Annual report 2020





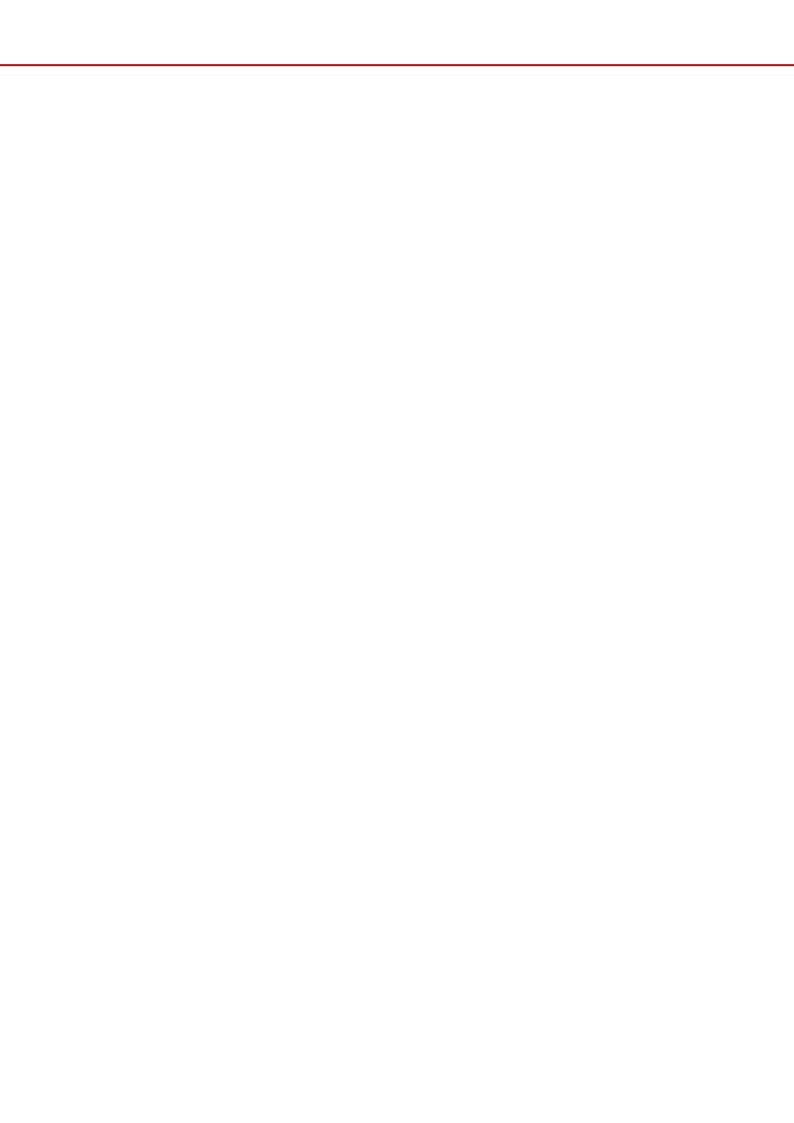


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Mission and vision

European Heart Network

The European Heart Network (EHN) is a Brussels-based alliance of foundations and associations dedicated to fighting heart disease and stroke and supporting patients throughout Europe.

Our mission

To play a leading role in the prevention and reduction of cardiovascular diseases, in particular heart disease and stroke, through advocacy, networking, capacity-building, patient support, and research so that they are no longer a major cause of premature death and disability throughout Europe.

Our vision

Every European has a right to a life free from avoidable cardiovascular diseases.





Message from the EHN's President, Director and incoming CEO

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2020 has been an immense challenge for the health of all people in Europe and beyond. COVID-19 decided to hit us hard, affecting millions of people in our member states.

Unfortunately, it did not substitute cardiovascular disease, but came on top of it, meaning that the necessary care for our patients came under threat. Despite the huge effort of all health care professionals, the research community and everybody involved in the fight against COVID, chances are slim that we will be back to normal, when you read this report.

However, our members, together with the staff of EHN in Brussels showed their resilience in supporting patients in Europe to keep cardiovascular disease high on the national and European agendas.

With our members continuing to work closely together and EHN continuing its cooperation with other organizations in the area of cardiovascular disease and healthy living, we will make progress in reducing the burden of cardiovascular disease in Europe.

Given all the challenges of last year, I am very proud of all the work that has been done by our members and our staff in Brussels to pursue a healthier Europe through promoting awareness of the importance of a healthier lifestyle, prevention, research and patient care.

I thank all the people that have contributed to the results that you will hopefully enjoy reading in this report.



Floris Italianer, EHN President

After 25 years with the European Heart Network (EHN), I stepped down in July 2020 to enjoy early retirement. The last months of my time with the EHN were not what I would have ideally wanted them to be as Covid-19 disrupted our mode of operating and business as usual was lost to the pandemic. Most sadly, I was not able to say good-bye in person to all the people in the EHN membership with whom I, in many cases, had worked for decades. However, EHN still managed to organise a video with farewell messages that deeply touched me.

For as long as it has existed, EHN has been a beacon for cardiovascular disease (CVD) prevention and cardiovascular health promotion. For most of its existence, EHN has witnessed and contributed to significant falls in cardiovascular death rates across Europe – and indeed the world. But this picture is now changing. Recent data demonstrate that, globally, death rates from CVD have risen more than deaths from any other disease in the past decade. In Europe, trends in rises in CVD death rates in younger age groups have been observed.

It seems that the party is over. In fact, while there have been good reasons to celebrate the significant falls in CVD death rates, a mistake might have been made in taking the eye of the ball and sinking into complacency. Even as overweight and obesity began to affect increasing numbers of people, and alarm bells should have gone off, it remained difficult to get attention and backing for policies that could effectively address many of the underlying problems, such as unhealthy dietary habits, high consumption of tobacco products and insufficient physical activity. EHN kept ringing these alarm bells. We pointed out that delegating the responsibility to individuals for health-damaging behaviours, which are principally driven by unsupportive societal and physical environments are not only unhelpful but plainly wrong.

And now the world is facing a whole new crisis – the Covid-19 pandemic has thrown everything and everybody into disarray. Not only has this life-threatening virus killed more than 2,6 million people world-wide (as I am writing), but it has also crashed economies, and taken away people's freedom to move and congregate. It has demonstrated that not having effective global policies and monitoring and alert systems in place to preserve people's health is fatal.

Disease, whether infectious or noncommunicable, matters to the world. Preventing it matters to the world. Treating and caring for people who are ill matters to everybody. In my 25 years with the EHN working on a vast range of policies to help promote cardiovascular health and prevent cardiovascular disease, particularly in the European Union, health has been a side-show delegated to one Directorate-General and otherwise largely disregarded by and lacking support from the rest of the European Commission (not including research). Certainly, this is how I have perceived it. Moreover, the mantra was that health was a matter for the EU Member States. Yet, EHN demonstrated time and again that health status in one country is often dictated by developments outside of that country and, indeed, outside of health systems.

