weakness in the hands, fingers, feet, or legs
- Unexplained fatigue
- Unexplained weight gain
- Unexplained fever
- Unexplained sweating
- Unexplained weight loss
- Unexplained weight gain
- Unexplained weight loss
- Unexplained weight gain

If you notice any signs of AL amyloidosis, contact your healthcare provider right away. Early diagnosis and treatment are crucial to preventing further damage to your heart and other organs.

**2 DIAGNOSIS**

Diagnosing AL amyloidosis can be tricky. Your healthcare provider may perform a series of tests to confirm your diagnosis. Along with a physical exam and a review of your medical history, diagnostic tests may include:

- Blood tests
- Urine tests
- Biopsy
- Immunofixation electrophoresis (IFE)
- Light chain assay
- Immunoglobulin G (IgG) kappa
- Immunoglobulin lambda
- Immunoglobulin kappa
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- Immunoglobulin kappa

**3 EDUCATION**

To better understand AL amyloidosis and how it may affect you, it's important to learn more about:

- CAUSES OF AL AMYLOIDOSIS
- IMPACT ON THE HEART OR LIVER OR KIDNEYS
- PROGRESSION OVER TIME

**4 TREATMENT OPTIONS**

While there is currently no cure for AL amyloidosis, there are treatments that can help improve the quality of your life, including:

- LIFESTYLE CHANGES
- MEDICATION
- CHEMOTHERAPY AND OTHER PROCEDURES

**5 LIVING WITH AL AMYLOIDOSIS**

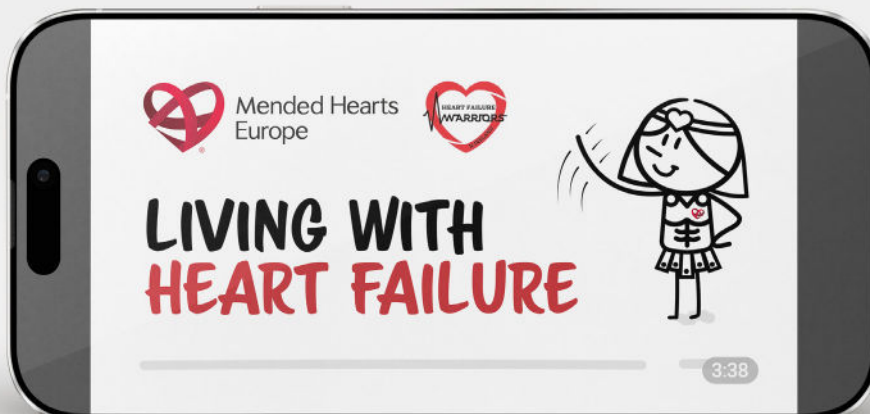
Although AL amyloidosis is a chronic condition, there are steps you can take to manage it effectively, support your wellbeing, and improve the quality of your life.

- TELL YOUR HEALTH CARE PROVIDER
- TAKE MEDICATION AS DIRECTED
- ADAPT YOUR DIET
- STAY ACTIVE
- SEEK SUPPORT FROM OTHER PATIENTS
- SEEK SUPPORT FROM OTHER PATIENTS
- SEEK SUPPORT FROM OTHER PATIENTS

Mended Hearts Europe

WWW.MENDEDHEARTSEUROPE.ORG

ALEXION



## Expanding Access Through the Resource Hub

In 2025, we launched our **Resource Hub**, a central digital platform bringing together multilingual educational materials in one accessible place. This hub allows patients, caregivers and healthcare professionals to easily explore resources by condition, format, and language.

The platform currently hosts **12 condition-specific educational pages**, offering clear and practical information on cardiovascular diseases and related risk factors. More than a repository, the Resource Hub represents a step toward more equitable access to cardiovascular education – ensuring that patients and families across Europe can find trustworthy information, wherever they are and in the language they understand.



“The Resource Hub represents a step toward more equitable access to cardiovascular education”



# SUPPORT

## FROM INFORMATION TO PRACTICE

In 2025, we began translating patient education into structured peer support through the introduction of the Welcome Home programme in Europe. The initiative focuses on a particularly vulnerable moment in the patient journey – the period following diagnosis and early discharge from hospital – when patients and families often need practical guidance, reassurance, and connection with others who share similar experiences.

