

**ECHDO**

# Annual Report



**ECHDO**  
European Congenital  
Heart Disease Organisation

Explore More



# President's Opening Statement

This year has been one of progress and growing visibility for ECHDO across Europe. Even though we're a small organisation in a very large landscape, we've continued to show how powerful our collective voice can be when we work together. The achievements of the past year reflect the commitment of our members and the shared belief that people living with congenital heart disease deserve strong, united representation at European level.

One of the standout moments of the year has been our closer collaboration with the European Patients' Forum (EPF) and the European Association for Cardiovascular Health (EACH). These partnerships are helping us amplify our message far beyond what we could achieve alone. We were especially delighted to celebrate Mirela's election to the EPF Board. This is a fantastic achievement that not only recognises her dedication but also strengthens ECHDO's presence within one of Europe's most influential patient advocacy networks.



Our advocacy work has remained steady and determined, particularly around the ongoing challenges of the EUMDR. Katarina has been working tirelessly to ensure the congenital heart community is heard in highlevel discussions, keeping our concerns firmly on the table. And while it was disappointing to see congenital heart disease missing from the EU Safe Hearts plan, our determination hasn't wavered. We continue to push for recognition and inclusion so that our members, and the people you represent, are not overlooked in this important piece of policy.

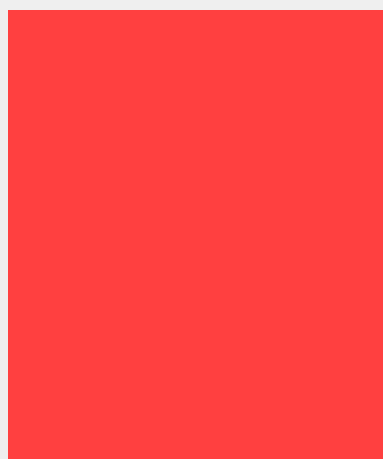
Like many small organisations, we continue to face funding pressures. Through stronger collaboration with European partners, we're exploring new funding opportunities and shared initiatives that can help secure our future. At the same time, we've been working behind the scenes to strengthen our administrative and banking arrangements, making sure ECHDO is built on solid, sustainable foundations.

As we look ahead, one message feels especially important: ECHDO's future depends on all of us. If this organisation matters, and we know it does, then its strength relies on members being willing to stand together, speak up, and actively support the work that keeps our community moving forward.

This year has shown what we can achieve when we unite our voices. With continued commitment and shared effort, the year ahead holds even greater promise.

**Karen Tomlin**

ECHDO President





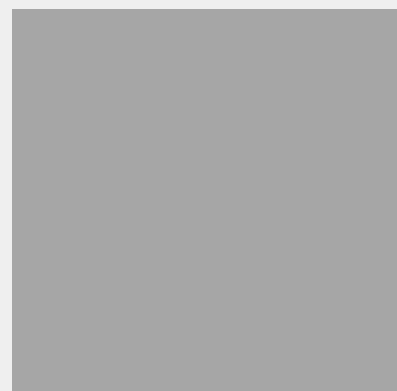
# Meet the board

At our AGM in Split, we were delighted to welcome three new members to the ECHDO Board. **Katarina Stano**, representing the Children's Cardiac Center's Foundation in Slovakia and mother to a daughter with CHD, brings both professional insight and lived experience. We also welcomed **Tsvetoslav Naydenov** from Child's Heart Bulgaria, who contributes his perspective as an adult living with CHD. Finally, **Michelle Woods** joined us as Treasurer, drawing on her expertise from the Somerville Heart Foundation in the UK. Their combined experience strengthens our shared mission and broadens the voices represented within ECHDO.

We also note that Amin Houari stepped down from the Board in June, and we thank him for his past contributions.



# Board reflections



## Mirela Dežman - Vice President

I would like to take this opportunity to thank the entire Board of Directors for a successful year, although it was full of challenges. Most of all, it showed how much can be achieved with volunteer work and if we all think in the same direction. Thanks to teamwork and the exceptional support of the members, I am proud to have become a member of the EPF Board of



Directors, in addition to my role as Vice President of ECHDO. This has allowed me to continue my cooperation at the highest level, enabling children with congenital heart defects and GUCH patients to become more visible in the EU institutions. EPF, as an umbrella organization has provided me with easier access to EU policy makers, and I will do my best to represent ECHDO in the best light. I am leading an EU project in cooperation with one of the ECHDO members, in which I have actively involved the ECHDO umbrella organization itself. Such initiatives are crucial for strengthening our network and the practical application of European funds for the benefit of patients.