With increasing death rates from CVD and an increasing number of people living with CVD already occurring before the pandemic, and now at risk of rising further in the wake of Covid-19, strengthening cooperation across countries and across sectors is needed more than ever. I know that EHN will continue to invest in multi-stakeholder cooperation to face the mountainous challenges. I am grateful to have been part of the EHN and its many achievements for more than two decades. And I am confident that my successor with the very able team in place will be proud to lead the EHN and look after the many people who live with cardiovascular disease



Susanne Løgstrup, Director, EHN

It is both a privilege and a great pleasure to be appointed as the new CEO of the European Heart Network. I already knew about EHN in the field of prevention when I worked for the Standing Committee of European Doctors (CPME) and was impressed by the excellent advocacy work done by the organisation. During my tenure as CEO of the European Cancer Organisation, I gained close insights into the challenges and opportunities faced by a disease specific health organisation. I very much appreciate working in European membership organisations, where the added value of a rich network of national expertise and cultural backgrounds from all over Europe allow for much joy and strength in achieving the mission of a value-based organisation such as the European Heart Network.

Of course, starting in the middle of a health and economic crisis is challenging. However, as with all crises, opportunities arise to adapt to the new situations and find solutions, which might at first look like obstacles, but ultimately can work to the advantage of the organisation. While the accelerated transition to *smart working* has been stressful for the EHN Secretariat, in the end, much has been achieved in 2020, as this report shows. The Covid-19 pandemic has also put a new focus on cardiovascular disease as my predecessor, Susanne Løgstrup, just described so eloquently. It is however, in all its tragic magnitude for CVD patients, who missed consultations due to limited services in general health care or Covid patients who ended up with a cardiovascular condition as a health outcome, the chance to make a change. A change in the cardiovascular political landscape, in the mindset of policy makers at European level, but also with national health ministers

The importance of a resilient and robust health care system and European coordination and solidarity have now become evident, while silencing those voices which referred to health care as a mere market commodity and financial burden to society or the health care system as a national fortress. The European Union reacted to this and the ministers in the council approved a budget of 5.4 billion for the EU4Health Programme, which is a truly historic figure for a Health Programme. The Covid-19 pandemic has also shed more light on CVD and its prevalence as the major cause of death in Europe and the world. It will be very difficult to turn a blind eye to this epidemiological fact in the future. With all these elements, including the imperative of multi-stakeholder cooperation on the table, there is a real possibility of taking a big step towards achieving a Europe, where CVD is no longer the debilitating human and economic burden it used to be. I am very proud to be part of an important era for health in general and, with my team, look forward to changing the course of CVD history in Europe.



Birgit Beger,Incoming CEO, EHN

Main achievements in 2020

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Below is a quick overview of EHN's main achievements.

To support our members, build skills and facilitate exchange of knowledge

The European Heart Network organised:

- a virtual Covid-19 strategy meeting to facilitate exchange of knowledge and best practices on how to tackle challenges imposed by the Covid-19 pandemic
- creation of a specific website on Covid-19 to provide links to reliable sources of information, including links to EHN member organisations' dedicated web pages with information for people with heart and circulatory diseases.
- three virtual seminars for EHN patient organisations
- one virtual training session for cardiovascular patients
- two virtual meetings of the EHN Research Platform for our research-funding members

Our work in cooperation with European and international organisations produced tangible outputs

- together with other civil society organisations united in the EU4Health Civil Society Alliance (CSA), EHN published 10 guiding principles for the new EU4Health programme.
- together with other health organisations of the European Chronic Disease Alliance (ECDA) and the European Public Health Alliance (EPHA) (EHN is a member of both organisations), EHN advocated for the budget of the new EU4Health programme not to be cut as by the Council meeting of 21 July 2020, from the initial € 9.4 billion to € 1.7 billion. On 10 November 2020, an agreement negotiated between the European Parliament and the Council set for a budget of € 5.1 billion. The final EU4Health programme, with a budget of €5.1 billion was adopted on 24 March 2021.
- together with other civil society organisations, EHN advocated for a strong pillar on prevention in Europe's Beating Cancer Plan.
- together with the European Chronic Disease Alliance (ECDA), EHN advocated for an extension of the mandate of the European Centre for Disease Control (ECDC) to include non-communicable diseases.

To increase knowledge about cardiovascular disease and the role of EU policy makers in reducing the burden

The European Heart Network:

- published "Fighting cardiovascular disease a blueprint for EU action" in collaboration with the European Society of Cardiology.
- met virtually with Health Commissioner Stella Kyriakides and Members of the European Parliament to present a range of actions to address the increasing burden of CVD and improve the care and treatment for patients.
- published papers on:
 - physical activity: an effective way to protect your heart
 - front of pack nutrition labelling
 - the value of digital tools for cardiovascular patients
- published news on the impact of Covid-19 on cardiovascular disease.

- advocated for CVD and prevention, early detection and innovation in management and overall care in the EU4Health Programme: EU4Health

 an opportunity to tackle the vast burden of cardiovascular disease, the number one cause of death in the EU.
- welcomed the Communication on a Farm to Fork Strategy for a fair, healthy and environmentally friendly food system.
- contributed to the European Consultation on the Pharmaceutical Strategy.
- represented patients' views and interests in a series of activities organised by the European Medicines Agency.
- on World Heart Day, EHN communicated the urgent need to address the increasing burden of CVD, particularly in these times of the Covid-19 crisis.

Our sustained advocacy activities bore fruit

- the EU reserves a budget of 5.1 billion EUR for the EU4Health programme with at least 20% dedicated to disease prevention and health promotion.
- the EU4Health programme includes specific references to cardiovascular disease.
- cardiovascular disease is specifically referenced in the Strategic Plan for implementing Horizon Europe, the EU's research framework programme 2021–2027.
- EHN published its views '<u>The future State of Health in the EU</u>'

Cardiovascular health in Europe

3

2020 will be remembered as the Covid-19 year. The virus, which started spreading in Europe in March 2020 turned the life of all Europeans upside down. We needed to reorganise our societies, and our way of working, let alone the topics that we as the European Heart Network were working on.

Cardiovascular disease in the context of the Covid-19 pandemic

The COVID-19 outbreak in 2020 has put a sharp focus on the weaknesses of healthcare systems across Europe and generated an unprecedented strain on hospitals and healthcare professionals beyond the human aspects of the pandemic. There is a strong call for rethinking and re-creating healthcare provision, taking research forward and translating innovative solutions into practice to support patients and healthcare professionals equally.

