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Heart Foundation series: The German Heart Foundation

Building a Bridge between Physicians and Patients

The German Heart Foundation is the leading patient organization fighting Cardiovascular Diseases in Germany and providing over €2.4 Million of funding for cardiovascular research in 2017



As Germany's leading non-profit patient organization in the field of cardiovascular diseases the German Heart Foundation (*Deutsche Herzstiftung*) has been committed for nearly 40 years to fighting cardiovascular diseases in Germany, where more than 356 000 people are still dying from heart and circulatory conditions every year. There are three outstanding key characteristics that outline the Foundation's mission to represent the interests and yearnings of heart patients and their relatives:

- The Foundation's financial independency from industry, especially the pharmaceutical, healthcare, and food industry.
- The fact that all medical publications are written by renowned (honorary) heart experts.
- The fact that all medical publications are written in lay language and thus comprehensible by everyone, also non-academic people.

Offering the public medical information in publications and through campaigns regarding causes, prevention, diagnosis, and therapy of cardiovascular diseases the Foundation supports heart patients, children as well as grown-ups with congenital heart disease (GUCH) and their parents/carers.

President of the German Heart Foundation from 2010 to June 2018 was Prof. Thomas Meinertz MD FESC FACC. His successor as president is Prof. Dietrich Andresen, MD, FESC, a Board member since 2010 and a cardiologist in Berlin.

Prof. Thomas Meinertz was elected to this position after his retirement as Head of the Clinic for General and Interventional Cardiology, University Heart Center, Hamburg, Germany. 'The presidency combined in a perfect way my yearning for social engagement with the general

need to help patients and improving their quality of life, by offering independent medical information on cardiovascular health and making the information more understandable for laypersons'. He was a board member of the Foundation since 1998 and a member of the editorial board for the Foundation's publications such as, the member magazine 'Herz heute' (Heart Today). One of his previous roles has been to ensure the high quality of these publications. In 'Herz heute' and 'herzblatt' (*Heart Journal*)—the magazine for children and grown-ups with congenital heart disease—

cardiologists, heart surgeons, and paediatric cardiologists communicate the latest developments in heart medicine and prevention to more than 150 000 to 190 000 readers per issue.



Board Members of the German Heart Foundation (2018-2022). Left: Prof. Heribert Schunkert MD. (L) to (R): Philipp Glaser; industrial engineer, representing the interests of patients with congenital heart diseases; Gunter Anders (Lawyer and Financial Adviser); Vera Cordes, Journalist; Prof. Jan Gummert, MD; Prof. Dietrich Andresen, MD, president since June 2018; Prof. Helmut Gohlke, MD; Prof. Thomas Voigtländer, MD. Right: Prof. Hans-Joachim Trappe, MD, a well-known organ player, who has enhanced the Foundation's reputation through charity organ recitals in German cathedrals.

Dr Irene Oswalt, a member of the Board from 1985 to 2018 and editor-in-chief of *Herz heute*, contributed to the magazine's high reputation among patients and physicians.

Today, more than 300 000 subscribers appreciate the medical content of the online newsletter for patients and physicians. During his presidency, Thomas Meinertz pushed forward the Foundation's independence as a non-profit organization by increasing the number of its supporting members to more than 100 000 in 2018 (1979:160), most of whom are heart patients.

In 2002, the Foundation renounced financial support from the pharmaceutical industry to increase its independence. 'This strategy gives the German Heart Foundation a high reputation in public opinion in times where medical information is often biased by commercial interests of the pharmaceutical and medical device industry', states Meinertz. The German Heart Foundation has been successfully promoted as an important voice for political issues in the German healthcare system by Prof. Hans-Jürgen Becker, MD, President from 1998 to 2010.