In further negotiations with representatives in the European Parliament, my goals remain clear: to ensure that every child has equal access to healthcare (especially innovative treatments) and that GUCH patients receive the support they need for the best possible quality of life. I hope that the next year will also be a confirmation of our joint action and the connection of all members in the interest of all patients and children with CHD.

## Katarina Stano - Advocacy

This past year felt both demanding and deeply rewarding. From leading our advocacy efforts and the February Heart Month campaign, to engaging more closely with the European Alliance for Cardiovascular Health (EACH), the European Society of Cardiology (ESC), and the EU-MDR landscape, I was constantly reminded how complex, and often overwhelming, this space can be.

Sitting in rooms filled with industry leaders, policymakers, clinicians, manufacturers, and other big stakeholders, the patient voice can feel like a very small fish in a pool of sharks. And yet, that is precisely why our work matters. The goal we are working toward is far bigger than any one of us, and it requires persistence, clarity, and courage. So we keep showing up. We keep speaking. And above all...we keep swimming.





### Michelle Woods - Treasurer

Whilst my first year has been defined by a paradox: I am a Treasurer who has yet to touch the treasury, it has been an interesting year. Although ongoing difficulties in securing signatory access to the charity's bank account have limited my ability to carry out the role as I intended, my charity role ensured I have the tools to navigate the practical administrative hurdles small charities face when dealing with banking systems.

Once the signatory issue is resolved I will prioritise strengthening our financial processes, creating a comprehensive Finance Manual and a Standardised Banking Protocol, and exploring the possibility of a more permanent finance role alongside the Treasurer to reduce disruption when board members change. These steps will help the organisation hit the ground running and ensure our systems support our long-term mission. What has stood out is the generosity and commitment of my fellow Board members, past and present, each giving their time and expertise voluntarily, and the steady, essential support of Charlie, our part-time administrator. I value being part of this community and I enjoy serving on the board and am fully supportive of the organisation's mission and I hope to continue this important work together with it's members and other board colleagues.





### **Xenia Patsalidou**

Being Part of Echdo board is very important to me, as it allows me to represent families and children with congenital heart disease from Cyprus.

Working together with organizations across Europe help us to share experiences and support our community. I look forward to becoming even more involved in the coming year especially as our association will host the ECHDO AGM in Cyprus in 2027

### **Tsvetoslav Naydenov**

It is an exceptional honor and privilege for me to be part of the board of ECHDO. I am truly grateful for the trust and opportunity to contribute to such an important and meaningful organization.

I strongly believe that when we are united by a shared vision and purpose, we have the power to achieve remarkable and lasting impact. Together, we can continue to strengthen our community, support those who need us most, and drive positive change.

I remain deeply committed to this mission and will continue to work with dedication and responsibility for the growth and development of both our association and ECHDO. I look forward to collaborating with all of you and building an even stronger future together.