France  
(HCM):

[LEARN MORE HERE](#)

### ♡ France (HCM):

In collaboration with the Ligue Contre la Cardiomyopathie, we laid the groundwork to adapt the Welcome Home programme for patients living with hypertrophic cardiomyopathy (HCM) in France. Our approach was aligned with existing care pathways, including Cardiogen and national Therapeutic Patient Education (ETP) programmes. The initiative focused on addressing information gaps at diagnosis, supporting psychosocial needs, and developing a coherent national model for peer support.



Northern  
Ireland  
(Heart  
Failure)

[LEARN MORE HERE](#)

♡ Northern Ireland (Heart Failure):

In Northern Ireland, we partnered with Heart Failure Warriors Northern Ireland to co-design a locally tailored Welcome Home Heart Failure programme. Developed in collaboration with patients, carers, and multidisciplinary healthcare professionals, the model reflects the realities of the local healthcare system. The Southern Health and Social Care Trust was identified as the initial pilot site, with clear next steps established for implementation, volunteer training, and evaluation.

Together, these initiatives lay the foundation for scalable peer-support models that can be adapted to additional countries and cardiovascular conditions across Europe.

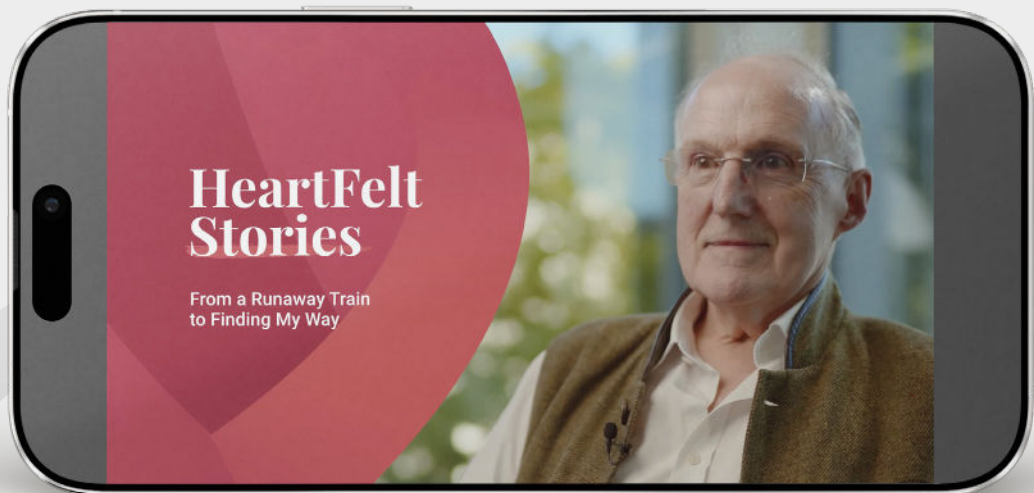
Heartfelt  
Stories:  
Lived  
Experience  
at the Centre

[LEARN MORE HERE](#)

♡ Heartfelt Stories: Lived Experience at the Centre

In parallel, we launched Heartfelt Stories, a dedicated platform where patients and caregivers share their personal experiences of living with cardiovascular disease. Through video and written formats, these stories highlight the emotional realities of diagnosis, treatment, and daily life with heart conditions.

By amplifying the voices of patients and families, Heartfelt Stories complements our educational resources and reinforces the value of lived experience in building compassionate, patient-centred care.





# ADVOCATE



## CKM Forum during the 78th World Health Assembly

In May 2025, we co-hosted a side event during the World Health Assembly in Geneva, together with the Global Alliance for Patient Access (GAfPA), the Partnership to Advance Cardiovascular Health (PACH), the International Atherosclerosis Society (IAS), and the Global Patient Alliance for Kidney Health (GloPAKH).

The event brought together patients, healthcare professionals, policymakers, and international organisations to discuss the growing burden of **cardiovascular–kidney–metabolic (CKM) diseases**.