Evidence and data collected during the pandemic have shown that COVID-19 has had a significant impact on cardiovascular health and the delivery of cardiovascular care. Already before the outbreak, cardiovascular disease was the leading cause of death in Europe and the EU. More than 60 million people live with cardiovascular disease in the EU and nearly 13 million new cases of cardiovascular disease are diagnosed each year. The pandemic has aggravated this already grim scenario, also leaving many patients with new cardiovascular conditions after recovering from COVID-19.

While national governments are responsible for organising and delivering healthcare, the pandemic has demonstrated that health action and coordination at EU level can be a real game-changer for European patients.

As more data on COVID-19 patients become available. the disease appears to be particularly devastating for cardiovascular patients. It goes well beyond the lungs, damaging the heart, brain and other organs. Furthermore, new observations regarding blood clotting also raise questions. To that end, the European Heart Network supports the CAPACITY COVID Registry (CAPACITY), led by the Dutch CardioVascular Alliance. CAPACITY registers data on cardiovascular history, diagnostic information, and occurrence of cardiovascular complications in patients with COVID-19. By collecting this information, in a standardised manner, CAPACITY aims to provide more insight into: (i) the vulnerability and clinical course of COVID-19 in patients with underlying cardiovascular disease; (ii) the incidence of cardiovascular disease in patients diagnosed with COVID-19; and (iii) more generally, investigates the role of cardiovascular disease in the COVID-19 pandemic. This should lead to providing cardiovascular patients with the best possible care, and to be prepared for future outbreaks.

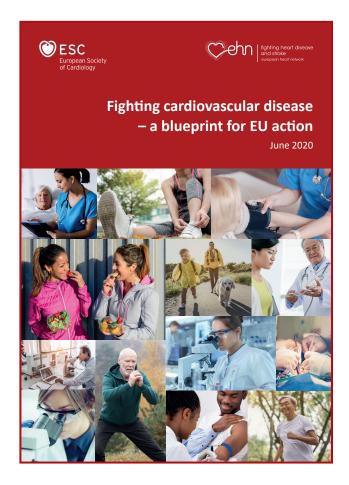


Fighting cardiovascular disease – a blueprint for EU action

The burden of cardiovascular disease (CVD) is greater than that of any other disease and the leading cause of death in Europe and in the world. While the EU is currently concentrating its main focus on the fight against cancer, cardiovascular disease cannot be forgotten. To assist policy makers and provide guidance on how to address this burden, the European Heart Network and the European Society of Cardiology have developed "a Blueprint for EU action".

Preventing cardiovascular disease remains the main and the most efficient priority. However, not all cardiovascular diseases are preventable. In the EU, over 60 million people live with cardiovascular disease. Cure from the disease is not possible, so for patients and their carers, a lifelong adjustment to living with the disease is necessary. Moreover, whereas over the last 50 years, a dramatic decline in CVD mortality was noticed, we now see that the rate of decline in CVD mortality is slowing down. Indeed, for the first time in 50 years, some EU countries have reported an increase in premature CVD death (before the age of 65). This was already the case before the outbreak of Covid-19 and the pandemic has worsened the situation dramatically.

The Blueprint contains 21 very specific policy recommendations to fight cardiovascular disease that can be achieved during the current policy mandate 2019-2024. It focuses on three pillars: measures in the field of prevention, research and patient care. We hope that policy makers will take up these recommendations so that CVD and the huge economic cost that goes with it (€ 210 billion annually – more than the total EU budget) can be reduced.



The Blueprint should have been launched in the early months of 2020, but the outbreak of Covid-19 changed the timeline. On 24 June 2020, EHN together with ESC and Members of the European Parliament presented the policy recommendations in the blueprint to the European Commissioner for Health, Stella Kyriakides.

Publications, position papers and statements, responses and media at a glance



Publications

- Physical Activity Policies for Cardiovascular Health
- Front of pack nutrition labelling
- Research paper on the value of digital tools for cardiovascular patients

For more information, please see next section 5



Position papers

- What is the value of digital tools for cardiovascular patients?
- Fighting cardiovascular disease a blueprint for EU action



Statements

EHN published statements on:

- Use heart to beat the increasing burden of cardiovascular disease in Europe
- The future state of health in the European Union
- Nutri-Score could become EU's front-of-pack nutrition labelling scheme if underlying algorithm is revised
- EU4Health an opportunity to tackle cardiovascular disease
- Statement on the EC proposal on Farm to Fork Strategy
- COVID-19 and cardiovascular disease complexities that beckon answers
- Cardiovascular patients' fears in a time of Coronavirus
- The missing heart attacks



EHN responses to Commission consultations

- EU Strategy on the Rights of the Child (2021–2024)
- Pharmaceutical Strategy
- Horizon Europe First Strategic Plan 2021-2024
- The roadmap: 'Sustainable Food Farm to Fork Strategy'



Press

- <u>Use Heart to beat the increasing burden of cardiovascular disease in Europe</u> September 28th 2020
- <u>Annual Report 2019</u> July 15th 2020
- Nutri-Score could become EU's front-of-pack nutrition labelling scheme if its algorithm is revised
 July 08th 2020
- New CEO for EHN July 01st 2020
- <u>EU Action on CVD needed now</u> June 25th 2020
- <u>EU4Health an opportunity to tackle cardiovascular disease</u> May 28th 2020
- Statement on the EC proposal on Farm to Fork Strategy May 18th 2020
- COVID-19 and cardiovascular disease complexities that beckon answers May 05th 2020
- <u>Cardiovascular patients' fears in a time of Coronavirus</u>
 April 24th 2020
- The missing heart attacks
 April 17th 2020
- <u>Valentine's Day call to join the MEP Heart Group</u> February 13th 2020
- European Heart Network Statement on Front of Pack Nutrition Labelling February 03rd 2020
- <u>Director of the European Heart Network (EHN), Susanne Løgstrup, retires</u> January 31st 2020
- Help us prevent cardiovascular disease in the EU January 27th 2020



Policies to advance cardiovascular health in Europe

Physical activity policies for cardiovascular health

In January 2020 EHN published its paper on "Physical activity polices for cardiovascular health". The main conclusions from this report are that physical activity is an effective way to protect your heart, that it is never too late to start with physical activity and any exercise is better than none – though more is better. Physical inactivity increases the risk of CVD by more than 20%. Yet, in Europe, it is estimated that 25% of women and 22% of men are physically inactive.

