



European Heart Network Annual Workshop and General Assembly



Savelletri, Puglia – Italy 21 – 23 May 2019





Borgo Egnazia, 21 May 2019

Dear Colleagues and Friends,

On behalf of ALT – the Italian Association against Thrombosis and Cardiovascular Disease, it is a great pleasure to warmly welcome all of you to the EHN Annual Workshop and General Assembly 2019.

Italy is an incredible paradise, thank you for coming all the way to Puglia, I hope you will enjoy it and keep it in your hearts and minds, and will come back in the future.

ALT was founded in the '80s thanks to a donation to be invested in something missing in the enormous panorama of disease prevention.

In those years cancer, Alzheimer's Disease and HIV were considered the most urgent topics to support. At the same time, **an epidemic was expanding silently: cardiovascular diseases.**

Experimental and clinical models were confirming that **thrombosis** is the common final mechanism that causes different diseases, commonly known as myocardial infarction, brain stroke, and pulmonary embolism: this is the reason we decided to start a fight against **thrombosis and its consequences**.

Furthermore, growing scientific evidence was confirming that CVDs could be **prevented at least in one case out of three**: but very few people were aware of the enormous potential of prevention in this field.

We felt that a huge and urgent effort was needed to educate people in understanding the role of thrombosis in occluding arteries and veins, provoking infarcts, ischemia, stroke and embolism.

We were convinced that the fight against thrombosis could be successful only through **team work**, involving physicians, scientists and patients, journalists and communication experts.

People have the **right to know** the risk factors that enhance the probability of disease and how to **recognise the early symptoms**: and they have the **responsibility to modify** their lifestyle.

Journalist and communication experts can make the difference in spreading knowledge, motivation and awareness on the importance of risk factors in determining loss of lives and in destroying quality of life caused by CVDs.

This is the mission of all the organisations participating in this meeting: we want to provide everybody in the future the chance to avoid preventable diseases, as is the case with CVDs, and as EHN's mission states.



We are honoured to have so many special guests and speakers, who, I'm sure, will give to all participants a global view of the potential of communication in preventing CVDs.

Being a member of EHN is a great opportunity for all of us to share success and failure stories, to learn from each other in order to be efficient in our mission and have a **positive impact** on the present and, more importantly, on future generations.

ALT has been a Member of EHN since the very first years in the '90s, when we were really few, and the annual meeting was something like a friends' reunion.

We learned a lot, sharing ideas and projects focused on spreading education and motivation to the general population, providing everyone with some fundamental knowledge and tools to be used to preserve health and to live without a preventable cardiovascular event.

I think that our engagement as Associations and Foundations has produced, and will continue to produce, results of paramount importance, in terms of saving lives and improving the quality of life for many people.

Our mission is to make it impossible for anybody in the future to say "...I did not know....."



Mouler

Lidia Rota Vender President ALT Onlus - Italian Association against Thrombosis and Cardiovascular Disease

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CARDIOVASCULAR DISEASE - A TOUR D'HORIZON EUROPEAN HEART NETWORK ANNUAL WORKSHOP AND GENERAL ASSEMBLY Puglia, Italia, 21 – 23 May 2019

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Programme Tuesday, 21 May 2019

- 08:00-14:00 Registration
- 12:30-14:00 Lunch
- 14:00-14:20 Opening and welcome

Simon Gillespie, President, European Heart Network, Chief Executive, British Heart Foundation

Dr. Lidia Rota Vender, President, ALT

14:20-17:15 Progress on NCDs: time to rekindle efforts

Chair: Floris Italianer, Vice President, European Heart Network Chief Executive, Dutch Heart Foundation

This session aims to take stock of the progress towards addressing NCDs, and have a critical eye particularly on the commitments made by governments in Europe

- 14:20-14:40 Outcome of the Third UN High-Level Meeting on NCDs – implications for WHO European Region Speaker: João Breda, Programme Manager Nutrition, Physical Activity and Obesity, Division of Non communicable Diseases and Life-course at WHO/Europe
- 14:40-14:50 Q&A
- 14:50-15:10 Civil society contribution at global level

Speaker: José Luis Castro, CEO Vital Strategies, President NCD Alliance (video presentation)

- 15:10-15:20 Q&A
- 15:20-15:50 Break



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	Programme Tuesday, 21 May 2019
15:50-16:05	ECDA: NCDs at the regional level
	Speaker: Susanne Løgstrup, Director, European Heart Network
16:05-16:15	Q&A
16:15-16:55	NCD engagement at national level: presentations from EHN members
	NCD activities in Germany
	Speaker: Christine Dehn, External Relations, German Heart Foundation
	Working together in NCD Alliance and other alliances to reach the goal of a healthier Sweden
	Speaker: Anette Jansson, Expert research, Swedish Heart-Lung Foundation
16:55-17:15	Q&A/general discussion
17:15-18:00	The economics of NCDs and CVD
	Chair: Prof. Dan Gaita, Director, Romanian Heart Foundation
17:15-17:45	Speaker: Melanie Bertram, Health Economist, World Health Organization

- 17:45-18:00 Q&A/general discussion
- 18:00 End of day 1

Social event: visit Alberobello





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Programme Wednesday, 22 May 2019

08:30-10:00 Impact

Chair: Tuija Brax, Secretary General, Finnish Heart Association

The IMPACT model was created to explain the decline in mortality rates from coronary heart disease observed in populations across the world over the past decades. It demonstrates the impact on death rates of changes in risk factors (smoking, high systolic blood pressure, elevated total blood cholesterol, obesity, diabetes and physical inactivity) as well as in medical and surgical treatments given to heart patients. The joint objective of EHN and its members is to reduce the burden of cardiovascular disease. How do we demonstrate to our target group, whether donors or policy makers, that what we do has the impact that we seek to achieve? This session will bring in experts from EHN member organisations that will initiate us into the art of establishing a link between our actions and the outcomes that people value.

- 08:30-08:50Identifying change as a starting point for making impactSpeaker: Hester Dijk, Marketing Strategist, Dutch Heart Foundation
- 08:50-09:10 **The impact journey to better cardiovascular health** Speaker: Sana Zakaria, Head of Strategic Performance and Impact, British Heart Foundation
- 09:10-09:40 Q&A
- 09:40-10:00 Talking about money: how the Finnish NCD-Alliance communicates about health promotion by showing concrete financial impacts of 17 different cases Speaker: Tuija Brax, Secretary General, Finnish Heart Association

EU regulation on trans fats Speaker: Susanne Løgstrup, Director, European Heart Network

10:00-10:15 Break

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Programme Wednesday, 22 May 2019

10:15-13:00 A global view on prevention and mechanisms of heart diseases and stroke

Chair: Dr. Lidia Rota Vender, President Italian Association against Thrombosis and Cardiovascular Diseases (ALT)

This session will describe the future of prevention of CVD, emphasise the importance of early prevention, and add a new point of view: from organ disease to the **multiple mechanisms of the diseases** – a concept which is emerging strongly from epidemiological, translational and clinical research.

Keynote Lectures

10:15 - 11:15Promotion of cardiovascular health in the future. A global view for a
possible mission
Speaker: Prof. Valentin Fuster, Director of Mount Sinai Heart, and
Physician-in-Chief at The Mount Sinai Hospital, New York City, United States
of America and President of the Scientific Board of ALT

Followed by Q&A/general discussion

11:15 – 12:15Thrombosis: Translational research and risk profiling of the individual
patient
Speaker: Prof. Zaverio M. Ruggeri, M.D. Professor, Department of Molecular
Medicine, The Scripps Research Institute, La Jolla, San Diego, California,
USA, Member of the Scientific Board of ALT

Followed by Q&A/general discussion

12:15 – 12:45 Round table on basic mechanisms of heart diseases and stroke

Atherosclerosis: Prof. Paolo Magni, Italian Heart Foundation and Department of Pharmacological and Biomolecular Science, University of Milan, Italy

Inflammation: Prof. Giovanni de Gaetano, President, IRCCS Istituto Neurologico Mediterraneo NEUROMED, POZZILLI (IS), Italy and Member of Board of ALT