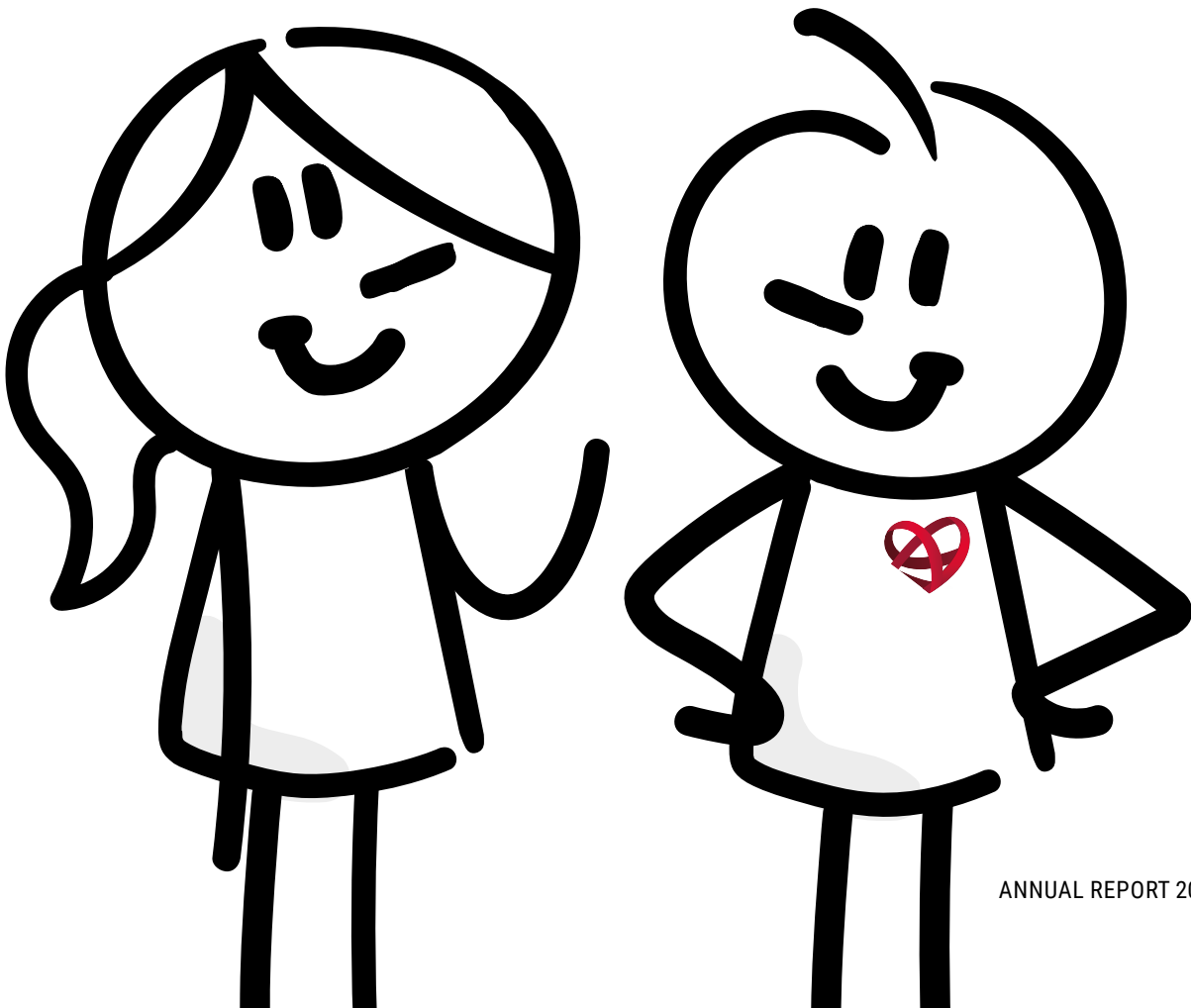
Discussions highlighted the importance of prevention, early detection, equitable access to treatment, and the meaningful integration of the patient voice into health system planning. The dialogue and resulting calls to action contributed to shaping our work on cardiovascular and kidney disease education and advocacy.

## Policy Engagement

We also contributed to European policy discussions aimed at improving cardiovascular prevention, early detection, and access to care. We endorsed the policy submission of the Heart Failure Policy Network to the European Commission, which calls for stronger action to improve the identification, diagnosis, and management of **heart failure** across Europe. The proposal highlights the importance of comprehensive cardiovascular health checks at the primary-care level, improved screening of at-risk populations, and the development of best-practice care models to support equitable access to high-quality heart failure management.

In parallel, we joined a coalition of organisations advocating for the recognition of **blood health** as a critical component of the future EU Cardiovascular Health Plan. The initiative calls for the integration of blood health into prevention strategies, including recognising anaemia as a modifiable risk factor that can worsen cardiovascular outcomes, incorporating relevant biomarkers into cardiovascular health checks, and strengthening policies that address health inequalities related to gender, socio-economic status, and geographic disparities.

Through these actions, we contributed to ensuring that the patient perspective is reflected in European policy discussions and to promoting a more comprehensive and preventive approach to cardiovascular health.