The report shows that engaging in physical activity is beneficial for healthy people and for people who live with cardiovascular diseases. The recommendation is for regular activity of at least 150 minutes a week of moderate-intensity or 75 minutes a week of vigorous-intensity physical activity or an equivalent combination. The report further demonstrates the effectiveness of physical activity in patients, highlighting the need for flexible, individualised and 'menu-based' programmes, tailored to the circumstances and needs of individual patients as part of cardiovascular rehabilitation.

The report also demonstrates that policy makers at EU, national, regional and local level play an important role in improving uptake of regular physical activity. However, it also shows the under-use of policy measures to promote physical activity at a population-level to prevent cardiovascular disease.



Click here for the long version of the report

Click here for the summary version of the report

Front of pack nutrition labelling

For many years, the European Heart Network (EHN) has actively advocated for an introduction of simplified nutrition information on the front of food packages as a cardiovascular health promoting measure. EHN repeatedly called for the EU to adopt mandatory EU-wide, simplified front-of-pack (FOP) nutritional labelling. The case for introducing FOP labelling has strengthened in recent years. All FOP labelling schemes can help consumers in their ability to make healthy choices and, in addition, can encourage food product reformulation. In this regard, EHN welcomes the European Commission's intention to come up with a legislative proposal in 2022 for a harmonised, mandatory front-of-pack nutrition labelling to enable consumers to make health-conscious food choices.



There is now increasing momentum at global and European levels for the implementation of FOP labelling, and the environment is now more favourable to the introduction of a single, EU wide scheme. The Nutri-Score labelling scheme has been selected by several EU governments (France, Belgium, Netherlands, Germany, Spain, Portugal) and non-EU governments (Switzerland) as the FOPL system to be used in these countries. However, concerns have emerged that the underlying algorithm needs to be adapted and aligned with scientific, food-based, dietary guidelines in order to be appropriate for prevention of cardiovascular disease in all European countries.

In its position paper on "Front of pack nutrition labelling", EHN recommends that:

- the EU should adopt a fully harmonised, mandatory, simplified, interpretive FOP nutrition labelling scheme.
- based on current evidence and recent developments, the EU should consider adopting Nutri-Score conditional upon a review and adaptation of the underlying algorithm and adoption of a new algorithm.

- a scientific committee of independent experts should be established to review and adapt the algorithm underpinning Nutri-Score and to assess whether and under what conditions the algorithm may be converted into a pan-European label.
- pending an EU-wide scheme, EU Member States and other countries within the WHO European Region that do not yet have a government-endorsed scheme should opt for Nutri-Score or another governmentendorsed scheme already in use in another European country, while ensuring that the underlying algorithm supports national dietary guidelines.

Click here to read the EHN paper on Front of Pack Nutrition Labelling

Research paper on the value of digital tools for cardiovascular patients?

Digital innovation in health can improve diagnosis, cardiovascular patients' care, treatment and management. This research paper, funded by the European Heart Network, offers an overview of existing evidence on effectiveness of digital tools for primary and secondary prevention, heart failure management, homehospitalisation for heart failure patients, diagnosis



and management of cardiac arrythmias and remote monitoring of cardiac implantable devices. In addition, the paper addresses the potential of big data and artificial intelligence in cardiology to personalise disease detection and treatment, develop new medicines, stratify patients and improve clinical trials and reduce costs for research.

Click here for the Executive Summary

Click here for the long version

Click here for the long version without the annexes

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Cardiovascular patients

Our member organisations work with cardiovascular patients and their families, the public, the wider scientific community, politicians, and other stakeholders to improve detection, treatment, care and quality of life for patients. They provide direct information and support to help patients manage their health. They enable patients and their carers to share experiences with their peers. They connect patients with the research community to ensure that innovation is relevant to patients' needs. Together with patients, our patient organisations advocate for better public policies and programmes to tackle the major heart and circulatory health care challenges.

As the independent European CVD patient organisation, EHN provides a forum for its member organisations and the patients they represent. Together, we elevate the patient voice to influence EU policies affecting people living with cardiovascular disease and improve cardiovascular health and care across Europe.

Due to the pandemic, EHN members could not meet physically, but held a series of virtual exchanges throughout the year. From April 2020 onwards, EHN created a members-only virtual space to share opinion pieces and updates on the impact of the pandemic on cardiovascular patients. This also facilitated information-exchange on new ways of working with patients and supporting them throughout the pandemic.

The 2020 European Heart Network (EHN) Patients' Seminar was replaced with two virtual meetings in autumn and brought together both patients and representatives of EHN-member patient organisations.

The first meeting, entitled: 'Digitalisation in health: what's in it for cardiovascular patients?', was an opportunity to delve deeper into the potential of digital technologies to improve cardiovascular prevention, diagnosis, patient care, treatment, and management. The discussion opened with findings of the EHN funded paper, explored members' activities and patients' interests in this field and closed with EHN's engagement in EU discussions on digitalisation in health.

In the second meeting, representatives of the European Medicines Agency's Public and Stakeholders Engagement Department presented the regulatory pathway of a medicine and the many stages in which patients are involved in the process.

European Medicines Agency

In 2020, EHN strengthened its engagement with the European Medicines Agency's (EMA) as a member of *Patients' and Consumers' Working Party (PCWP)*. The PCWP is a platform where European patient groups meet to discuss key issues of relevance to patients, as well as providing the EMA with recommendations from a patient's perspective.

EHN's interaction with the EMA developed considerably with an active engagement in all meetings organised by the PCWP. In addition, EHN was invited to speak at two EMA events. In September 2020, EHN presented patients' views on secondary use of data for medicines and public health purposes. In December 2020, EHN raised cardiovascular patients' questions and concerns at the EMA's public stakeholder meeting on COVID-19 vaccines.

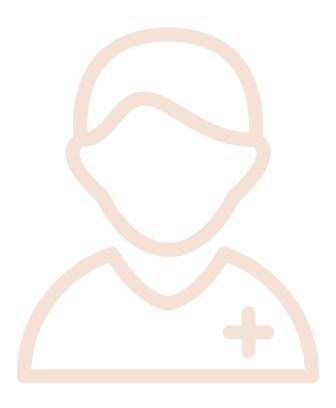
Early in 2020, EHN was appointed as member of the European Medicines Agency (EMA) and Heads of Medicines Agencies (HMA) joint Big Data Steering group.

The Steering Group advises the EMA Management Board and HMA on prioritisation and planning of actions to implement the ten priority recommendations for the European medicines regulatory network, to make best use of big data in support of innovation and public health in the European Union (EU).

The Steering Group began its work in May 2020. Since then, EHN attended 11 meetings and events of the group. In December 2020, EHN spoke at the EU Big Data Stakeholder Forum and raised patients' perspectives and priorities on big data use for research and medicinal innovation.