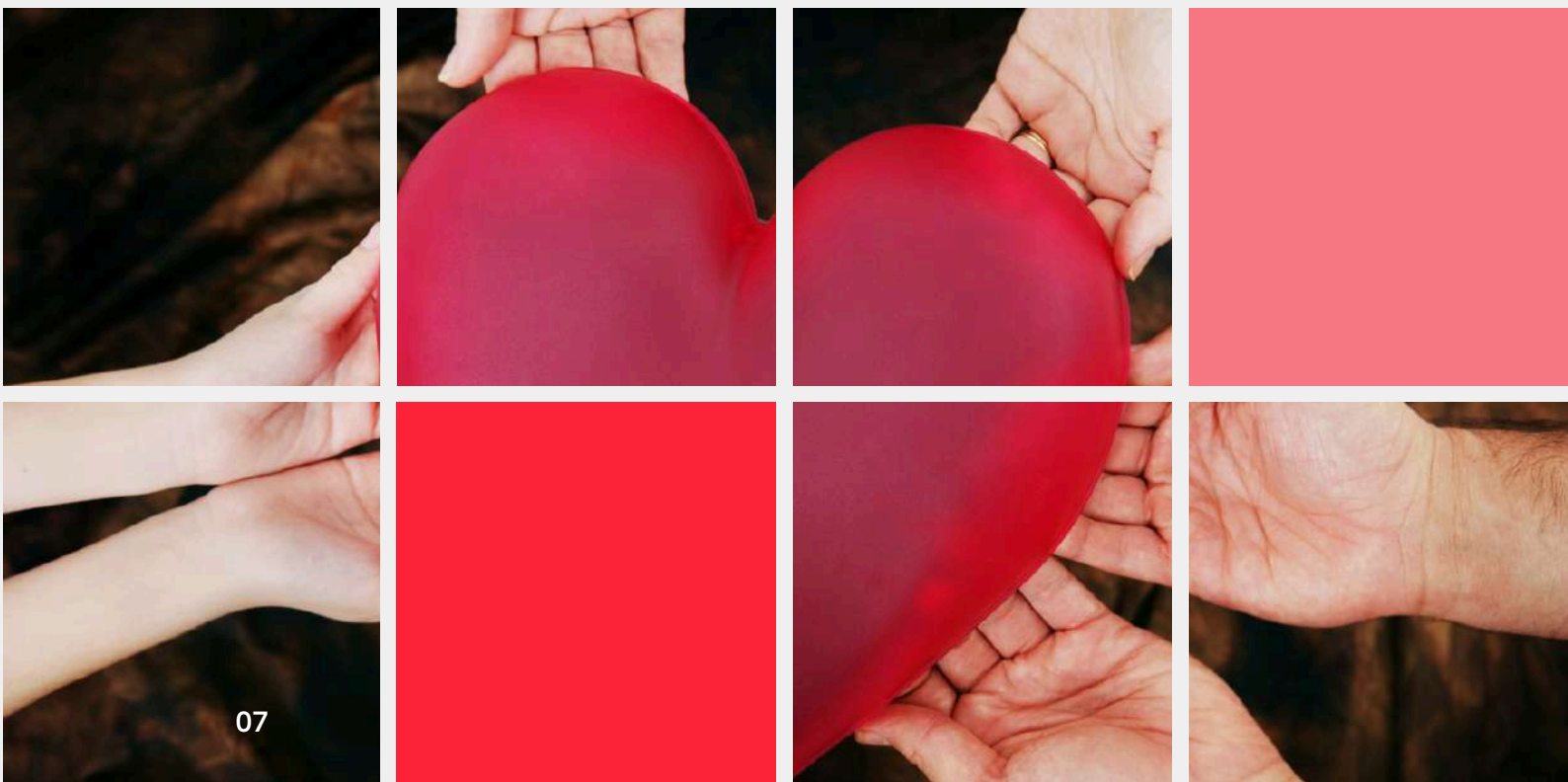


# Highlights of the Year

ECHDO's year was marked by meaningful connection, strong advocacy, and growing influence across Europe. From a vibrant AGM in Split and a successful summer camp in Finland to a series of engaging member meetings and webinars, the community continued to thrive.

Our advocacy efforts remained central throughout the year, with ECHDO submitting responses to European consultations on medical devices and the Cardiovascular Health Plan, and continuing to push for the inclusion of congenital heart disease in the EU's Safe Hearts Plan. A major milestone came in November when Mirela and Katarina represented ECHDO at the EPF Congress and Mirela was elected to the EPF Board, strengthening our voice within European patient advocacy.

The year closed with continued momentum, including a February awareness campaign, and deeper engagement with EU-MDR through Katarina's role on the ESC Taskforce on Medical Devices.



### May 2025

We were thrilled to welcome more than 40 people to our annual AGM in Split, Croatia.

### July 2025

The annual European Summer Camp was held in Finland, welcoming over 50 young people from across Europe for a week of activities.



### June 2025

We held our first members meeting of the new year, announcing next years AGM.

### August 2025

ECHDO submitted responses to European Consultations on medical devices and the Cardiovascular Health Plan. Our member meeting hosted David Toms sharing his poetry.





### September 2025

Following a successful talk at the AGM, we welcomed psychologist Andri Christoudia for a webinar for members.

### November 2025

Our first regular newsletter was sent out. Mirela and Katarina attended the EPF congress where Mirela was elected to the EPF board.

### December 2025

The EACH Summit in Brussels featured Karen's story, raising newborn screening up the agenda. We ended 2025 with a members meeting featuring a quiz.

### December 2025

The European Union released The Safe Hearts Plan and we continue to advocate for the inclusion of CHD in the plan.