# EVENTS

## DERRY, N. IRELAND



### Amyloidosis Ireland International Conference

In June 2025, we participated in the International Conference on Amyloidosis organised by Amyloidosis Ireland in Derry, Northern Ireland. During the meeting, we presented a dedicated session focused on educational resources designed to support patients and families affected by amyloidosis. The event also marked the launch of the AL Amyloidosis and ATTR-CM Discussion Guides, developed in collaboration with Amyloidosis Ireland. The conference brought together healthcare professionals, researchers, patient organisations, patients, and caregivers, providing an important opportunity to strengthen collaboration and raise awareness of these rare cardiovascular conditions.



## MADRID, SPAIN



### ESC Congress – “Fit Stop” Activation

At the European Society of Cardiology (ESC) Congress in Madrid, we partnered with Novartis to deliver the first “Fit Stop” activation focused on lipoprotein(a), or Lp(a). The initiative encouraged participants to learn about their cardiovascular risk factors and highlighted the importance of measuring Lp(a) levels at least once in a lifetime. Educational materials and digital resources were distributed to attendees. The initiative demonstrated the value of engaging both healthcare professionals and the broader community in practical conversations about cardiovascular prevention.



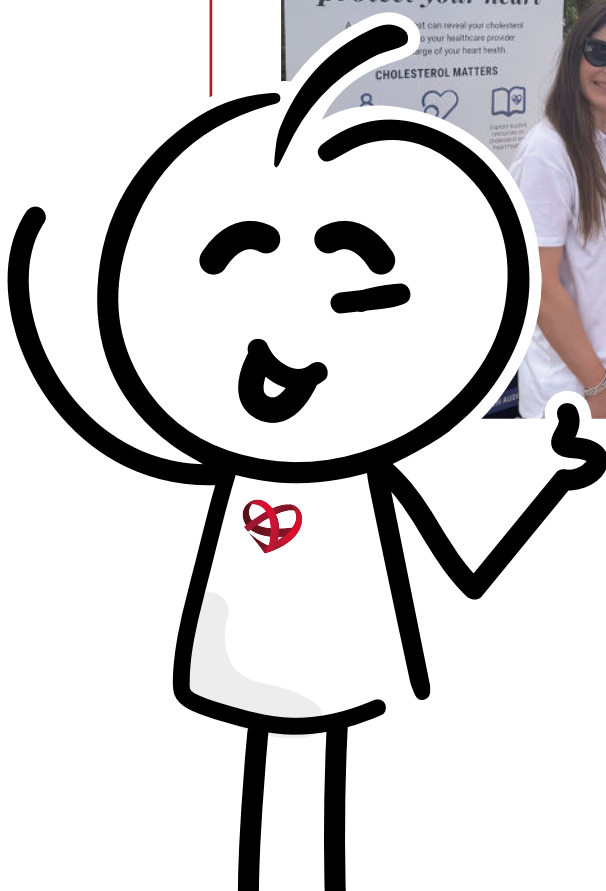
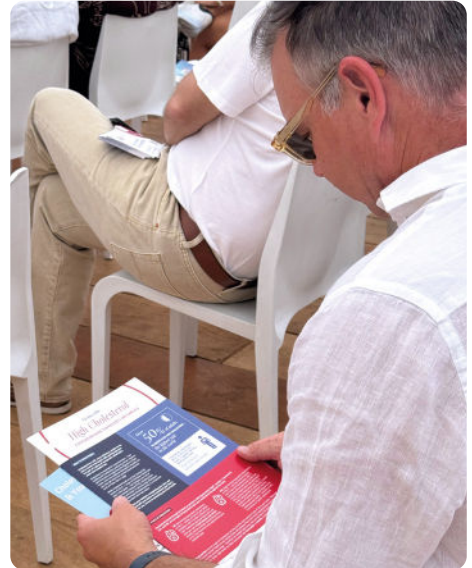
## CANNES, FRANCE



### Cannes Lions International Festival of Creativity

In June 2025, we partnered with Amgen on a cholesterol awareness initiative during the Cannes Lions International Festival of Creativity. Through an educational stand and on-site engagement, we shared practical information about cholesterol, cardiovascular risk, and prevention with a broad and diverse audience.

The collaboration also included support for the documentary screening *"The Making of a Heart Attack"* featuring Barry Sanders, former NFL player and cardiovascular health advocate, followed by a panel discussion on cardiovascular awareness.