Finally, EHN was appointed to participate in the group, which was assigned to test and assess the functionality of the Clinical Trials Information System public portal, one of the main deliverables of the Clinical Trial Regulation. During 2020, EHN participated in all group meetings and testing activities. EHN provided feedback on changes to be made for the audit and go live versions of the portal.

Click here for further information



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Research

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EHN Research Platform

About one third of EHN members fund CVD research, with a combined annual contribution of over €200 million (based on 2019 figures). The EHN Research Platform facilitates learning and information exchange, as well as interaction with cardiovascular patient organisations.

Due to pandemic restrictions, the 2020 Research Platform autumn meeting was replaced with two virtual meetings. The first meeting looked at international collaboration on CVD research. The discussion opened with members' experiences from past and ongoing collaboration initiatives and closed with an interactive reflection on aspirations for future collaborations and role the EHN platform can play to facilitate those. The reflection continued at the Platform's second meeting which focused on EHN working approaches to facilitate information flow, coordination and help pilot collaborations to emerge.



European grants and projects

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BigData@Heart was launched in 2017. It is a five-year project funded by the Innovative Medicines Initiative (IMI 2), a public-private



initiative between the European Union and the European umbrella association of pharmaceutical companies (EFPIA). The project aims to improve patient outcomes and reduce the societal burden of acute coronary syndrome (ACS), atrial fibrillation (AF) and heart failure (HF). It is one of the four disease-specific consortia of the IMI Programme Big Data for Better Health Outcomes.

In 2020, EHN hosted two virtual meetings connecting project researchers with patients.

The first virtual meeting took place on 5 June 2020 and focused on patient and public involvement in Big Data research. During this webinar, Dr Ghislaine van Thiel, Associate Professor in Julius Centre for Health Sciences and Primary Care, Medical Humanities Research University Medical Centre Utrecht, opened the discussion with a presentation of the BigData@Heart project and the main outcomes from a literary review about patient and public views and attitudes on the sharing of health data for research. Dr van Thiel then presented a draft survey of the BigData@Heart project aimed at increasing knowledge in this field by gathering views of patients and the wider public. During the discussion, 10 patients and 5 patient representatives from 6 European countries provided concrete input on whether questions reflect

patients' concerns over health data sharing and how to tailor the questionnaire for the purposes of the BigData@ Heart research. Following-up from the meeting, the draft questionnaire was shared with 13 patient organisations for additional comments and feedback.

The second virtual meeting took place on 9 December 2020 and focused on dynamic interfacing for data intensive health research. Patients and citizens are increasingly asked to share personal health data for international scientific health research. The concept of dynamic interfacing, also referred to as dynamic consent, builds upon a patient-centred, digital communication interface for providing information, obtaining consent, and facilitating involvement. Yet, while dynamic consent is increasingly put forward as a promising approach, the concept is not yet clearly defined and entails many different elements at once. The BigData@Heart research seeks to provide greater insight into its practical applicability and implementation.

During the exchange, Dr Ghislaine van Thiel and PhD candidate Sam Muller gave an overview of their research. 10 patients and patient representatives from 5 European countries gave their insights on the concept, participation in governance, and communications. They reflected on hypothetical scenarios for practical implementation and shared points of interest that are important to patients and would be relevant for the research team to include in their research. The input will feed into research led by the Julius Centre for Health Sciences and Primary Care.

Click here for more information

Annual Report 2020

Annual workshop

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The Annual Workshop is the major event for EHN members, where knowledge-sharing and capacity-building take place in a convivial atmosphere. The Workshop provides an unparalleled occasion for networking with colleagues from large and small heart and stroke organisations and patient associations across Europe.

In 2020, however, due to Covid-19, the live version of the three-day EHN Annual Workshop, which was scheduled to take place in May 2020 in Stockholm, needed to be cancelled. Instead, EHN organised three virtual meetings, on 8 April and on 4 and 5 June 2020.

The meeting of 8 April had its focus on Covid-19 and how EHN members could support CVD patients at national, as well as at European level. Three themes were discussed:

- introduction to CAPACITY a European registry of patients with Covid-19 including cardiovascular risk and complications.
- how do we communicate with CVD patients in times of crisis?
- challenges in fundraising, an important topic since live events and direct contact with CVD patients, as well as the wider public were restricted. The session addressed how different EHN members addressed the challenge.

The virtual meeting of 4 and 5 June focused on the following topics:

- tobacco A smoke free Europe by 2030 from global to local
- big data research patient and public involvement

As the Annual workshop could not be held in its usual in-person format much of the usual interaction and communication could not take place. However, the shorter, virtual events enabled more participants from the EHN membership to attend and allowed for a more targeted discussion, since different experts and participants contributed to the virtual meetings as travel costs and time were saved.

Working with the EU institutions

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Virtual meeting with Commissioner Kyriakides

On 25 June, the European Heart Network launched the Blueprint for action on Cardiovascular disease in the EU during a virtual meeting in the presence of EU Commissioner for Health, Stella Kyriakides.

- participants in the meeting: Commissioner Kyriakides, the two co-chairs of the MEP Heart Group (MEP Maria da Graça Carvalho and MEP Brando Benifei), President of EHN (Floris Italianer), Professor Barbara Casadei, FESC President, European Society of Cardiology
- topic: presentation of the document Fighting Cardiovascular Disease – a Blueprint for EU Action

The meeting was an opportune moment to demonstrate the collaboration between EHN and ESC in contributing with concrete solutions for CVD health. The Commission is aware of the significant contribution both organisations can make together and considers them important stakeholders, offering expertise in pro-active health policy, notably for non-communicable diseases.

EU Health Policy Platform

The EU Health Policy Platform is an online forum for exchange between the European Commission and the community of EU health stakeholders. The online platform facilitates online discussions and frequent webinars. Online exchanges and collaborations lead up to the Platform's Annual Meeting.

In 2020 EHN participated in various activities of the Platform throughout the year.



Virtual meeting with Commissioner Kyriakides, 25 June 2020



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Cooperation

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World Health Organization (WHO) – Regional office for Europe

Due to Covid-19, there were no in-person meetings with WHO in 2020. However, EHN participated in the WHO



Regional Committee for Europe online meeting of 15 September. EHN also participated in the WHO webinar on Accelerating salt reduction in Europe (24 July) and in the NCD Advisory Council Meeting on 14 December in which EHN CEO, Birgit Beger, was invited as a member in a private capacity.

In 2020, EHN decided to send an application for accreditation of regional non-State actor, not in official relations with WHO, but to attend meetings of the WHO Regional Committee for Europe. As requested by WHO, a 3-year cooperation plan was prepared. In 2021, WHO will decide whether EHN's application is retained.