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	Programme Wednesday, 22 May 2019
	Haemostasis and blood coagulation: Prof. Sergio Coccheri, Former Full Professor of Cardiovascular Medicine, University of Bologna, Italy, and Member of Board of ALT
12:45-13:00	Q&A/general discussion
13:00-14:00	Lunch
14:00-15:30	Lifting the veil on CVD knowledge and perceptions Chair: Martin Vestweber, Managing Director, German Heart Foundation
	In Europe, as in many of the countries in which EHN member organisations operate, cardiovascular disease (CVD) is the first cause of death in both men and women. Nevertheless, this fact and the fact that the cost of CVD is very high do not seem to translate into concern or urgency about it. Rather, cancer seems to be uppermost in the minds of donors and policy makers. Is there a perception that CVD is a 'good death' that comes to you in your sleep when you are 95? That we have solved all the problems? This session intends to review audits and campaigns carried out by EHN member organisations.
14:00-14:15	Introduction to CVD perception audit: knowing our audiences' unknowns Speaker: Susanne Løgstrup, Director, European Heart Network
14:15-15:00	It's all connected. Growing relevancy and support through the launch of our new brand proposition <i>Speakers: Harriet Foxwell, Head of Brand Marketing & Victoria Kubie,</i> <i>Head of Brand & Planning, British Heart Foundation</i>
15:00-15:30	Q&A/general discussion
15:30-16:00	Break

16:30-18:00 EHN General Assembly

18:00 End of day 2

19:30 Gala dinner in piazza

Dress code: elegant casual



General Assembly Agenda Wednesday, 22 May 2019 16:30 – 18:00

Opening	President
1. Approval of Minutes, Lucerne, 2018	President
2. Approval of Annual Report 2018	Director
3. Approval of Audited Accounts 2018	Treasurer/Director
4. Approval of Draft Budget 2020	Director
5. Approval of Draft Work Programme 2020	Director
 6. Approval of new members: (i) Norwegian Heart and Lung Association (LHL) (ii) Norwegian Health Association (Nasjonalforeningen for Folkehelsen) 	President
7. Election of President	President
8. Election of Board Members	President/Vice President
9. Election of Auditor	President
 10. Any Other Business: Cooperation with ESC/WHF Date and Place of 2020 EHN Annual Workshop Forthcoming issues 11. Formal handover of Presidency 	President Simon Gillespie Tuija Brax All Simon Gillespie
Closing	President

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Programme Thursday, 23 May 2019

09:00-11:00 Communication: Old school media vs. new world communication 2.0

Chair: Kristina Sparreljung, Treasurer, European Heart Network General Secretary, Swedish Heart Lung Foundation

In these rapidly evolving times, this session will explore how we can best use the communication tools available (traditional and new innovative media) to structure efficient population-based prevention campaigns aiming to prevent heart and brain diseases connected with thrombosis.

Shifting from traditional to new methods and using them in a complementary mode could enhance the effectiveness of our campaigns and build a better future for millions of people, helping them to avoid preventable cardiovascular diseases.

Facilitators: Alberto Contri, President of Pubblicità Progresso, and Giulio Malgara, Past President of UPA, Founder and past President of Auditel

11:00-11:30 Break

11:30 – 13:00 Genome testing

Chair: Simon Gillespie, Chief Executive, British Heart Foundation

This session is about risk assessment. New tools for assessing individual risk for cardiac diseases are being developed. New technology has provided genome tests, which are available for consumers. Is it possible to evaluate the risk of polygenic diseases like coronary artery disease based on new genome tests? Are these commercial tests reliable? Can we already recommend these tests to people or not? What is the current opinion about genome testing? This session will include ethical aspects and further implications for patients and health care systems.

11:30-12:10Genomic innovation and ethics: Genomics as a personalised medicine
approach in disease risk prediction
Speaker: Prof. Dr, Markus Perola, Research Professor, National Institute
for Health and Welfare, Finland12:10-12:40Knowing your genome – does that change anything? An Estonian

experience Speaker: Dr. Liis Leitsalu, University of Tartu, Estonia

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Programme Thursday, 23 May 2018

12:40 -13:00 Q&A/general discussion

13:00-13:15Closing remarks from the Presidents of EHN and ALT
Onlus – outcomes of our Annual Workshop 2019

13:15 End of workshop and lunch





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Abstracts Tuesday, 21 May 2019

José Luis Castro

Civil society contribution at global level

Non communicable diseases account for a staggering 7 out of 10 deaths worldwide. Confronting the leading risk factors that contribute to the majority of these diseases is a global challenge, but it is the key to preventing their unnecessary toll of death and disability worldwide - and ensuring that countries are on the right path to achieving the Sustainable Development Goal target of reducing premature deaths from NCDs by one-third by 2030.

Civil society organisations have been fierce advocates for strong policies and sufficient funding to address this global crisis. These efforts helped shape the outcome of the Sustainable Development Goals, and resulted in numerous changes to the draft resolution on NCDs that the third High Level Meeting produced. Moving forward, civil society must continue to put pressure on governments and health organisations to close the financing gaps for NCDs, and bring attention to neglected issues of mental health and air pollution as among the primary drivers of NCDs.

Susanne Løgstrup

ECDA: NCDs at the regional level

EHN is a founding member of the European Chronic Disease Alliance (ECDA), an organisation which brings together 10 organisations working on common risk factors for cardiovascular diseases, cancer, diabetes, respiratory, kidney and liver diseases as well as allergy and clinical immunology.

The alliance has gone through several stages to get to where it is today. The presentation will outline the history of the ECDA from an informal meeting, in summer 2009, consisting mostly of scientists, to today's professionally run organisation. The presentation will include key strategic decisions that the member organisations have had to deliberate, such as agreeing on a paper within a very short time and moving on to introduce membership fees to pay for a secretariat.

Christine Dehn

NCD activities in Germany

The German Heart Foundation is a partner in DANK – the German NCD Alliance. This talk informs about current activities regarding non-communicable chronic diseases (NCD), barriers as well as planned activities.



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Tuesday, 21 May 2019

Anette Jansson

Working together in NCD Alliance and other alliances to reach the goal of a healthier Sweden

The Swedish NCD Alliance was formed in connection with the UN high-level meeting on the prevention and control of NCDs (non-communicable diseases) in mid-September 2011. The alliance consists today of 27 Swedish non-governmental organisations (NGOs).

The alliance's overall aim is to increase the number of years of healthy life. By sharing information, cooperating and acting together, we can do much more to reduce the incidence of NCDs. The alliance seeks to help increase and broaden knowledge about the problems and opportunities surrounding NCDs and their associated risk factors and to foster awareness of the importance of putting appropriate measures into place. This is done through improved dissemination of information and vigorous advocacy.

Melanie Bertram

The Economics of NCDs and CVD

Non-communicable diseases are responsible for 62% of the global burden of disease (IHME, 2018), and 60% of health expenditure across OECD countries (OECD, 2016). Despite this, estimates indicate that 2.35 trillion dollars are lost from the global economy each year due to untreated NCDs (WEF, 2010). This arises as people living with untreated NCDs are less likely to participate in the workforce, and those who do work do so at lower levels of productivity than those in equivalent positions who do not have an NCD. NCDs are associated with poverty, and create inequity both within and across countries (Lancet, 2018).

On the flip side, recent estimates indicate CVD prevention is a very cost-effective, low-cost investment that saves lives and contributes to economic growth, leading to high returns on investment (WHO, 2018). Many of these policies can be designed to have positive equity impacts (Lancet, 2018). In addition to prevention, many highly cost-effective treatment options exist, the implementation of which is crucial to achieving the sustainable development goal of decreasing premature mortality due to NCDs by one-third by 2030.

Recent global events such as the UN High Level meeting on NCDs in 2018 have sought to focus attention on the growing epidemic and create political will to accelerate country-level responses. This presentation will explore the economic data associated with NCDs and CVD treatment, and present methodologies to make the case for additional investments in NCDs at the country level.

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Abstracts Wednesday, 22 May 2019

Hester Dijk

Identifying change as a starting point for making impact

Impact management is 'hot' in the charity sector in The Netherlands, especially when trust is low and the call for transparency is growing. This makes sense, since impact management helps you to communicate the effect of your work.

But there is more to it: impact management is a mindset focused on structuring continuous learning and optimisation of impact. It helps you to adjust and improve your interventions.

Where to start? Identifying desired change is the first step, followed by setting up a monitoring system. In this presentation Hester Dijk, Dutch Heart Foundation, will explain how the DHF has benefited from Theory of Change thinking in its current strategy, and what they have learned so far.

Sana Zakaria

The impact journey to better cardiovascular health

At the British Heart Foundation, we recognise the importance of capturing and disseminating our organisational impact and are committed to doing so in order to maintain the highest standards of transparency and accountability, and to ensure we are investing donors' money in the most effective way possible. We are developing an organisation-wide impact monitoring framework to capture and articulate how our donors' investments translate into real-world benefit in the short- and the long-term. Embracing this approach is not only a critical charitable duty – it will also deliver significant organisational benefits by enabling better strategic decision-making and prioritisation. Others in the sector also recognise the importance of impact measurement: the public and third sector has increasingly been engaged in the 'impact measurement agenda' over the last decade.