# COLLABORATION AND PARTNERSHIP

Partnership with national patient organisations lies at the heart of our work. Since our creation, we have focused on strengthening national patient communities by amplifying their initiatives, supporting peer-to-peer connections, and providing accessible educational resources across Europe.

Throughout the year, we developed programme-based collaborations with patient organisations in several countries:



**Belgium:** We partnered with *AmyBel* to co-develop initiatives on ATTR-CM and AL amyloidosis, while laying the groundwork for a future hypertrophic cardiomyopathy support group.



**Italy:** We supported a coalition of five national patient organisations and collaborated with *GAfPA* to launch a national cholesterol awareness campaign.



**France:** We collaborated with the *Ligue contre la Cardiomyopathie* to adapt and disseminate cardiomyopathy educational resources, aligned with national needs.



**Ireland:** Together with *Amyloidosis Ireland*, we adapted AL Amyloidosis and ATTR-CM educational resources and presented them at the 2025 International Amyloidosis Conference.



**Northern Ireland:** We partnered with *Heart Failure Warriors Northern Ireland* to pilot our Heart Failure Education & Support Program, including the first European implementation of the Welcome Home – Heart Failure model.

These partnerships go beyond programme implementation. They play a central role in shaping our strategy and priorities, ensuring that our work remains grounded in local realities and responsive to the needs of patients and communities across Europe.

## Regional and Global Alliances

While national partnerships remain central to our work, we also engaged in several regional and global alliances that strengthen the collective voice of patients and increase visibility for cardiovascular health at the European and international levels.

These include:



**ERN GUARD-Heart**  
Supporting Partner



**Global / European Alliance for Patient Access (GAfPA / EAfPA)**  
Strategic Partner



**Global Heart Hub (GHH)**  
Affiliate Member



**PICC United**  
Knowledge Partner



**World Patients Alliance**  
Full Member

Through participation in these networks, we contribute to broader dialogue, knowledge exchange, and patient advocacy initiatives, while remaining closely connected to the real needs and experiences of people affected by cardiovascular disease across Europe.



# COMMUNICATION AND AWARENESS



Our multilingual website and Resource Hub provide open access to patient education in multiple languages and formats, supported by targeted awareness campaigns across social media, video platforms, and digital channels. These efforts aim not only to raise awareness of cardiovascular conditions but also to guide patients and caregivers toward practical educational resources.

Throughout the year, we delivered a series of multilingual campaigns covering cardiomyopathy, heart failure, secondary prevention of stroke, amyloidosis, cholesterol, and related conditions. Together, these initiatives generated **14.8 million impressions**, reflecting strong engagement with patient-focused cardiovascular education.

## Key campaign highlights included:



**Cardiomyopathy Campaigns:** Two campaigns generated over 2.1 million impressions and more than 31,000 link clicks, significantly increasing visibility and engagement.



**Heart Failure Campaign:** Reached 4.45 million people, generating 5.6 million impressions, over 205,000 YouTube views and 444 educational resource downloads.



**Secondary Prevention of Stroke Campaign:** Generated 3.8 million impressions, reaching 3.2 million people and nearly 2,000 link clicks.