**Patient Spotlight**  
EACH Summit 2025 Brussels 10- 11 December



*"At 4-weeks old, Sam was diagnosed with critical aortic stenosis and had a cardiac arrest a few hours later - thankfully we were in hospital, where they saved his life."*

Sam - born in 2009

*"Routine pulse oximetry screening could have detected his condition earlier and prevented the cardiac arrest."*

Sam today



### February 2026

We mark February with a social media campaign highlighting stories, facts and lived experiences.

### February 2026

During Heart Week we welcomed Andri for a webinar on the impact of CHD on the wider family.

### March 2026

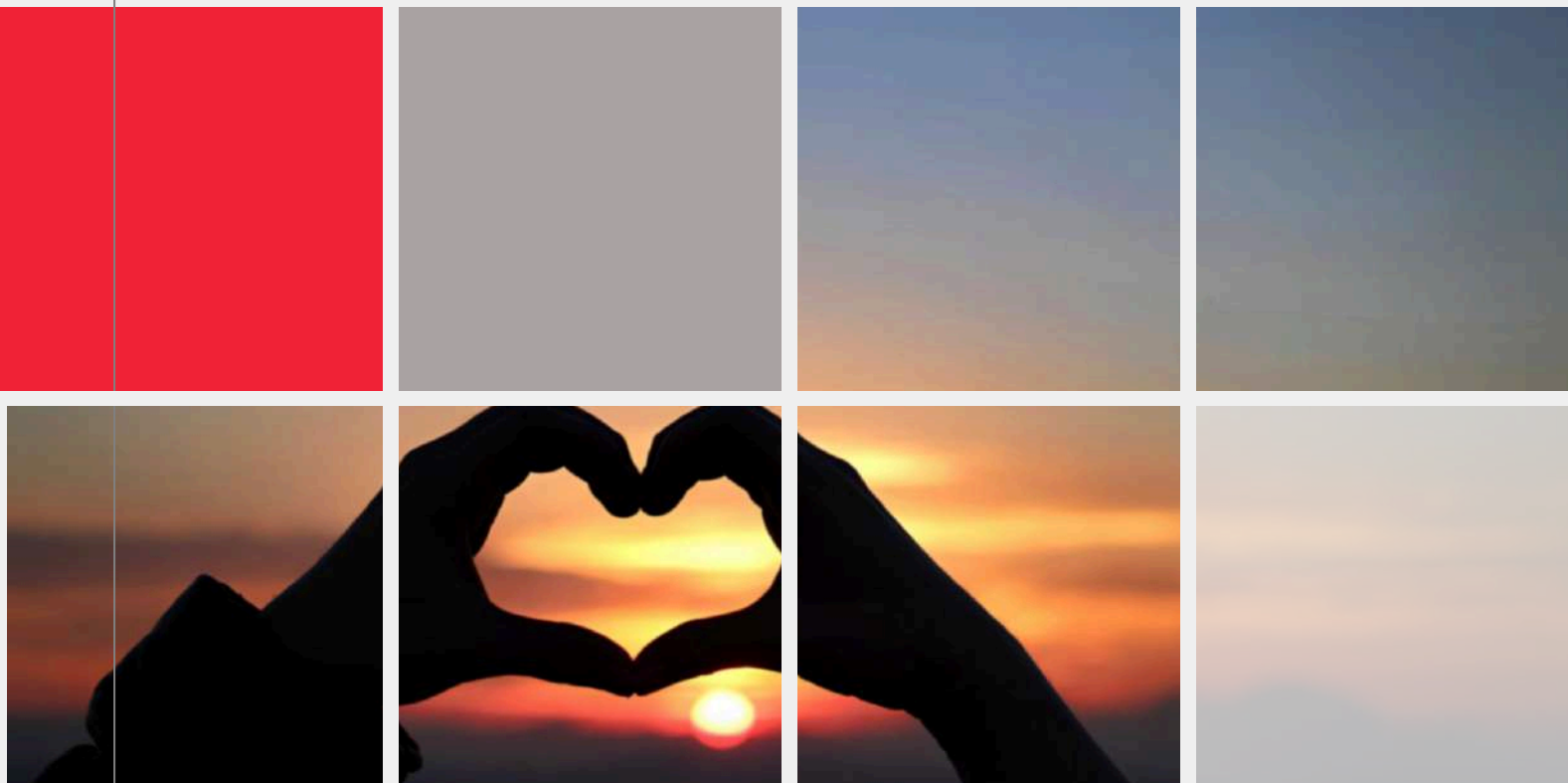
Katarina joins the EPF Taskforce on Medical Devices and attends the European Commission High-Level Conference on Medical Devices.