Our impact framework is centred around our new organisational strategy to 2030, which serves as a blueprint to distilling out the BHF's unique contribution to the desired impact on the health outcomes of people living with heart and circulatory diseases. Although health impact is largely driven through cross-sector collaborative effort, our framework seeks to articulate the BHF's role in driving long-term change in the research and healthcare landscape.

Zaverio M. Ruggeri

Thrombosis: Translational research and risk profiling of the individual patient

Paolo Magni

Round table on basic mechanisms of heart diseases and stroke: atherosclerosis

Cardiovascular diseases (CVD) caused by an ischemic event, like myocardial infarction or stroke, are due to the sudden obstruction of the blood flow mostly within large/medium-size arteries, like the coronary arteries in the heart. This process is called atherothrombosis and consists of the formation of a thrombus (i.e., intravascular coagulation of blood) in a site of the artery affected by atherosclerotic plaques.



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The atherosclerotic plaque is defined as a focal specialised form of chronic inflammation, whose starting feature is endothelial dysfunction, which facilitates the deposition of cholesterol crystals in the intima of the vessel wall, followed by attraction of inflammatory cells, like monocyte/macrophages, and eventually also smooth muscle cells from the tonaca media. Dyslipidemia is one of the major causal factors of atherosclerosis and includes elevated LDL cholesterol (LDL-C) as well as atherogenic dyslipidemia (low HDL cholesterol and high triglycerides), and other less frequent forms. Based on this evidence, exposure to high circulating levels of LDL-C for a long time appears to be a strong risk factor for atherosclerosis, leading to the accepted strategy of lowering LDL-C to reduce CVD. Based on this evidence, the concept of "the lower, the better", referred to LDL-C lowering, may be integrated with the other concept of "the earlier, the better", with reference to the role of long-term exposure to high LDL-C, as it is observed in genetic forms of hypercholesterolemia. Additional important risk factors to be considered for atherosclerosis are diabetes mellitus and the metabolic syndrome, together with low-grade chronic inflammation.

Giovanni de Gaetano

Round table on basic mechanisms of heart diseases and stroke: inflammation

Low-grade inflammation as a contributing factor to cardiovascular risk

Giovanni de Gaetano*, Marialaura Bonaccio*, Chiara Cerletti*, Maria Benedetta Donati* and Licia Iacoviello*^

*IRCCS Neuromed, Pozzilli (Isernia) and ^Università dell'Insubria, Varese, Italy

Low-grade (subclinical) inflammation has been proposed as a crucial mechanism contributing to increased CVD/mortality risk. Findings from the population-based prospective Moli-sani Study cohort of 25 000 adult men and women, showed that increased levels of low-grade inflammation, as measured by a score including C-reactive protein, leukocyte and platelet count, and the granulocytes to lymphocytes ratio, is associated with 44% increased risk of total death, independently of other risk factors; moreover, such a condition over doubled the risk of premature death and CVD death in subjects with history of CVD. Among possible determinants, results from the Moli-sani Study indicated that lifestyles play a major role in favourably modulating low-grade inflammation. Adherence to a traditional Mediterranean diet, or a diet rich in polyphenols; being physically active; abstention from smoking, and absence of abdominal obesity are all positively associated with lower levels of low-grade inflammation, suggesting that a global healthy lifestyle may dramatically lower the risk of disease/mortality. Indeed, lifestyle also accounts for a substantial proportion of the socioeconomic patterning of low-grade inflammation, which was found to be higher in disadvantaged groups compared to well-off individuals. In addition, it has been found that subclinical inflammation is on the pathway between healthy lifestyle and lower mortality risk, especially in highrisk groups, such as individuals with diabetes or those with a history of CVD.

Sergio Coccheri

Round table on basic mechanisms of heart diseases and stroke: haemostasis and blood coagulation

Major cardiovascular events (such as myocardial infarction, stroke, pulmonary and systemic embolism), responsible for about 45% of deaths and 1/3 of cases of disability, are mainly due to Thrombosis, the formation of a blood clot inside blood vessels or within the heart cavities.

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Thrombi are caused by mechanisms similar to those of Haemostasis, the process that stops bleeding at the sites of wounds. Thus, thrombosis is an inappropriate haemostasis occurring inside vessels, leading to partial or total obstruction of blood flow. The mechanism of thrombosis is initiated by microscopic damage of the inner lining of the vascular wall, the endothelium, caused by hypertension, LDL cholesterol, diabetes, inflammation. Endothelial damage triggers an "inappropriate" repair process, initiated by <u>adhesion and aggregation of platelets</u>, and activation of blood coagulation with thrombus formation. Thus, partial or total thrombotic obstruction in coronary arteries produces ischemia and infarction in the heart. In the brain, ischemic stroke can be caused by thrombosis in large, brain related arteries (14%) or in small intracranial vessels (20%). Finally, stroke can be due to intracardiac thrombosis releasing emboli into the brain (cardiogenic embolism, 35%). The remaining 30% of strokes are due to other or undetermined causes.

Susanne Løgstrup

Introduction to CVD perception audit: knowing our audiences' unknowns

In Europe, as in many of the countries in which EHN member organisations operate, cardiovascular disease (CVD) is the first cause of death in both men and women. Nevertheless, this fact does not seem to translate into concern or urgency about it. This presentation will set the scene for the session on Lifting the veil on CVD knowledge and perceptions. It will present the findings of surveys that have been carried out by EHN members with respect to attitude to health causes, to understand why the public view them differently. Findings include: heart disease is not seen as a threat; you do not hear so much about heart disease as you do about cancer; heart disease is not relevant to me because it is life-style related (people's own fault); it is treatable and curable. There are similar findings for heart attack and stroke.

Harriet Foxwell and Victoria Kubie

It's all connected. Growing relevancy and support through the launch of our new brand proposition

In July 2018 the British Heart Foundation (BHF) launched an exciting new brand promise. Beat heartbreak forever aimed to extend the BHF's appeal to a wider group of consumers by communicating its work beyond hearts. It moved them into a more emotional territory, whilst allowing them to take credit for the wider spectrum of research it funds. With a communications spotlight on stroke, vascular dementia and diabetes - known areas of significant concern for the public - the aim was to make the charity feel more modern, more relevant, and more of an urgent cause, all with the aim of significantly increasing active support.

This presentation will share the story so far. How and why the charity developed the new proposition, how it took the proposition to market, and the resulting success in increasing relevancy and active engagement from supporters. As part of this story, the BHF will include lessons learned to date and its plans to continue to harness the power of the BHF brand to win support in the future.





Abstracts Thursday, 23 May 2019

Markus Perola

Genomic innovation and ethics: Genomics as a personalised medicine approach in disease risk prediction

We will utilise polygenic risk scores to provide personalised information on the individual disease risk related to three common diseases (coronary heart disease (CHD), type 2 diabetes and venous thromboembolism) for 3 400 volunteering participants in a biobank study called P5 – Genomics to Healthcare. We study the value of returning genetic risk information and hypothesise that it would improve prevention, diagnosis and treatment. Our main interest is how the study participants perceive the information on genomic risk, how they understand it and how it affects their behaviour.

We used polygenic risk scores containing up to 7 million genomic regions and validated them in whole genome genotyped population-based FINRISK cohorts (N=20 000) using Cox regression models. Follow-up data from national health care registers allowed us to model the impact of genetic and traditional risk factors such as smoking, cholesterol, blood pressure and BMI on a person's risk of disease within the next 10 years.

We use these estimates to assess the future risk of CHD in P5 FinHealth participants who will receive this disease risk information, including genetic risk, via a web portal. We will start returning personalised health reports to the P5 participants in May 2019. The impact of our intervention will be studied by following up with the participants via questionnaires, and through national health registers for five years. Our approach enables us to identify the individuals within the highest genetic risk, and those with pre-disease symptoms. The P5 study serves as a pilot study for a larger study on 100 000 individuals. The P5 pilot will help us to estimate the most prominent ethical challenges in applying these new technologies.

Liis Leitsalu

Knowing your genome – does that change anything? An Estonian experience

The population-based biobank of the Estonian Genome Center includes biological samples and health information and genome-wide data on 51 000 adults. As the Estonian biobank legislation gives participants the right to receive their research results, an approach was established to offer individual genetic results to biobank participants. By February 2019, through several return of results projects conducted, over 2 000 participants have received some results from the biobank. These projects include informing biobank participants of familial hypercholesterolemia, reporting polygenic risk estimates for coronary artery disease, as well as sharing pharmacogenomic reports. Disclosure of genomic results to population biobank participants with long-term follow-up can provide valuable information on how individuals from the general population would respond to potentially unexpected genetic information and whether this information changes their medical management.