European Society of Cardiology

EHN cooperates closely with the European Society of Cardiology (ESC). The two organisations jointly support the MEP Heart Group.



EHN and ESC join forces to ensure that prevention of and research into cardiovascular disease remain a priority in EU policies and programmes.

In 2020, the two organisations worked closely together to publish a blueprint for action on cardiovascular disease in the European Union. The two organisations also jointly organised the virtual meeting with Commissioner Kyriakides on 25 June 2020, where the blueprint was presented.

European Association of Preventive Cardiology

The objective of the European Association of Preventive Cardiology (EAPC) is



to promote excellence in research, practice, education and policy in cardiovascular health, and primary and secondary prevention.

The CEO of EHN is a member of EAPC, its Cardiovascular Prevention Implementation Committee and is a consultant in the section on Population Science and Public Health.

In 2020, EHN's Director participated in EAPC's annual congress and meetings organised by the Cardiovascular Prevention Implementation Committee and the section on Population Science and Public Health during the congress.

World Heart Federation

Through its membership of the World Heart Federation (WHF), EHN participates in international work to advance the cause of cardiovascular health promotion worldwide. In 2020, EHN's Treasurer, Kristina Sparreljung, Secretary General of the Swedish Heart Lung Foundation, was a member of the WHF Board.



EHN's CEO is a member of the WHF's Advocacy Committee. In 2020, the work of the Committee included surveying finance ministry views on the importance, strengths and limitations of tobacco tax revenue and its uses.

European Chronic Disease Alliance

The European Chronic Disease Alliance (ECDA) is a coalition of 11 European health organisations (EHN being one of them) sharing the same interests in combating preventable chronic diseases through European policies that impact health. ECDA represents millions of chronic disease patients and over 200 000 health professionals.



Click here for more information about ECDA

Smoke Free Partnership

The Smoke Free Partnership (SFP) is a large European coalition of more than 45 partner organisations working on EU policy analysis and advocacy



to mobilise decision makers to make tobacco control a political priority. SFP's main partners are the Belgian Foundation Against Cancer, Cancer Research UK, the Dutch Cancer Society, the Norwegian Cancer Society, and the European Heart Network. The Belgian Foundation Against Cancer is SFP's Associate Partner. The EHN Director, Susanne Løgstrup, was President of SFP from 2016 to 2018. The EHN CEO, Birgit Beger, joined the SFP Board as a member in December 2020.

Click here for more information about SFP

Public Health Organisations

EHN is an active member of the European Public Health Alliance (EPHA), which unites a range of organisations throughout Europe that cover a broad spectrum of health issues.

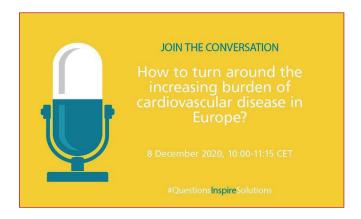
EHN participated in the Policy Coordination meetings of EPHA (transformed into 'action group meetings' on specific topics).

EHN participated in the EPHA meeting of Directors, where EPHA's strategy for the coming years was discussed and adopted.

EFPIA – European Federation of Pharmaceutical companies

Joint webinar with EFPIA on 8 December 2021





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Conferences and meetings

JANUARY

EPHA Meeting I Prevention in the Beating Cancer Plan I, 17 January

Bruegel Event: The state of health in the EU and digitalisation of health promotion

Meeting with John Ryan, Deputy Director General for Health responsible for Public Health, on the Blueprint for an EU action plan on CVD, 24 January

Meeting with MEP Heart Group Co-chairs, 30 January.

FEBRUARY

Stakeholder meeting on sustainable food systems, 18 February

EMA Virtual meeting on the development of a concept paper on best practices to prevent shortages, 24 February

MARCH (from March 2020 onwards, all meetings were virtual)

EMA Patients and Consumers' Working Party and Healthcare Professionals' Working Party joint meeting, 3-4 March

SFP Virtual meeting on tobacco taxation, 26 March

Virtual meeting with EHN working group on Front of Pack Nutrition Labelling, 30 March

APRIL

Virtual EHN Covid-19 Webinar, 8 April

SFP Virtual meeting on Tobacco Products Directive, 8 April

EPHA virtual meeting on Healthy Marketing, 27 April

EP Health Working Group, 28 April

MAY

SFP Coalition meeting, 7 May

EPHA webinar 'New opportunities for health in European Food and Agriculture policies', 11May

Meeting with MEP Cerdas, 25 May

HMA-EMA joint Big Data Steering Group teleconference, 4 May

JUNE

SFP webinar on World No Tobacco Day, 2 June

ECDA meeting with MEP Benifei, 4 June

ECDA meeting with DG Santé, 8 June

Ad Hoc Advisory Group meeting on the Farm-to-Fork Strategy, 17 June

EPHA Healthy Marketing Alliance, 22 June

HMA-EMA joint Big Data Steering Group teleconference, 11 June

EMA Patients and Consumers' Working Party and Healthcare Professionals' Working Party joint virtual meeting, 2-3 June

JULY

EU4Health EHN members' meeting, 3 July

SFP Coalition meeting, 9 July

WHO webinar: Accelerating salt reduction in Europe, 24 July

HMA-EMA joint Big Data Steering Group teleconference, 27 July

SEPTEMBER

WHO Regional Committee for Europe, 15 September

ECDA meeting with Commissioner Kyriakides, 18 September

HMA-EMA joint Big Data Steering Group virtual meeting, 8 September

EMA Workshop on the application of the General Data Protection Regulation (GDPR) in the area of health and Secondary Use of Data for Medicines and Public Health Purposes - Virtual Meeting with EMA Patient and Consumers' Working Party (PCWP) and Healthcare Professionals' Working Party (HCPWP), 23 September

OCTOBER

HMA-EMA joint Big Data Steering Group virtual meeting, 7 October

25 Years of EMA: building, learning and adapting to new challenges, virtual conference, 22 October

EMA Training session for patients, consumers and healthcare professionals interested in EMA activities, 23 October

NOVEMBER

International Whole Grain Day 2020, 19 November

HMA-EMA joint Big Data Steering Group virtual meeting, 9 November

DECEMBER

HMA-EMA joint Big Data Steering Group virtual meeting, 11 December

HMA-EMA EU Big Data Stakeholder Forum, 15 December

EMA public stakeholder meeting, COVID-19: how safe and effective vaccines are developed and authorised in the EU, 11 December

EHN governance

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Information about EHN and its structure, governance and finances are publicly available on its website.

Membership

In 2020, EHN had member organisations from 24 countries in Europe.

General Assembly

The General Assembly is comprised of all the member organisations of EHN.