# Advocacy and Policy Impact

This year marked a step forward in strengthening ECHDO's influence across Europe, with our advocacy work reaching new levels of visibility, credibility, and strategic impact.

Through engagement with EU institutions, alliances, and patient-led networks, ECHDO ensured that the needs of children and adults with congenital heart disease (CHD) were firmly represented in key policy debates.



A major highlight was our deepened collaboration with the European Patients' Forum (EPF). At the EPF Congress in Brussels, ECHDO was represented by Mirela Dežman and Katarina Stano, who contributed to discussions on digital health, equity, and cross-border care. The Congress brought together patient advocates, policymakers, academics, EU institutions, and industry partners to shape the future of European health policy.

Mirela Dežman's election to the EPF Board was a milestone achievement, securing CHD representation at the highest level of Europe's patient movement. Her appointment gives ECHDO direct access to key policy discussions, early information flows, and strategic decision-making spaces, strengthening our ability to influence EU-level health policy.

ECHDO also played a role in shaping the European Commission's Safe Hearts Cardiovascular Health Plan. While the final plan overlooked congenital heart disease, our response made clear that a truly comprehensive cardiovascular strategy must recognise the full spectrum of conditions including those present from birth and carried throughout life. We continued this work through our renewed partnership with the European Alliance for Cardiovascular Health (EACH), joining their Younger Adults Working Group to ensure lifelong and congenital conditions are not sidelined in prevention-focused agendas.

Our advocacy on the EU Medical Devices Regulation (EU-MDR) intensified significantly. With Katarina Stano joining the EPF Taskforce on Medical Devices, ECHDO gained a formal seat at the table during a pivotal moment for device regulation. CHD patients depend on a wide range of medical devices, often from infancy and throughout their lifespan, making our presence in these discussions essential.

Throughout the year, ECHDO submitted evidence to EU consultations and supported allied organisations. This collective effort ensured that the lived experiences of CHD patients shaped the evolving regulatory landscape.

We strengthened alliances, secured representation in high-level bodies, and ensured that CHD voices were heard where it matters most: at the heart of European health policy.



# Scientific Committee Report

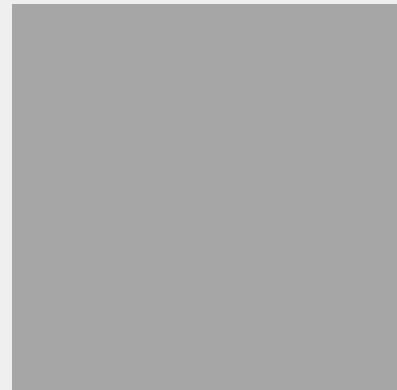
Over the past year, I represented the congenital heart disease (CHD) community at major international congresses, consistently highlighting the role of ECHDO and the essential contribution of non-profit organisations in advancing patient care.

## Key Congress Participation

I delivered invited lectures, chaired scientific sessions, and contributed to expert panels across Europe and internationally, including:

- **ECHDO Annual General Meeting (Split, Croatia)** – Honoured to receive the ECHDO Fellow Award for contributions to the CHD community.
- **AEPC 2025 (Hamburg, Germany)** – Presented on psychosocial care in transplantation pathways; chaired the joint session on Health Disparities in CHD; and moderated an interactive panel discussion.
- **AICCA Patient Day (Milan, Italy)** – Participated in a round table on making the “invisible” aspects of CHD visible.
- **“Rare but Real” Conference (Milan, Italy)** – Speaker at a national event dedicated to rare genetic diseases.
- **SICP National Congress (Genova, Italy)** – Invited speaker on psychosocial support for CHD patients and families.
- **World Congress of Pediatric Cardiology & Cardiac Surgery (Hong Kong)** – Delivered multiple talks and chaired sessions on psychosocial outcomes, AI and machine learning in CHD, telepsychology, and lifespan neurodevelopmental screening.
- **Malta Health Network (Malta)** – Led a Training in Society workshop on patient empowerment, “From Individual Patient to Patient Community”.

Recordings and presentation materials are publicly available for the Malta workshop.