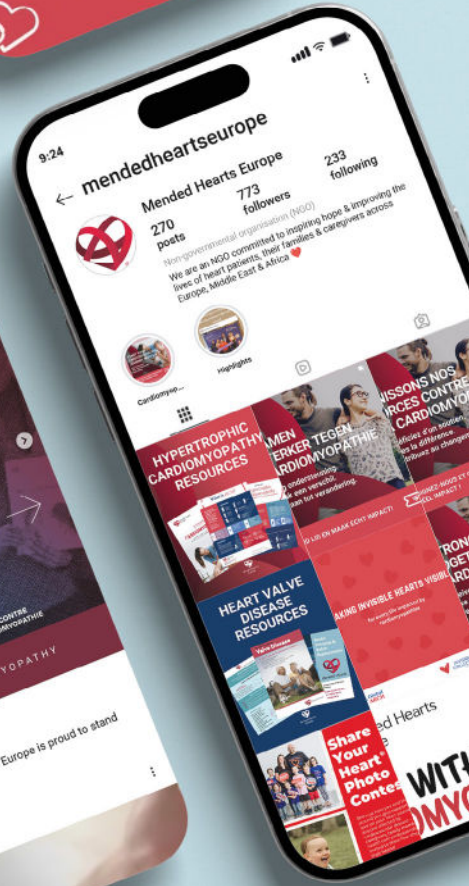
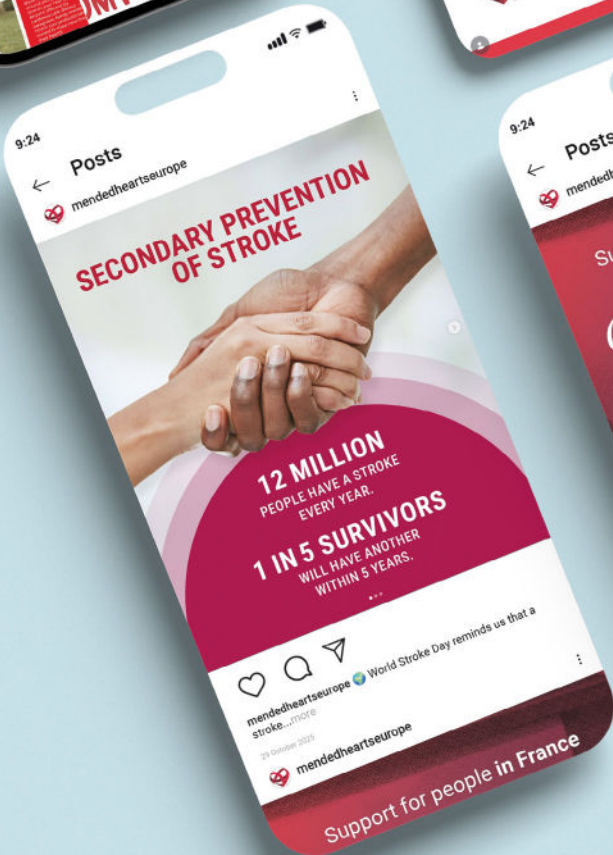
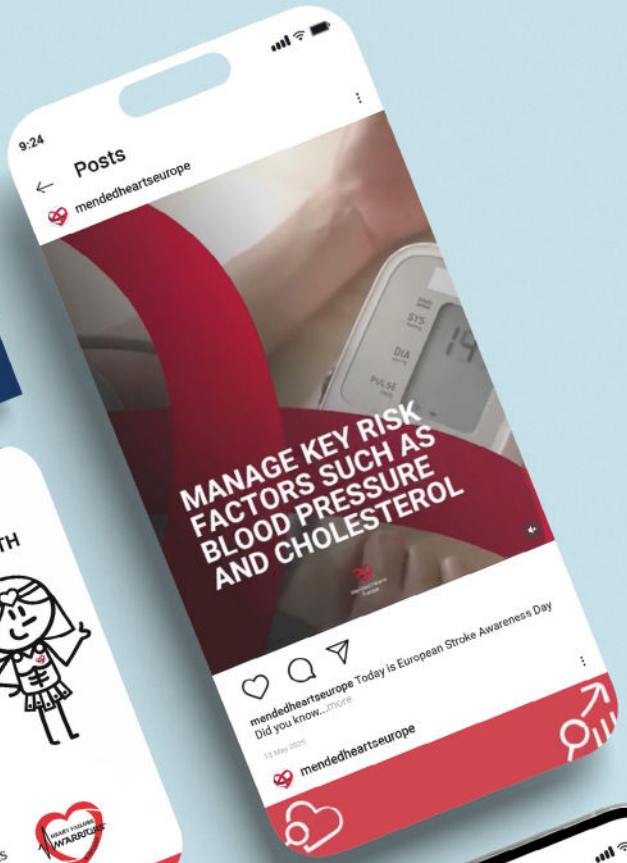
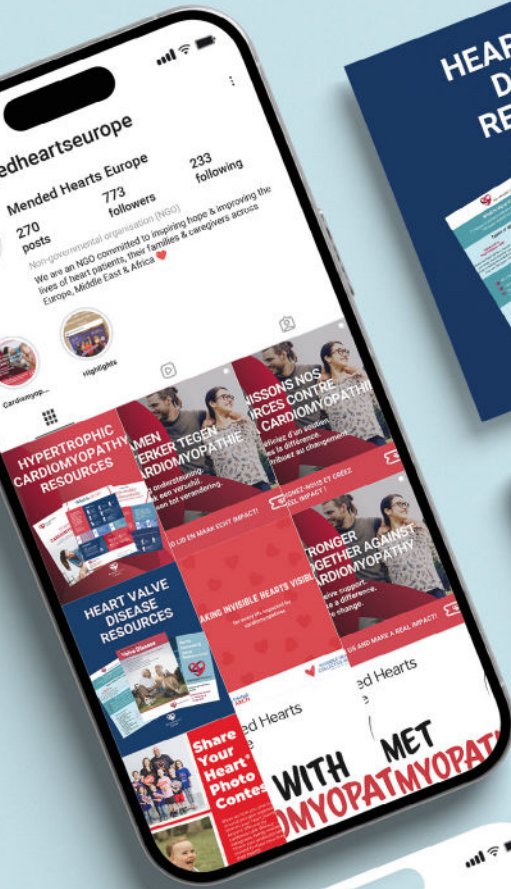