Biographies Tuesday, 21 May 2019

Simon Gillespie

Simon joined the British Heart Foundation in March 2013. Before joining the BHF, he was Chief Executive of the Multiple Sclerosis Society for seven years.

Like far too many people in the UK, Simon has a personal connection with heart disease – his Father died of a heart attack in 1979. As part of the BHF's 'Fight for Every Heartbeat', Simon runs and walks to raise money for the BHF's work. He is also the President of the European Heart Network. He previously worked as Head of Operations at the Healthcare Commission, where he was responsible for the inspection of NHS and independent healthcare facilities in England. From 2000 to 2004, he was Director of Operations at the Charity Commission, modernising the regulation and support of the 180 000 registered charities. His earlier career was with the Royal Navy, including time as Commanding Officer of HMS Sheffield and as an advisor to government ministers. Simon has extensive experience of charity and non-profit governance.

Lidia Rota Vender

Dr. Lidia L. Rota was born in Bergamo in 1951. She graduated in Medicine in 1976 at the University of Milan where she specialised in Haematology.

From 1976 to 1996 she worked as a researcher in the field of haemostasis, particularly on platelets function, and she practiced as clinical resident at the A.Bianchi Bonomi- Haemophilia and Thrombosis Center at the Policlinico Hospital in Milano, where she organised the Anticoagulation Clinic.

From 1996 until 2015 at the Humanitas Hospital in Milano, she started a pioneering Thrombosis Center, also including an Anticoagulation Clinic, a unique example of interdisciplinary approach for Thromboembolic disorders in terms of prevention, diagnosis and treatment in thousands of patients, who were investigated on genetic and functional aspects of the coagulation system in different clinical situations.

From 2015 to 2017 she founded, in the same hospital, the first international Center for global cardiovascular disease prevention, and guided the Center for Translational Research in Thrombosis and Haemostasis. This was dedicated to exploring with innovative methods the specific mechanism of activation of the haemostatic system in healthy subjects and patients in anticoagulant or antiplatelets therapy with the aim of tailoring the therapy to the individual patient, taking into account the single peculiarity of every patient. During her medical career she published many papers in national and international scientific magazines, and was invited to give speeches in interdisciplinary scientific and clinical congresses.

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She participated in the initiation and development of SPREAD (Stroke Prevention and Awareness Diffusion), an interdisciplinary working group which produced, published and diffused the first National Guidelines for stroke prevention and therapy, and was a founder member of the Stroke Forum.

In 1987 in Milano she founded ALT, Association against thrombosis and cardiovascular disease (www.trombosi.org), a not-for-profit organisation focused on spreading education and raising awareness on the prevention of diseases commonly known as CVD, where thrombosis and embolism played a pivotal role. ALT's mission has been, since the beginning, to implement programs of education for the population; to emphasise the importance of lifestyle in increasing or reducing the probability of CVD, to promote in the medical community the necessity of a multidisciplinary approach to CVD taking into account the important role of thrombosis, and to fund scientific translational research aimed at improving knowledge of the pathogenetic mechanisms of thrombosis. Dr. Lidia L. Rota served as a member of the EHN Board for three years, and has been serving as the President of ALT since 1987.

João Breda

Dr. João Breda is the Head of the NCD Office in Moscow, Russian Federation. This office leads WHO work on strengthening national capacity in all 53 countries in the WHO European Region, to prevent and control NCDs, promote an intersectoral approach and develop policies to tackle NCDs. The office has been set up as the innovation powerhouse for NCD prevention and management in Europe and beyond.

During the previous 8 years before moving to Moscow, João Breda was the Programme Manager: Nutrition, Physical Activity and Obesity at the WHO Regional Office for Europe based in Copenhagen, responsible for providing support to Member States of the WHO European Region on the implementation of the European Food and Nutrition Action Plan 2015- 2020 & the Physical Activity Strategy for the WHO European Region 2016-2025, as well as evaluating their implementation process.

João Breda has a PhD in Nutritional Sciences from Porto University, where he defended a thesis focused on alcohol and young people. He did his Master's Degree in Public Health at the Faculty of Medical Sciences of Lisbon University, and an MBA at the European University in Barcelona.

Before joining WHO in 2010, João worked as a Public Health Specialist at the General Health Directorate of Portugal and in other institutions such as the Ministry of Health at local and national level, particularly in the fields of nutrition, physical activity, obesity and alcohol abuse. In these positions he

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closely liaised with WHO and the EU. In 2007, in collaboration with WHO, he organised the first meeting of the WHO European Childhood Obesity Surveillance Initiative in Portugal. Nowadays, the Initiative is unique in the world and has expanded considerably. It involves more than 300,000 children and 36 Member States of the European Region.

João was the first coordinator and for several years led the National Platform against Obesity. As an academic, J. Breda chaired the Department of the Nutritional Sciences of Atlantic University (Lisbon). He also collaborated with Algarve University, Coimbra College of Agriculture and Coimbra Hospitality School. Among his several dozens of published scientific papers and original books, emerges the number one best-selling book on infant nutrition in Portugal.

José Luis Castro

José Luis Castro is the President & CEO of Vital Strategies, as well as the Executive Director of The International Union Against Tuberculosis and Lung Disease.

Mr. Castro has led a rapid expansion of Vital Strategies' portfolio, working with governments to tackle the world's leading killers, primarily in low- and middle-income countries. The organisation now reaches into 73 countries, with offices in six, and has touched the lives of more than 2 billion people.

During Mr. Castro's leadership, The Union expanded its global portfolio of activities and forged new strategic partnerships, including with the Global Fund, USAID, DFID and Bloomberg Philanthropies. In 2014, Mr. Castro co-founded the Global TB Caucus, an international network of over 2 300 parliamentarians from 132 countries, with the Rt Hon. Nick Herbert MP of the UK, to accelerate progress against the TB epidemic.

Between 1993 and 2001, Mr. Castro provided technical, financial management and logistical assistance to the Indian government in establishing the largest tuberculosis control program in the world. During the largest outbreak of multi-drug resistant tuberculosis ever to occur in the United States, Mr. Castro helped build the program that is still the foundation for tuberculosis control protocol in New York City.

Mr. Castro also currently serves as President of the NCD Alliance, a network of over 2 000 civil society organisations in more than 170 countries dedicated to combating the global Non-Communicable Disease epidemic. He earned a Masters of Public Administration from the University of Pennsylvania and was awarded a Doctor of Humane Letters, *honoris causa*, from Pace University.

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Susanne Løgstrup

Susanne Løgstrup is Director of the European Heart Network (EHN), a Brussels-based alliance of foundations and associations dedicated to fighting heart disease and stroke and supporting patients throughout Europe. She has worked on policies relating to the promotion of cardiovascular health and the prevention of cardiovascular diseases since 1995.

Ms Løgstrup leads the development and implementation of EHN's strategy and advises the Board of current EU thinking, and policies and programmes that have an impact on the work of the EHN and its members. She has led several major pan-European projects, including the European Heart Health Strategy II (2011-2014), part-funded by the EU. In 2017, EHN was awarded a Framework Programme Agreement which provides EHN access to operating grants from the European Union for a four-year period (2018-2021).

Susanne Løgstrup represents EHN in the European Chronic Disease Alliance (ECDA), where she chaired the writing group on the Alliance's first paper 'A unified prevention approach'. She was President of the Smoke Free Partnership (SFP) from January 2016-December 2018. Ms Løgstrup represents EHN on the EC's Platform for Action on Diet, Physical Activity and Health; she was a member of the EC's TTIP Advisory Group where she represented health interests from 2013 to 2017 (when TTIP negotiations were suspended). Ms Løgstrup was also a member of the task force which produced the European Heart Health Charter (2007); this task force included representatives from the European Commission (EC) and the European Regional Office of the World Health Organisation (WHO). Previously, Susanne Løgstrup was an Attorney-at-law in Copenhagen and Paris.

Ms Løgstrup's academic background is in law and business administration, in which she holds master's degrees. She is a Fellow of the European Society of Cardiology (FESC).

Christine Dehn

Christine Dehn is a graduate translator and joined the German Heart Foundation (GHF) in 2002 as Assistant to the Chief Editor. She is the GHF contact person for all external relations and represents patients' interests on national as well as international level. She also engages with like-minded organisations on patient-relevant topics.