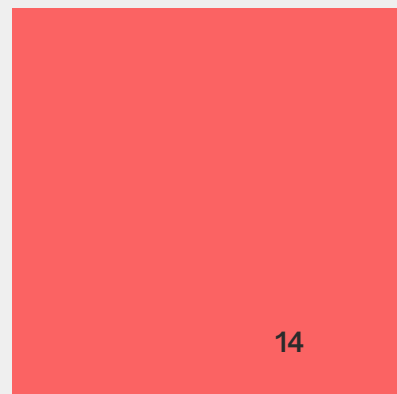
Alongside clinical and academic collaborators, I contributed as co-author to several major publications within the global APPROACH-IS II consortium. These studies represent one of the largest international efforts to understand lived experiences, psychosocial outcomes, and care needs in adults with CHD.

### Recent Publications

- **Heart (Aug 2025):** Perceived health, psychological distress and quality of life in 8,415 adults with CHD across 32 countries.
- **Canadian Journal of Cardiology (Dec 2025):** Quality of life in adults with transposition of the great arteries.
- **International Journal of Cardiology (Feb 2026):** Person-centred care in CHD: international variation in patient-reported experiences.
- **Canadian Journal of Cardiology (Jan 2026):** Advance care planning practices and needs among 8,281 adults with CHD.

These publications strengthen the evidence base for psychosocial care, patient-centred services, and international collaboration - areas central to ECHDO's mission.

Prof. Edward Callus  
PhD Clinical Psychology  
Psychotherapist

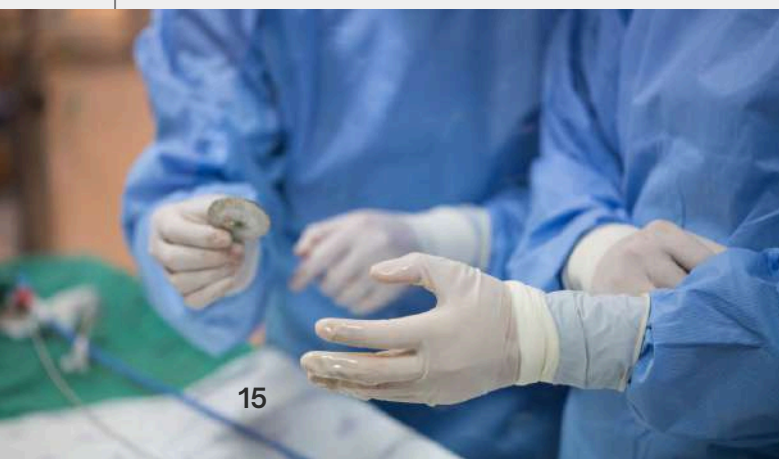


# EU-MDR - where do we stand?

The EU Medical Device Regulation (MDR) was introduced to strengthen patient safety, but its strict and costly certification requirements for companies to place devices on the EU market are already leading to the disappearance of certain devices, alongside delays in access and rising costs. For congenital heart patients, this is not theoretical; it is happening now. The focus has therefore shifted toward urgent simplification and recalibration of the system.

In this context, ECHDO has worked to ensure the patient voice remains present and heard, pooling forces with clinicians and larger patient organizations, and thereby strengthening its voice when engaging with EU institutions to advocate for a balanced approach, where safety and access to essential, life-saving devices go hand in hand.

Katarina Stano has formally joined the European Patients' Forum (EPF) Taskforce on Medical Devices. This strengthens our voice at a crucial moment for congenital heart disease (CHD) patients across Europe.



# Campaigns and Communications

This year, ECHDO strengthened its digital presence with a renewed focus on consistent, story-driven communication across social media. Our aim was to increase visibility, engage wider audiences, and reinforce ECHDO's role as a collective European voice for people living with congenital heart disease (CHD). This work came together most prominently during our February Heart Month campaign.

## February Heart Month 2026: Stories That Build Awareness

Throughout February, ECHDO delivered a dedicated awareness campaign on Instagram, sharing daily posts that combined personal stories, educational content, and advocacy messages. The campaign highlighted:

- patient and family journeys
- CHD awareness facts
- representation from member organisations
- promotion of ECHDO activities and webinars