**Amyloidosis Campaign:** Reached 3.3 million impressions, including 49,000 YouTube views and 139 educational resource downloads.



**Cholesterol Campaign in Italy:** launched in 2025 and concluded in 2026, reaching 633,000 impressions and generating more than 13,000 clicks.

Across all initiatives, these efforts translated into thousands of link clicks, hundreds of resource downloads, and strong video engagement, confirming the growing demand for clear, accessible, and trustworthy patient information.





# MEMBERSHIP

As part of the wider Mended Hearts international network, Mended Hearts Europe connects patients, caregivers, and advocates living with or affected by cardiovascular disease across Europe. Through this community, members can access educational resources, awareness initiatives, and peer-support opportunities designed to help them better understand and navigate their cardiovascular journey.

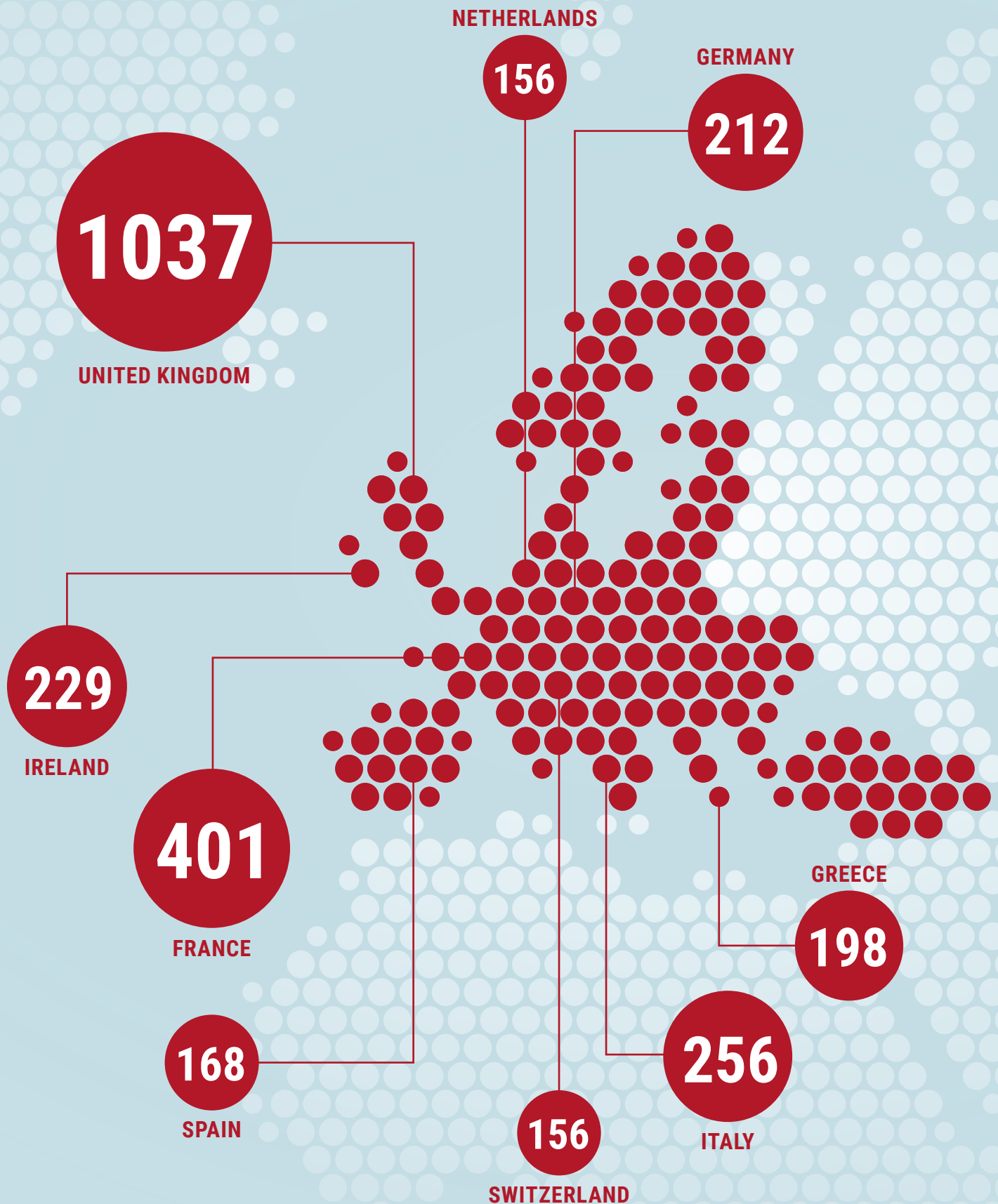


IN 2025, OUR EUROPEAN COMMUNITY INCLUDED

*4,268 members.*

Membership remains free of charge, ensuring that patients, families, and supporters can access education, resources, and peer connections regardless of their background or location.