Anette Jansson

Anette Jansson has specialised in dietetics, public health and communication. She has held several positions in these areas. For the past two years, Anette has been employed as an expert to build public opinion and influence political decisions in favour of tasks linked to the work of the Heart-Lung Foundation in Sweden.

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From 2010-2017, Anette worked in the Swedish National Food Agency. At the Agency, among other things, she was a manager of the Keyhole health label and she worked with the National Board of Health and Welfare with targeting to support health care professionals to give dietary advice to patients to help them make lifestyle changes.

From 1999-2005 Anette worked at the Swedish Heart and Lung Foundation, with preventive tobacco control, and she was a member of a lobbying group that made it possible for the Swedish government to legislate on smoke free restaurants in Sweden.

Melanie Bertram

Melanie Bertram is a Health Economist with over 15 years' international experience based at the World Health Organization in Geneva where she works for the Department of Health Systems Governance and Financing, leading a work stream on Value for Money and Efficiency. She holds a PhD in Public Health majoring in Health Economics from the University of Queensland, and has authored more than 50 peer-reviewed publications in the field of health economics and policy. Her work focuses on economics to support both short- and long term health sector planning, priority setting and projections of future health needs. She supports analytic and policy work on NCDs and mental health, including as the lead analyst for WHO's best-buys on NCDs and the "Saving Lives, Spending Less" report on the return on investment for NCDs. In addition, she works on Health Technology Assessment, supporting countries to develop evidence informed decision-making processes and health benefit packages which are bolstered by economic considerations.



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Hester Dijk

Hester completed International Business Studies in Enschede, the Netherlands and has a background in marketing. Over the years, she has gained work experience in various sectors: sports, IT services, logistics/supply chain management and financial services. During her career, she has worked for companies such as TNT and PwC in marketing communications and business development roles.

Almost 8 years ago, she joined the Dutch Heart Foundation and is now a member of the Strategy team. She is involved in impact management, market research and market analysis.

Sana Zakaria

Sana Zakaria is the Head of Strategic Performance and Impact at the British Heart Foundation. Previously a post-doctoral researcher at King's College London, she is now based in the third sector with research interests in health, policy and research evaluations. She is committed to understanding how insights based on evaluative techniques and impact assessments can drive political reform and societal change. Her current work involves assessing the role of research funding organisations, such as the BHF, in driving better health outcomes for the public.

Tuija Brax

Tuija Brax was born in Helsinki in 1965. She is a lawyer and Secretary General of the Finnish Heart Association. Tuija is a former Member of Parliament (1995-2015) and former Minister of Justice (2007 – 2011).

Susanne Løgstrup

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Previously, Susanne Løgstrup was an Attorney-at-law in Copenhagen and Paris. Ms Løgstrup's academic background is in law and business administration, in which she holds master's degrees. She is a Fellow of the European Society of Cardiology (FESC).

Valentin Fuster

Dr. Valentin Fuster serves The Mount Sinai Medical Hospital as Physician-in-Chief, as well as Director of Mount Sinai Heart Center. Dr. Fuster is the General Director of the National Center for Cardiovascular investigation or CNIC (equivalent to NHLBI) in Madrid, Spain.

The numerous positions he has held include those of President of the American Heart Association, President of the World Heart Federation, member of the US National Academy of Medicine, where he chaired the Committee for the document on "Promotion of Cardiovascular Health Worldwide", and presently Co-Chairs the Advisory Committee on "the Role of the United States on Global Health" as advisor to the new President, Member of the European Horizon 2020 Scientific Panel of Health, Council member of the US National Heart, Lung and Blood Institute and President of the Training Program of the American College of Cardiology.

After qualifying in medicine at the University of Barcelona, Valentin Fuster continued his studies in the USA. He was Professor in Medicine and Cardiovascular Diseases at the Mayo Medical School, Minnesota and in 1982 at the Medical School of Mount Sinai Hospital, New York. From 1991 to 1994 he was The Mallinckrodt Professor of Medicine at Harvard Medical School and Chief of Cardiology at the Massachusetts General Hospital, Boston post he has combined since 2012 with that of Physician-in- Chief of the Hospital.

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In 1994, he was named director of the Cardiovascular Institute at Mount Sinai, a Dr. Fuster has been named Doctor Honoris Causa by thirty-three universities. He is an author on more than 1 000 scientific articles (HI-145). He was named Editor-in- Chief of the journal Nature Reviews in Cardiology and recently Editor-in-Chief of the Journal of the American College of Cardiology, the ACC's flagship publication and the main American source of clinical information on cardiovascular medicine (Impact factor 17.7). His research into the origin of cardiovascular events, which has contributed to improved treatment of heart attack patients, was recognised in 1996 by the Prince of Asturias Award for Technical and Scientific Research (highest award in Spanish speaking countries). And in June 2011, he was awarded the Grand Prix Scientifique of the Institute of France (considered a most prestigious award in cardiology), for his translational research into atherothrombotic disease. Among his many achievements, it is noteworthy that Dr. Fuster is the only cardiologist to have received the highest awards for research from the three leading cardiovascular organisations: the American Heart Association (Gold Medal and Research Achievement Award), the American College of Cardiology (Living Legend and Life Achievement Award 2017) and the European Society of Cardiology (Gold Medal). In addition, in May 2014, King Juan Carlos I of Spain granted Dr. Fuster with the title of Marquis for his "outstanding and unceasing research efforts and his educational outreach work".

Zaverio M. Ruggeri

Paolo Magni

Prof. Paolo Magni, MD-PhD, is Assistant Professor of Clinical Pathology at the Universita' degli Studi di Milano, Milan, Italy, and member of the Italian Heart Foundation.

He and his group are conducting both experimental and clinical research in the following research domains: molecular pathophysiology of cardiovascular and metabolic diseases (atherosclerosis, dyslipidemia, obesity, diabetes, metabolic syndrome) and the nutritional/nutraceutical modulation of cardiovascular and metabolic risk, aging and health-related issues. P. Magni is the author/co-author of over 98 scientific papers in international peerreviewed journals, 50 full-length other scientific papers/book chapters, and over 170 scientific communications to scientific congresses.

Giovanni de Gaetano

Giovanni de Gaetano was born on the Gargano Promontory during the Second World War. During the admission exams to the newly-opened Catholic Medical School in Rome, he met a student, Maria Benedetta Donati, with whom he later had two daughters and is still sharing life, research work and full-time interests.

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Giovanni de Gaetano has an MD degree (Rome Catholic University, 1968), is a Laboratory and Clinical Haematology specialist (Rome, 1971), and has a PhD degree (Leuven University, Belgium, 1973). He was appointed Director of the Laboratory for Haemostasis and Thrombosis at Mario Negri Institute, Milan, while still a post-doc fellow. At the end of the eighties, with a group of young Pilgrim Investigators he moved to the Abruzzo region, to found the new "Mario Negri Sud". In 2002 he was appointed Director of the Research Laboratories at the Catholic University, Campobasso and in 2013 he became the Director, Department of Epidemiology and Prevention, IRCCS Neuromed, Pozzilli (Isernia). He is a member of the Steering Committee of the Moli-sani Project. Presently he is President of the Neuromed Board of Directors.

For his research on blood platelets, aspirin and thrombosis, he holds two honorary doctorates from the University of Debrecen (Hungary) and Bialystok (Poland) respectively, and is a Knight of the Italian Republic. Author of more than 550 peer-reviewed publications (Pubmed), with a H-index of 80 and more than 26 000 citations, his more recent scientific contributions are related to the characterisation of moderate wine and beer consumption (in the context of a traditional Mediterranean diet) as associated with reduced cardiovascular outcomes. Science communication and philosophical reading (but soccer too) are his preferred week-end activities.

Sergio Coccheri

Sergio Coccheri was born in Bologna, Italy, in 1932 and got his degree in Medicine at the University of Bologna in 1956, summa cum laude. From late 1959 until 1964, he joined the group of Tage Astrup in Copenhagen and in Washington DC. Back in Italy, he established the first Unit of Thrombosis and Haemostasis in the country. He continued his activity of clinical research in the field, and became President of the Italian Society on Thrombosis and Haemostasis, then of the Italian Society for Vascular Medicine, and the Euro-Mediterranean League on Thromboembolism.

In 1980 he was appointed Associate Professor of Medical Pathophysiology, and became Full Professor of Cardiovascular Diseases in 1990.

Since retiring from official academic duties in 2002, he has continued active research and teaching activity. As President or member of Educational Committees of international societies, he has organised post-graduate teaching courses, especially in several emerging countries, both in the Mediterranean and in Eastern Europe areas, and has participated in various activities of EHN on behalf of ALT.