## Reach and Engagement

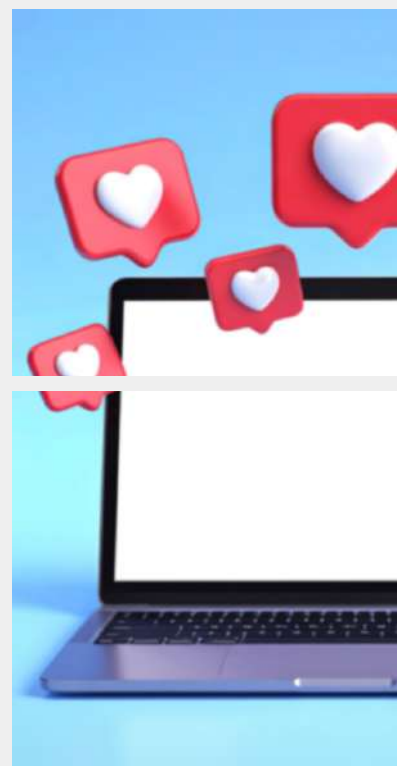
The campaign generated strong organic engagement and extended ECHDO's visibility:

- 27,637 total views
- 6,103 accounts reached
- 783 interactions
- 38 new followers
- 156 pieces of content shared
- 50.6% of views from non-followers

Posts featuring lived experience consistently performed best, reaffirming that personal stories remain the most powerful tool for raising awareness and building connection within the CHD community.

## Community Contribution

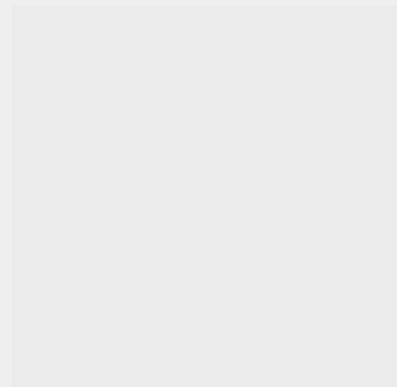
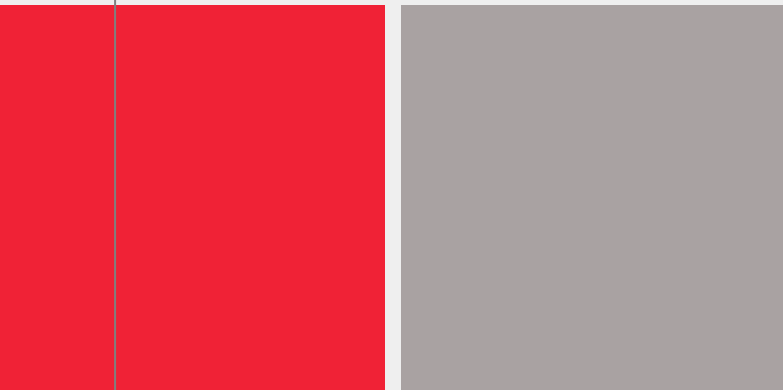
The campaign's success was made possible by the individuals and families who generously shared their stories. Their openness transformed the campaign from a communications activity into a collective expression of resilience and lived experience. We also thank member organisations, partners, and followers who contributed content, reposted messages, and helped amplify awareness across Europe.



# Financial Overview

ECHDO's finances for 2025 reflect a remarkably stable year, with the organisation ending the period with only a small loss of €700 — a testament to Mirela's outstanding work in managing costs, including securing an AGM with no venue fees.

Our sincere thanks go to Rob Nicoll for his continued financial guidance and support even after stepping down from the board, and to Katja Laine for her excellent auditing skills, which ensure our accounts remain transparent, accurate and trusted year after year.



## ECHDO Income and Expense Statement for 2025

Published Date: 7<sup>th</sup> January 2026

| <b>Income and Expense Statement for ECHDO</b>  |                         |  |
|--|-------------------------|--|
| Period: 1st January 2025 to 31st December 2025 |                         |  |
|  |                         | <u>Notes</u>                                       |
| <b>Income</b>                                  |                         |  |
| Membership                                     | 5,490.00                |  |
| Conference Fees                                | 490.00                  |  |
| Other Fees                                     | 25.78                   | KBC bank refund                                    |
| <b>Total Income</b>                            | <b><u>€6,005.78</u></b> |  |
| <b>Expenses</b>                                |                         |  |
| Administration                                 | 3,242.16                |  |
| Office Rental                                  | 1,650.43                |  |
| Banking  | 325.53                  |  |
| Internet & Website                             | 422.26                  |  |
| Marketing                                      | 0.00                    |  |
| Organisation Membership                        | 253.93                  | World Heart Federation & European Pts subscription |
| <b>Total Expenses</b>                          | <b><u>€6,386.81</u></b> |  |
| <b>AGM</b>                                     |                         |  |
| Venue  | 0.00                    | No conference fee costs                            |
| Travel Expenses                                | 492.50                  |  |
| Board Meetings                                 | 0.00                    |  |
| <b>Total Expenses</b>                          | <b><u>€6,386.81</u></b> |  |
| <b>Profit / Loss</b>                           | <b><u>-€381.03</u></b>  |  |