## Top countries represented:





# 2025 EXECUTIVE COMMITTEE AND STAFF

## Our Executive Committee



**Al Voss**  
President



**Kathryn Taubert**  
Vice-President



**Laurence  
Humphreys-Davies**  
Member

## Our Team



**Emmanuel Chevron**  
Executive Director



**Andreea Gheorghe**  
Director of  
International Affairs



**Paula Anabalon**  
Project Manager



# THANK YOU TO OUR SPONSORS

## Corporate Roundtable Members



**Johnson & Johnson**



## Other Sponsors





## *Join us*

**Join us:** Be part of a patient-centred community advancing peer support, education, and advocacy across Europe.



## *Donate*

**Support our work:** Donations help expand multilingual resources, strengthen local partnerships, and grow structured peer-support models.



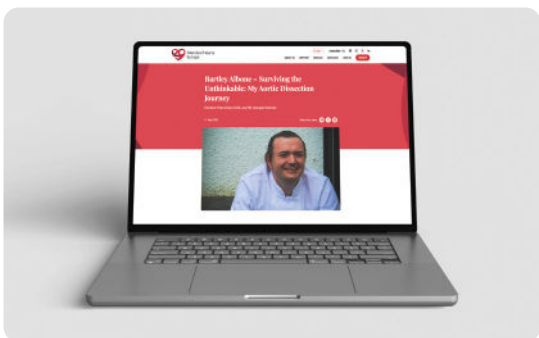
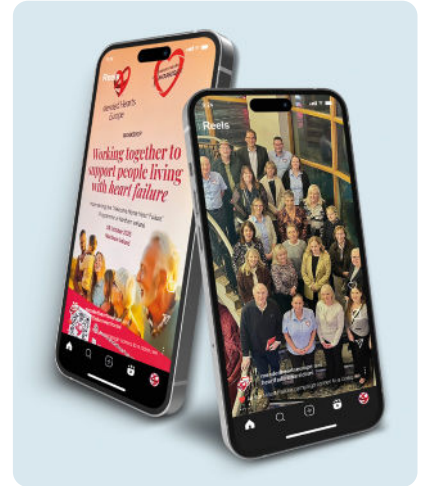
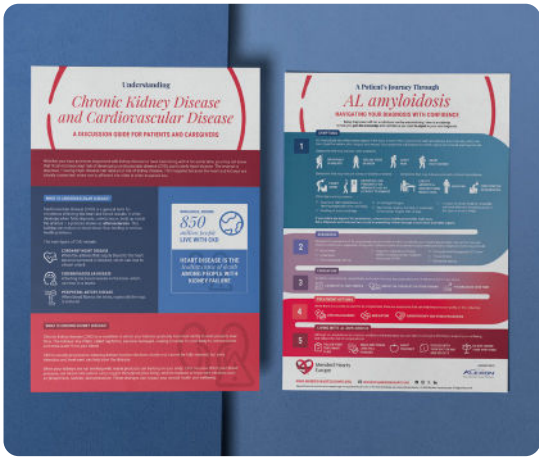
## *How to connect*

 [mendedheartseurope.org](https://mendedheartseurope.org)

 [mheurope@mendedhearts.org](mailto:mheurope@mendedhearts.org)







Mended Hearts  
Europe

[WWW.MENDEDCHEARTSEUROPE.ORG](http://WWW.MENDEDCHEARTSEUROPE.ORG)