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Susanne Løgstrup

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Victoria Kubie

Victoria joined the British Heart Foundation (BHF) in February 2017 as the Head of Brand & Planning. She leads development of the charity's brand strategy, working to ensure the brand is central to the thinking of all BHF initiatives. Last year, she oversaw the development and launch of a new brand strategy which saw the BHF broadening its customer base by starting to talk about the full spectrum of heart & circulatory diseases it researches(including stroke and vascular dementia), and a new brand promise to beat heartbreak forever. Victoria also leads development of integrated marketing strategy and planning. She loves working for the BHF, potential to save lives. She previously worked at the Royal Mail for many as nothing could be more motivating than knowing your work has the years in a variety of brand, marketing, communications and commercial roles.

As a mum of a teen and a tween, she recently found herself attending a Drake concert and says her ears are still ringing.

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Harriet Foxwell

Harriet has over 18 years' marketing communications experience delivering powerful campaigns in both the commercial and not-for-profit sectors. Harriet joined the British Heart Foundation (BHF) in 2010. As Head of Brand Marketing she leads an ambitious integrated marketing programme to inspire more people to support the BHF and its life changing, life saving work. In 2018 she led the successful launch of the BHF's new brand proposition. The unmissable campaign established the connection between heart and circulatory diseases and the charity's vital research to keep hearts beating and blood flowing.

Harriet is particularly passionate about driving support for the BHF's research, as her own father has a pacemaker. At 76 he runs every day, volunteers for multiple organisations, and inspires his eight grandchildren with his gardening skills proving the power of breakthroughs.



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Alberto Contri

Alberto has been in communications for over fifty years. He has worked as a copy writer, creative director and the CEO of multinational advertising companies. He has been the president of various institutions: President of the Italian Association of Advertising Agencies, Italian Federation of Communication, and he was the only Italian ever co-opted on the Board of the European Association of Advertising Agencies. He was a director of RAI, art director for RaiNet and the president and director general of the Lombardy Film Commission. He has been chairing the Progresso Advertising Foundation gratis since 1999, transforming it into a Permanent Center for Training in Social Communication, with a network (Athena) of over 100 teachers, from 85 faculties and Masters. He teaches Social Communication at the IULM of Milan. In 2010 he was awarded an Honorary Degree in Public Relations of Companies and Institutions. He has published "McLuhan no longer lives here? Communication in the era of constant partial attention" (Bollati Boringhieri – 2017) and "Social Communications and Digital Media" (Carocci – 2018).

Giulio Malgara

Giulio Malgara is an Italian entrepreneur. He started as a marketing manager of the Mars Group in Italy, then he joined Quakers Oats as President of Europe. He was one of the protagonists of the 'Big Brands' including Gatorade beverages, Cuore oil, Haagen Dazs, Fini balsamic vinegar and Negroni cold cuts and Levissima water, just to name a few. Understanding the importance of marketing and advertising, he created, and was President of Auditel for 25 years. The Auditel system is able to control the 'real audience' of each commercial. He was involved with Top Level advertisers as the head of UPA- the Advertisers Association.

Markus Perola

Dr. Markus Perola MD, PhD, is a Research Professor and Head of the Genomics and Biomarkers Unit at the National Institute of Health and Welfare (THL), Finland and the vice-director of the Clinical and Molecular Metabolism Research Program, Faculty of Medicine, University of Helsinki. He is leading a research team focusing on the genomics and other omics in relevance to common human traits and personalised medicine. He is a member of the FinnGen Study Scientific Committee and the PI of the P6-Genomics to Healthcare – study. He is the vice-chair of the Academy of Finland's Research Council for Biosciences, Health and the Environment.

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He is the vice-president of the IVth Ethical Board of the Helsinki University hospital and a member of the European Society of Human Genetics Public and Professional Policy Committee. His publication list includes over 300 original articles and he is listed in the Clarivate Analytics Highly Cited Scientists. Dr. Perola is also a Consultant in Public Health Medicine and a practicing physician in Haartman Hospital, Helsinki University Hospital.

Liis Leitsalu

Liis Leitsalu has been a genetic counsellor and researcher at the Estonian Genome Center of the University of Tartu since 2010. Her work at the genome center focuses on behavioural research in genomics and the ethical, legal and societal issues related to the use of genomic information generated by the genome center. She holds a PhD in Gene Technology from the University of Tartu with her thesis on "Communicating genomic research results to population-based biobank participants", and an MSc in Genetic Counselling, from Sarah Lawrence College (USA). Liis is a member of the Research Ethics Committee of the University of Tartu and a member of the ELSI working group at the European research infrastructure for biobanking, BBMRI-ERIC.


Delegates List

Organisation	Delegate	Function	Email
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British Heart Foundation	Harriet Foxwell	Head of Brand Marketing	foxwellh@bhf.org.uk
British Heart Foundation	Simon Gillespie	Chief Executive	gillespies@bhf.org.uk
British Heart Foundation	Victoria Kubie	Head of Brand & Planning	kubiev@bhf.org.uk
British Heart Foundation	Sana Zakaria	Head of Strategic Performance & Impact	zakarias@bhf.org.uk
Danish Heart Foundation	Claus Beck-Tange	Head of Secretariat	clausbt@hjerteforeningen.dk
Danish Heart Foundation	Morten Ørsted- Rasmussen	Head of Prevention	mortenoer@hjerteforeningen.dk
Dutch association for people with cardiovascular diseases (Harteraad)	Anke Vervoord	Managing Director	anke.vervoord@harteraad.nl
Dutch Heart Foundation	Hester Dijk	Marketing Strategist	h.dijk@hartstichting.nl
Dutch Heart Foundation	Floris Italianer	CEO	f.italianer@hartstichting.nl
Dutch Heart Foundation	Marina Senten	Director Research & Health Care	m.senten@hartstichting.nl
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European Heart Network	Susanne Løgstrup	Director	slogstrup@ehnheart.org
European Heart Network	Michelle Mildiner	PA to Director	info@ehnheart.org

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European Heart Network	Marilena Vrana	Manager Patients and Research	mvrana@ehnheart.org
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German Heart Foundation	Martin Vestweber	Managing Director	vestweber@herzstiftung.de
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Italian Association against Thrombosis and cardiovascular diseases (ALT Onlus)	Isabella Melchionda	Press and Communication Office	<u>comunicazione@trombosi.org</u>
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Italian Association against Thrombosis and cardiovascular diseases (ALT Onlus)	Lidia Rota Vender	President	lidiarotavender@gmail.com
Italian Association against Thrombosis and cardiovascular diseases (ALT Onlus)	Paola Santalucia	Vice-President	paolasantalucia1@gmail.com

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Department of Pharmacological Science, University of MilanRoberto.volpe@cnr.itItalian Society for Cardiovascular Prevention (SIPREC)Roberto VolpeMD, PhD at the National Research Council of talyRoberto.volpe@cnr.itUithuanian Heart AssociationSigita GlaveckaitéPresidentSigita.glaveckaite@santa.ltLithuanian Heart AssociationRaimondas Kubilius Branch of the Lithuanian Heart AssociationHead of Kaunas branch of the Lithuanian Heart Association, Head of Kaunas clinics Kulautuva Rehabilitation HospitalRaimondas.Kubilius@kaunoklinikos.Northern Ireland Chest Heart & Stroke (NICHS)Declan CunnaneChief Executive Executive Boarddcunnane@nichs.org.ukPortuguese Heart FoundationLuís Brás Rosário Executive Boardsecretariado@fpcardiologia.ptRomanian Heart FoundationDan GaitaDirectordgaita@cardiologie.roSpanish Heart Foundation SasociationLorenzo SilvaGeneral Secretary, Spanish Society of Cardiologygelie.johansson@hiart-lung.seSwedish Heart and Lung FoundationAnette JanssonResearch Research Research on Policypelle.johansson@hiart-lungfonden.seSwedish Heart-Lung FoundationSofie Redzematovic CoordinatorDonor Loyalty Coordinatorsofie redzematovic@hiart-lungfonden.seSwedish Heart-Lung FoundationPeter FerloniCommunicationferloni@swissheart.chSwiss Heart FoundationPeter FerloniCommunicationferloni@swissheart.chSwiss Heart FoundationPeter FerloniCommunicat	Italian Heart Foundation	Paolo Magni	Professor and	<u>paolo.magni@unimi.it</u>
Pharmacological Science, University of MilanPharmacological Science, MilanRoberto volpePharmacological Science, MilanRoberto volpe@cnr.itItalian Society for Cardiovascular Prevention (SIPREC)Roberto VolpeMD, PhD at the MD, PhD at the AssociationRoberto volpe@cnr.itLithuanian Heart AssociationSigita GlaveckaitéPresidentsigita glaveckaite@santa.itLithuanian Heart AssociationRaimondas KubiliusHead of Kaunas branch of the Lithuanian Heart Association HeatRaimondas Kubilius@kaunoklinikos. Kulautwa Rehabilitation HospitalRaimondas Kubilius@kaunoklinikos. Menbart Heart Association, Head of Kaunas clinics Kulautwa Rehabilitation HospitalRaimondas Kubilius@kaunoklinikos. Menbar of the Executive BoardRaimondas Kubilius@kaunoklinikos. Menbart Heart Secretary. Spanish Heart FoundationDeclan CunnaneChief Executive Secretary. Spanish Society of Cardiologydcunnane@nichs.org.ukSwedish Heart Foundation Swedish Heart A Lung FoundationDan GaitaDirectordgaita@cardiologie.roSwedish Heart Lung FoundationAnette JanssonSecretary. Spanish Society of Cardiologygelie.johansson@hiart-lung.seSwedish Heart-Lung FoundationAnette JanssonSpecial Advisor on Policyanette.jansson@hiart-lung.seSwedish Heart-Lung FoundationSofie Redzematovic CordinatorDonor Loyalty Cordinatorsofie.redzematovic@hiart-lung.seSwedish Heart-Lung FoundationRristina Sparreljung RetreformitSofie.redzematovic@hiart-lung.seSwed			•	
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			Director	