The principal role of the General Assembly is to set broad strategic and policy guidelines. Its other responsibilities include:

- electing the Board and its President
- approving the admission of new member organisations
- approving budgets and annual accounts

Board

EHN is governed by a Board that can comprise no fewer than three members and no more than eight. In 2020, EHN's Board consisted of Tuija Brax, Finnish Heart Association; Tim Collins, Irish Heart Foundation; Dan Gaita, Romanian Heart Foundation; Charmaine Griffiths, British Heart Foundation; Floris Italianer, Dutch Heart Foundation; Paola Santalucia, Italian Association against Thrombosis and cardiovascular diseases; Kristina Sparreljung, Swedish Heart Lung Foundation; and Martin Vestweber, German Heart Foundation.

The Board met four times in 2020. Its role is to develop and monitor implementation of EHN's strategy, provide policy and procedural direction, and supervise the finances. The Board has three key positions: President, Vice President and Treasurer



Floris Italianer, President



Tuija Brax, Vice-President



Kristina Sparreljung, Treasurer



Martin Vestweber



Dan Gaita



Tim Collins



Paola Santalucia



Charmaine Griffiths



Secretariat

EHN has maintained an office in Brussels since 1992. The Network has functioned as a legally registered, non-profitmaking association in Belgium (AISBL) since 1993.

The EHN Brussels office has a team of five people to co-ordinate EHN's work. In July 2020, the European Heart Network said farewell to its longstanding Director, Susanne Løgstrup, who directed the organisation for 25 years in a dedicated and outstanding manner.

In August 2020, EHN welcomed the arrival of Birgit Beger, the new Chief Executive Officer, a senior executive of

European Health Organisations for over 10 years. In July 2020, the Personal assistant of the Director, Michelle Mildiner, left the organisation and the European Heart Network welcomed Maria Cummins as Executive Assistant to the CEO, Editor and proof-reader.

-The Brussels office acts as the central point for communication between the member organisations, facilitates its advocacy work with the institutions of the European Union, steers the research and publications work, and organises the Annual Workshop, seminars and meetings for members, as well as special European conferences. EHN also participates in pan-European projects.



EHN Staff, left to right: Marilena Vrana; Joëlle De Beys; Marleen Kestens, in front: Birgit Beger, Maria Cummins

EHN board members

Tuija Brax

Finnish Heart Association

Tim Collins

Irish Heart Foundation

Dan Gaita

Romanian Heart Foundation

Charmaine Griffiths

British Heart Foundation

Floris Italianer, President

Dutch Heart Foundation

Paola Santalucia

Italian Association Against Thrombosis and Cardiovascular Diseases (ALT Onlus)

Kristina Sparreljung, Treasurer

Swedish Heart Lung Foundation

Martin Vestweber

German Heart Foundation

EHN member organisations in 2020

Country	Member name
Belgium	Belgian Heart League*
Bosnia and Herzegovina	Foundation of Health and Heart
Croatia	Croatian Heart House Foundation
Denmark	Danish Heart Foundation*
Faroe Islands	Faroese Heart Foundation
Finland	Finnish Heart Association*
Germany	German Heart Foundation*
Greece	Hellenic Heart Foundation
Hungary	Hungarian National Heart Foundation
Iceland	Icelandic Heart Association
Ireland	Irish Heart Foundation*
	Italian Association against Thrombosis and Cardiovascular Diseases (ALT)
Italy	Italian Heart Foundation
	Italian Society for Cardiovascular Prevention (SIPREC)
Lithuania	Lithuanian Heart Association

Country	Member name	
Netherlands	Dutch Heart Foundation	
Netherlands	Harteraad (Heart Council)*	
Portugal	Portuguese Heart Foundation*	
Romania	Romanian Heart Foundation*	
Serbia	Serbian Heart Foundation	
Slovakia	Heart to Heart League	
Slovenia	Slovenian Heart Foundation*	
Spain	Spanish Heart Foundation*	
Sweden	Swedish Heart and Lung Association*	
	Swedish Heart Lung Foundation	
Switzerland	Swiss Heart Foundation*	
Turkey	Turkish Heart Foundation	
	British Heart Foundation*	
United Kingdom	Northern Ireland Chest, Heart and Stroke*	

^{*} these member organisations are either dedicated patient organisations or organisations in which work for and with patients makes up an important part of their activities

Accounts

Auditor's report to the board of the European Heart Network for the year ended December 31, 2020.

Respective responsibilities of the board and auditors

The Board and the Company's management are responsible for the preparation of these financial statements. Our responsibility is to issue a report on these financial statements based on our review.

We conducted our review in accordance with the International Standard on Review Engagements 2400. This Standard requires that we plan and perform the review to obtain moderate assurance as to whether the financial statements are free of material misstatement. A review is limited primarily to inquiries of company personnel and analytical procedures applied to financial data and thus provides less assurance than an audit.

Opinion

We certify that we have obtained all the information and explanations required by us as auditors and that the attached income and expenditure accounts for the year ended December 31, 2020 and the balance sheet at that date are in accordance with the records maintained by the European Heart Network.

Based on our review, nothing has come to our attention that causes us to believe that the accompanying financial statements are not presented fairly, in all material respects, in accordance with International Accounting Standards.

Kortrijk, 20/05/2021 VANDELANOTTE BEDRIJFSREVISOREN C.V.B.A.

VANDELANOTTE BEDRIJFSREVISOREN C.V.B.A.
Represented by
Frank VANDELANOTTE
Certified Public Accountant

Key figures

	2020	2019	2018	2017	2016	2015
Member subscriptions	581.761,96	558.600,00	564.827,00	564.827,00	548.372,00	532.400,00
EU grants & other income	67.287,54	391.335,61	380.650,52	65.143,64	51.351,88	43.500,00
Financial income	617,86	408,17	692,05	987,22	2.579,23	5.632,92
Total income	649.667,36	950.343,78	946.169,57	630.957,86	602.303,11	581.532,92
					-	
Regular expenditures	622.390,02	563.014,05	561.008,45	519.949,36	461.688,55	501.741,22
Project expenditures	60.616,16	220.636,43	197.924,95	168.504,87	129.031,95	50.716,84
Total expenditures	683.006,18	783.650,48	758.933,40	688.454,23	590.720,50	552.458,06
Surplus / (Deficit)	(33.338,82)	166.693,30	187.236,17	(57.496,37)	11.582,61	29.074,86

	2020	2019	2018	2017	2016	2015
Reserve	550.000,00	550.000,00	550.000,00	550.000,00	550.000,00	550.000,00
Net current assets	696.680,11	730.018,93	563.325,63	376.089,46	433.585,83	422.003,22
Total Equity	1.246.680,11	1.280.018,93	1.113.325,63	926.089,46	983.585,83	972.003,22