| <b>Balance Sheet</b>                           |                        |                                      |
|--|------------------------|--------------------------------------|
| Period: 1st January 2025 to 31st December 2025 |                        |                                      |
|  | 2025                   | <u>Notes</u>                         |
| <b>Assets</b>                                  |                        |                                      |
| Cash at bank                                   | 9,185.74               |                                      |
| Creditors                                      |                        |                                      |
| <b>Total</b>                                   | <b><u>9,185.74</u></b> |                                      |
| <b>Liabilities</b>                             |                        |                                      |
| Current  | 285.42                 | Administrators fee for December 2025 |
| Long Term                                      |                        |                                      |
| <b>Total</b>                                   | <b><u>285.42</u></b>   |                                      |
| <b>Net Assets</b>                              | <b><u>8,900.32</u></b> |                                      |

## ECHDO Budget for 2026



Published Date: 13th April 2026

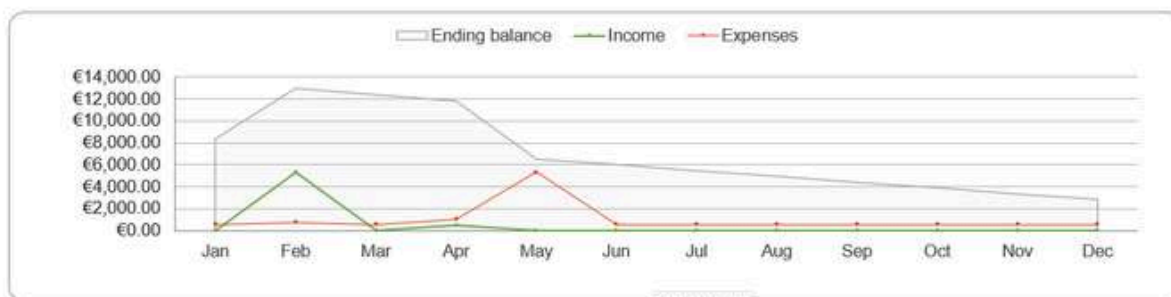


Chart Area

### Summary

|                        | Jan       | Feb        | Mar        | Apr        | May        | Jun       | Jul       | Aug       | Sep       | Oct       | Nov       | Dec       | Total      | Average   |
|------------------------|-----------|------------|------------|------------|------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|------------|-----------|
| <b>Income</b>          | €0.00     | €5,350.00  | €0.00      | €480.00    | €0.00      | €0.00     | €0.00     | €0.00     | €0.00     | €0.00     | €0.00     | €0.00     | €5,830.00  | €3,225.00 |
| <b>Expenses</b>        | €530.00   | €762.00    | €540.00    | €1,034.00  | €5,330.00  | €530.00   | €530.00   | €530.00   | €530.00   | €530.00   | €530.00   | €530.00   | €11,906.00 | €1,185.46 |
| <b>Net Change</b>      | -€530.00  | €4,588.00  | -€540.00   | -€554.00   | -€5,330.00 | -€530.00  | -€530.00  | -€530.00  | -€530.00  | -€530.00  | -€530.00  | -€530.00  | -€6,076.00 | €2,739.54 |
| <b>Ending balance</b>  | €8,370.32 | €12,958.32 | €12,418.32 | €11,884.32 | €6,534.32  | €6,004.32 | €5,474.32 | €4,944.32 | €4,414.32 | €3,884.32 | €3,354.32 | €2,824.32 |            | €7,401.98 |
| <b>Opening Balance</b> | 8,900.32  |            |            |            |            |           |           |           |           |           |           |           |            |           |



# Thank You

We know that every organisation, every family, and every individual in the CHD community has a story worth telling.

Your contributions help us:

- Celebrate the amazing work happening across our member organisations
- Spread awareness and strengthen our collective voice
- Inspire others with real stories of resilience, innovation, and hope

Find us on social media @echdoheart

info@echdo.eu

www.echdo.eu



**ECHDO**  
European Congenital  
Heart Disease Organisation