Norwegian Health Association	Øivind Kristensen	Professional Advisor	oivind.kristensen@nasjonalforeningen .no
Italian Association against Thrombosis and cardiovascular diseases (ALT Onlus)	Nicola Ciavarella	Hematologist and Coordinator of Thrombosis of AReS Puglia	emocoag@gmail.com
Italian Association against Thrombosis and cardiovascular diseases (ALT Onlus)	Chiara Mannelli	PhD in Bioethics - – Ministry of Health - Italy	<u>ch.mannelli@gmail.com</u>
Speaker	Name	Function	Email
Invited Speaker	Melanie Bertram	Health Economist, World Health Organisation	bertramm@who.int
Invited Speaker	João Breda	Programme Manager Nutrition, Physical Activity and Obesity, Division of Noncommunicabl e Diseases and Life-course, WHO-Europe	rodriguesdasilvabred@who.int
Invited speaker - virtual	José Luis Castro	CEO Vital Strategies, President NCD Alliance	executiveoffice@vitalstrategies.org
Invited Speaker	Sergio Coccheri	Former Full Professor of Cardiovascular Medicine, University of Bologna, Italy	<u>coccheris.angio@libero.it</u>
Invited Speaker	Alberto Contri	President, Pubblicità Progresso	europa@trombosi.org

Invited Speaker	Giovanni de Gaetano	President, IRCCS	giovanni.degaetano@moli-sani.org
		Istituto	
		Neurologico	
		Mediterraneo	
		NEUROMED,	
		POZZILLI (IS), Italy	
		and Member of	
		Board of ALT.	
Invited Speaker	Valentin Fuster	Director of Mount	<u>yvarela@cnic.es</u>
		Sinai Heart, and	
		Physician-in-	
		Chief, Mount	
		Sinai Hospital,	
		New York City,	
		USA	
Invited Speaker	Liis Leitsalu	Research fellow	Liis.Leitsalu@ut.ee
		and genetic	
		counsellor,	
		Genome Center,	
		University of	
		Tartu, Estonia	
Invited Speaker	Giulio Malgara	Past President of	europa@trombosi.org
		UPA, Founder and	
		past President of	
		Auditel	
Invited Speaker	Markus Perola	Research	markus.perola@thl.fi
		Professor,	
		National Institute	
		for Health and	
		Welfare, Finland	



Notes



Social Programme Tuesday, 21 May 2019

8.00 a.m. – 2.00 p.m. 12.30 a.m. – 2.00 p.m.	Registration Buffet lunch at <i>Due Camini</i> Restaurant
2.00 p.m. – 6.00 p.m.	Workshop
18.30 p.m. – 11.30 p.m.	Meet up at main reception for a trip to Alberobello's trulli.
	Evening at Alberobello with complementary travel (40 min) and tour guide provided (90 min).
	Please note there will be a short walk around Alberobello, mostly
	uphill. You may therefore want to wear comfortable shoes for this part of the journey.
	Free time at Alberobello (there will be ample time for dinner if you wish).
11.30 p.m.	The bus leaves to take you back to Borgo Egnazia.

Wednesday, 22 May 2019

8.30 a.m. – 1.00 p.m.	Workshop (break at 10.00 a.m.)
1.00 p.m. – 2.00 p.m.	Buffet lunch at Due Camini restaurant
2.00 p.m. – 4.00 p.m.	Workshop
4.30 p.m. – 6.00 p.m.	EHN General Assembly
7.30 p.m.	Festa del Borgo: gala dinner at the Borgo, the central square of Borgo
	Egnazia.
	Festa del Borgo: a traditional Puglian party with dancing show and

Thursday, 23 May 2018

artisan stands.

9.00 a.m. – 1.15 p.m.	Workshop (break at 11.00 a.m.)
1.15 p.m.	End of EHN Workshop and General Assembly 2019
	Buffet lunch at Cala Masciola restaurant



Restaurant Suggestions Puglia

RESTAURANTS "NOWHERE ELSE"

- LA MAREA (Savelletri di Fasano) <u>www.lamarearistorante.com</u>
- PESCHERIA DUE MARI (Savelletri di Fasano)
- IL CORTILETTO (Speziale di Fasano)<u>www.ristoranteilcortiletto.com</u>
- ZIO PIETRO (Cisternino) www.ziopietro.it
- ANTICO BORGO (Cisternino) <u>www.rosticceria-lanticoborgo.it</u>
- OSTERIA DEL CAROSENO (Castellana Grotte) <u>www.osteriadelcarosenobeb.com</u>
- TRATTORIA TERRA MADRE (Alberobello) www.trattoriaterramadre.it
- CASA SAN GIACOMO (Ostuni)
- DA TUCCINO (San Vito di Polignano a Mare) www.tuccino.it
- CIBUS (Ceglie Messapica) <u>www.ristorantecibus.it</u>

RESTAURANTS WITH MICHELIN STAR

- PASHÀ (Conversano) www.ristorantepasha.com
- OSTERIA GIÀ SOTTO L'ARCO (Carovigno) <u>www.giasottolarco.it</u>

RECOMMENDED RESTAURANTS

- MASSERIA GARRAPPA (Capitolo di Monopoli) www.masseriagarrappa.com
- IL CAVALIERE (Capitolo di Monopoli)
- IL PUNTO (Torre Canne) <u>www.ristoranteilpunto.it</u>
- AMARE (Torre Canne)
- LA LOCANDA DI MARTUMÈ (Fasano)
- SILVÈ (Fasano)
- ANTICALAMA (Torre Spaccata) <u>www.anticalama.it</u>
- VIANTICA DI CIBO E DI STORIE (Pezze di Greco) www.vianticaristorante.business.site
- MASSERIA NARDUCCI (Speziale di Fasano) www.agriturismonarducci.it
- MASSERIA LISI ANNA (braceria) (Selva di Fasano) www.masserialisianna.com
- OSTERIA PERRICCI (Monopoli)
- PIAZZA PALMIERI (Monopoli) <u>www.piazzapalmieri.it</u>
- IL GUAZZETTO (Monopoli) <u>www.ristoranteilguazzetto.it</u>
- LA LOCANDA SUL PORTO (Monopoli) <u>www.lalocandasulporto.it</u>
- LA TORRETTA DEL PESCATORE (Monopoli)
- LA CANTINA (Alberobello) http://www.ilristorantelacantina.it
- L'ARATRO (Alberobello) www.ristorantearatro.it
- EVO (Alberobello) <u>www.evoristorante.com</u>



CARDIOVASCULAR DISEASE -A TOUR D'HORIZON EUROPEAN HEART NETWORK ANNUAL WORKSHOP AND GENERAL ASSEMBLY Puglia, Italia, 21 – 23 May 2019

Restaurants cont.