Income

1 Marshay authoristicae	2020	2019
1. Member subscriptions	(Euro)	(Euro)
Belgian Heart League	4.654,00	4.519,00
Bosnia Herzegovina, Foundation of Health and Heart	1.164,00	1.130,00
British Heart Foundation	189.075,00	183.567,00
Croatian Heart House Foundation	1.164,00	1.130,00
Danish Heart Foundation	49.191,00	49.586,00
Dutch Heart Foundation	116.034,00	107.000,00
Faroese Heart Foundation	1.153,96	1.130,00
Finnish Heart Association	34.319,00	15.160,00
German Heart Foundation	30.897,00	29.937,00
Hellenic Heart Foundation	1.164,00	1.130,00
Hungarian National Heart Foundation	1.164,00	1.130,00
Icelandic Heart Association	4.654,00	4.519,00
Irish Heart Foundation	12.017,00	19.000,00
Italian Association against Thrombosis and Cardiovascular Diseases	2327,00	2.259,00
Italian Heart Foundation	1.164,00	1.130,00
Italian Society for Cardiovascular Prevention	1.164,00	1.130,00
Lithuanian Heart Association	1.164,00	1.130,00
Netherlands, Heart and Vessel Group	5.543,00	5.240,00
Northern Ireland Chest, Heart & Stroke	8.670,00	8.325,00
Portuguese Heart Foundation	2.327,00	4.519,00
Romanian Heart Foundation	1.164,00	1.130,00
Serbian Heart Foundation	1.164,00	565,00
Slovenian Heart Foundation	4.654,00	4.519,00
Spanish Heart Foundation	4.654,00	4.519,00
Swedish Heart and Lung Association	4.724,00	7.516,00
Swedish Heart Lung Foundation	79.956,00	79.673,00
Swiss Heart Foundation	14.109,00	15.748,00
Turkish Heart Foundation	2.327,00	2.259,00
SUB TOTAL	581.761,96	558.600,00

Income

2 Special contributions	2020	2019
2. Special contributions	(Euro)	(Euro)
British Heart Foundation Grant	42.029,00	
Big Data at Heart Project	15.866,54	5.258,24
Other reimbursements	2.132,00	
Refunding car SL	7.260,00	
HeartMan Project		19.797,13
EU operating grant		366.280,24
SUB TOTAL	67.287,54	391.335,61
	2020	2019
3. Financial income	(Euro)	(Euro)
Investment income	617,86	408,17
TOTAL INCOME	649.667,36	950.343,78

Expenditures

	2020	2019
	(Euro)	(Euro)
Personnel	530.855,98	423.065,38
Office	10.741,55	14.841,97
Property (incl. insurance)	44.107,58	44.552,14
Travel, subsistence, meetings and conferences (incl. Board)	3.400,44	36.396,68
Office equipment, computers, IT support	8.894,34	18.440,06
Depreciation (office equipment/computers)	6.278,31	2.666,71
Professional fees	12.035,73	16.897,24
Membership fees	3.487,52	3.397,43
Bank charges	229,03	320,08
Taxes	2.359,54	2.436,36
Total regular expenditures	622.390,02	563.014,05

Continued over the page

Expenditures

	2020	2019
	(Euro)	(Euro)
Smoke Free Partnership	25.000,00	25.000,00
European Chronic Disease Alliance	3.999,99	3.300,00
Annual Workshop	1.516,90	30.024,20
Patients Group seminar		2.734,92
Capacity-building seminar		5.689,26
Fundraisers seminar		4.365,00
Research platform		1.654,46
Nutrient profiling model	1.920,00	
MEP Heart group	29,04	29,04
World No Tobacco Day		
Consultancy support		20.424,80
Communication	21.646,20	21.386,28
HeartMan		15.837,71
Big Data at Heart	9.929,03	4.206,65
Physical Activity Paper		21.000,00
Prevention Guidelines Task Force		290,86
Training Patients		7.575,49
E-/m Health Paper	-3.425,00	50.031,91
Expert Meetings / teleconferences		4.004,86
Project fund		3.080,99
Total operational and project expenditures	60.616,16	220.636,43
TOTAL EXPENDITURES	683.006,18	783.650,48
TOTAL INCOME	649.667,36	950.343,78
SURPLUS/DEFICIT	-33.338,82	166.693,30
RETAINED RESULT BEGINNING OF PERIOD	730.018,93	563.325,63
RETAINED RESULT END OF PERIOD	696.680,11	730.018,93

Balance sheet as at December 31, 2020

	2020	2019
	(Euro)	(Euro)
Fixed Assets	8.215,81	3.658,19
Current Assets		
Debtors and prepayments	18.844,44	19.270,40
Cash at bank	1.614.270,13	1.561.600,81
	1.641.330,38	1.584.529,40
Current Liabilities and Provisions		
Reserve	550.000,00	550.000,00
Accrued costs and expenses	171.622,27	180.938,47
Prepaid income	223.028,00	123.572,00
	944.650,27	854.510,47
Net current assets (liabilities)	696.680,11	730.018,93

HeartMan

	2020	2019
	(Euro)	(Euro)
Project expenses	0	19.797,13
Personnel cost		9.234,21
Staff travel and subsistence		6.603,50
Other costs		3.959,42
Project income	0	19.797,13
HeartMan	0	0

BigData@Heart

	2020	2019
	(Euro)	(Euro)
Project expenses	9.929,03	5.258,24
Personnel cost	8.021,03	4.064,15
Staff travel and subsistence	1.908,00	142,50
Other costs		1.051,59
Project income	15.866,54	5.258,24
BigData@Heart	5.937,51	0

Operating grant

	2020	2019
	(Euro)	(Euro)
Total expenses	0	610.467,06
Direct Personnel cost		414.823,81
General administrative expenditure		80.205,97
Operational expenditure		115.437,28
Income generated & financial contributions		244.186,82
EU contribution requested	0	366.280,24

Income

1. Staff costs	2020	2019
	(Euro)	(Euro)
Salaries	341.357,65	304.047,89
Group insurance	27.244,35	34.782,24
Social security employers	75.465,03	71.282,77
Accrued vacation pay	-9.775,75	9.282,96
Insurance personnel	4.281,10	3.055,23
Meal vouchers	7.331,12	7.655,71
Other personnel charges	452,43	479,25
Social office	6.615,02	5.777,69
Recruitment fee	32.670,00	
Interim	53.236,06	
Personnel costs to recover	-8.021,03	-13.298,36
	530.855,98	423.065,38

2. Principal accounting policies

The following accounting policies have been applied consistently in dealing with items which are considered material in relation to the organisation's accounts:

Accounting basis

The accounts have been prepared under the historical cost convention.

European Heart Network

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european heart network