- ANTICHE MURA (Polignano a Mare) <u>http://www.ristoranteantichemura.it</u>
- OSTERIA PIGA (Polignano a Mare) <u>http://www.osteriapiga.com</u>
- PESCARIA (Polignano a Mare) <u>www.pescaria.it</u>
- GRAECALIS (Polignano a Mare) <u>www.graecalis.it</u>
- MINT (vegetariano) (Polignano a Mare) <u>www.mintcucinafresca.com</u>
- LA COLONNA (San Vito di Polignano a Mare) <u>www.ristorantelacolonna.it</u>
- IL CUCCO (Cisternino) <u>www.enotecailcucco.it</u>
- OSTERIA BELL'ITALIA (Cisternino)
- TAVERNA DELLA TORRE (Cisternino) http://www.tavernadellatorre.it
- OSTERIA SANT'ANNA (Cisternino) <u>www.osteriasantanna.it</u>
- IL CASALICCHIO (Castellana Grotte)
- OSTERIA GROTTA BIANCA (C. Grotte) ristoranteosteriagrottabiancacastellanagrotte.com
- CESARINO 36 (Castellana Grotte) <u>www.cesarino36.it</u>
- OSTERIA 'A CRIANZ (Putignano)
- OSTERIA DEL TEMPO PERSO (Ostuni) <u>www.osteriadeltempoperso.com</u>
- OSTERIA PIAZZETTA CATTEDRALE (Ostuni) <u>www.piazzettacattedrale.it</u>
- LA RISACCA 2 (Ostuni) <u>www.larisaccaostuni.it</u>
- PORTA NOVA (Ostuni) www.ristoranteportanova.com
- MASSERIA IL FRANTOIO (Ostuni) <u>www.masseriailfrantoio.it</u>
- U CURDUNN (Locorotondo) www.ristoranteucurdunn.it
- BINA (Locorotondo) <u>www.binaristorante.it</u>
- PIETRANUDA (Locorotondo)
- LA GREPPIA DEL FRATE (Locorotondo) <u>www.lagreppiadelfrate.it</u>
- GARIBALDI BISTROT (Martina Franca)
- TERRA TERRA (Martina Franca)
- NAUSIKAA (Martina Franca) <u>www.ristorantenausikaa.it</u>
- TRATTORIA LE RUOTE (Martina Franca)
- ATLANTIS (Otranto) <u>www.atlantisbeach.it</u>
- OSTERIA DEL TEMPO PERSO (Ostuni) <u>www.osteriadeltempoperso.com</u>

BEST PIZZA

- PIZZERIA DEL PORTICO (Fasano)
- IL RIFUGIO DEI GHIOTTONI (Fasano)
- TRATTORIA PIZZERIA DA ZÌ OTTAVIO (Monopoli) <u>www.facebook.com/TrattoriaZioOttavio</u>
- RISTORANTE PIZZERIA LA DOLCE VITA (Monopoli) <u>www.ristorantepizzerialadolcevita.it</u>
- CASA MIA TRATTORIA PIZZERIA (Polignano a Mare)
- BELLA 'MBRIANA (Polignano a Mare) <u>www.labellambriana.it</u>
- TRATTORIA PIZZERIA IL PINNACOLO (Alberobello) <u>www.ilpinnacolo.it</u>

CARDIOVASCULAR DISEASE -A TOUR D'HORIZON EUROPEAN HEART NETWORK ANNUAL WORKSHOP AND GENERAL ASSEMBLY Puglia, Italia, 21 – 23 May 2019

Restaurants cont.

- QUANTOBASTA (Locorotondo) www.facebook.com/qbpizzeria
- DOPPIOZERO (Cisternino) <u>www.govirtualtour3d.com/cisternino-doppio-zero</u>
- PIZZERIA NOTTI BIANCHE (Ostuni)

BEST ICE CREAM

- CAFFÈ ROMA (Monopoli) <u>www.cafferoma1monopoli.it</u>
- GELATERIA CARUSO (Monopoli) <u>www.gustocaruso.it</u>
- BAR TURISMO (Polignano a Mare)
- CARUSO NOTE D'ECCELLENZA (Polignano a Mare) www.gustocaruso.it
- ARTE FREDDA (Alberobello) <u>www.artefredda.com</u>
- MARTINUCCI (Alberobello, Bari, Lecce, Otranto, Gallipoli) www.martinucci1950.com

COCKTAIL BARS

- ALCHEMICAMENTE (Savelletri di Fasano)
- QUATTRO (Savelletri di Fasano) <u>www.quattro-creative-wine-bar.business.site</u>
- LIDO BAMBÙ (Capitolo di Monopoli) www.lidobambu.it
- CI PORTI (Fasano) <u>www.ciporti-pub-ai-portici.business.site</u>
- SOTTO SOPRA (Fasano)
- PREMIATO CAFFÈ VENEZIA (Monopoli)
- CARLOQUINTO (Monopoli) <u>www.facebook.com/carloquintomonopoli</u>
- TAMBORR (Monopoli)
- FLY (Polignano a Mare) <u>www.flypolignano.it</u>
- CAFFÈ DELLA VILLA (Locorotondo)
- DOCKS 101 (Locorotondo) <u>www.docks101.it</u>
- GIARDINI 36 (Cisternino)
- RICCARDO CAFFÈ (Ostuni) <u>www.riccardocaffe.com</u>
- WHITE OSTUNI TITO SCHIPA (Ostuni) <u>www.whiteostuni.it/titoschipa</u>
- WHITE BEACH CLUB (Monticelli di Ostuni) <u>www.whiteostuni.it/beachclub</u>
- CAFFÈ TRIPOLI (Martina Franca)



Borgo Egnazia Things to do

IYENGAR YOGA

For a mind and body in perfect balance. Master the lyengar experience, wisely dispensed in the form of morning sessions by Vair therapist-artists, the best way to gently awaken the muscles and prepare the body for the activities of the day. Calm mind, psycho-physical balance, posture alignment, and Pranayam breath control techniques will be a great opportunity for your body and mind.

BORGO JOGGING

Jogging is good for mind to body because it improves mood, delays muscle aging and helps to keep weight under control, engaging the whole muscular system. Especially when practiced in the morning before breakfast, and with consistency, a little healthy jogging will allow you to discover a pleasant path in the Puglian countryside, as well as in the wonderful setting of the Borgo.

FITWALKING IN PUGLIA'S COUNTRYSIDE

Fitwalking is a walking practice that goes beyond the simple act of walking. It is "the art of walking for physical fitness", that is to say, making sustained and energetic steps, and observing correct mechanic of movement. Fitwalking is practiced open-air and in a group in the quiet streets of the countryside around the Borgo, adding in this way a beneficial community relevance to the healthy experience, thus favouring social interaction as well.

STRETCHING AMONG THE OLIVE TREES

Practicing stretching in the morning is a great elixir against body aging. Suitable for all ages and individual differences in muscle tension and flexibility, this type of training helps reduce stress, rebalances the natural psycho-physical tensions, for a better awareness of your body: both its potential and its limitations. Stretching benefits will be perceived by the body as much as by the mind.

SAN DOMENICO GOLF

Borgo Egnazia has reserved a special price for EHN guests who want to relax by playing golf at San Domenico, which is on Borgo Egnazia's property.

BIKE

Borgo Egnazia offers bicycles to explore the grounds and village. The first hour is free, then 20€ per hour, depending on the kind of bicycles.

VAIR SPA

Borgo Egnazia has a lovely Spa, the VAIR SPA. Sauna, steam room, gym and indoor pool/outdoor pool are free, and all treatments are 20% off for EHN guests.



Evaluation of EHN Annual Workshop

Puglia, Italy, 2019

Please kindly write as clearly as possible on this form. Many thanks!

Question 1:Was the Annual Workshop valuable in terms of sharing information,
experiences and networking with other Heart Foundations?

Yes

No

Comments and suggestions for improvement:	

Question 2: Do you feel that the Annual Workshop, generally, provided you with information that will help you improve your work in the areas that were the focus of the Workshop?

	Yes			No
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Comments and suggestions for improvement:

48 (AIT.)

Question 3:	Would you say that overall the Workshop met your expectations?
	Completely Largely Somewhat Not at all
Comments and	suggestions for improvement:
	What is were apirises on the following*.
Question 4:	What is your opinion on the following*: a) Venue and transport facilities?
	VG G N B
	b) Technical facilities?
	VG G N B
	c) The organising of the Workshop (e.g. information sent to you
	beforehand, running of the event whilst in Puglia etc.)?
	VG G N B
	* VG = very good; G = good; N = neutral; B = bad
Question 5:	Any suggestions for the 2020 EHN Annual Workshop?

Question 6: Any other comments not covered above?

Please return this form to Michelle Mildiner at the European Heart Network (<u>info@ehnheart.org</u>) by Friday 7 June.

Your views will help to shape next year's Annual Workshop.

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Notes









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