A further key objective is the financial support of clinical and basic research in cardiovascular diseases (funding, scholarships, awards) with the support of the German Cardiac Research Foundation [Deutsche Stiftung für Herzforschung (DSHF)], founded by the German Heart Foundation in 1988. The exchange and cooperation with the German Cardiac Society (DGK), the German Society for Thoracic and Cardiovascular Surgery (DGTHG), the German Society of Paediatric Cardiology (DGPK), and other scientific societies focused on issues in cardiovascular science and medicine, is an important strategy to provide best service to heart patients.

German Heart Report: in what condition is Germany's cardiac health care?

A further major step and milestone was the publication of the first German Heart Report (Deutscher Herzbericht) with the German Heart Foundation being the leading editor in collaboration with an editorial board consisting of board members of the DGK, the DGTHG,

and the DGPK. The German Heart Report formerly edited and published by Ernst Brucknerberger, PhD ('Brucknerberger-Report') until 2011, is published annually. The report provides a comprehensive analysis of morbidity and mortality in patients with coronary artery disease, acute myocardial infarction, cardiac valve diseases, cardiac arrhythmias, heart failure, and congenital heart diseases. It also includes a clear overview of all important services and care aspects such as the provision of diagnostic and therapeutic procedures in cardiology, paediatric cardiology, and cardiac surgery in Germany.

The German Heart Report is the result of a multidisciplinary collaboration. 'It is an important resource for all stakeholders in the healthcare system regarding heart disease conditions and their treatment in Germany. The report stands in Germany as the most important and most comprehensive analysis in the field of cardiovascular diseases and has also increased the reputation of its publishers', explains Prof. Meinertz. Whereas the German Heart Foundation is the leading editor of this report it also acts as a mediator, working closely together with the three main cardiac societies DGK, DGTHG, and DGPK, that are responsible for the aggregation and interpretation of the data in this report.

The report's data attract a lot of public and media attention as it reveals the uneven health situation regarding the in-hospital morbidity and mortality from heart diseases between eastern and western regions of Germany. 'From this point of view the German Heart Report has been a trigger for introducing a number of regional heart disease registers that investigate the causes for significantly higher cardiovascular morbidity and mortality rates', says Meinertz. 'Due to a boost of reputation and public awareness the German Heart Foundation as well as the collaborating cardiac societies benefit from the outcome of this report'.

Heart patients on the waiting list were dying due to a shortage of medical facilities

The German Heart Foundation was founded in 1979 by cardiologists Prof. Kurt Bachmann, MD, Prof. Hans Blömer, MD, Prof. Franz Grosse-Brockhoff, MD, Prof. Martin Kaltenbach, MD, and Prof. Wolfgang



Presentation of the German Heart Report in Berlin (from left): Prof. Hugo A. Katus, MD, President of DGK; Prof. Meinertz, MD; PD Wolfgang Harringer, MD, President of DGTHG; Prof. Sven Dittrich, MD, President of DGPK. Photograph: Daniel Schmidt/GHF. Right: German Heart Report 2017 Collage: Christina Marx/GHF.

Kübler, MD, together with heart surgeon Prof. Hans-Georg Borst, MD, pharmacologist Prof. Franz Gross, MD, banker Helmut Haeusgen, and lawyer Prof. Hans-Joachim Mertens, PhD. The Foundation's aims were to promote the prevention of heart diseases in Germany and to fight the shortage of facilities for cardiac surgery and catheter interventions. Thomas Meinertz reports that in those days 'the waiting time often led to the deaths of patients on the waiting list. We were forced to send patients to London, England, for cardiac surgery. Immediate change in Germany's medical care system for heart patients was then needed'.

Also playing a constitutional role in the Foundation's history, was the cardiac rehabilitation specialist Prof. Max Halhuber, MD, who introduced the concept of the patient as an expert in his own disease. In 1981, he started patient seminars that were attended by thousands of patients in Frankfurt, Erlangen, Hannover, Bad Oeynhausen, and Düsseldorf. In these patient seminars hosted by heart experts giving lectures in 3-h sessions, patients could ask individual questions concerning their own heart condition. Today, patient seminars are held nationwide throughout the year with over 1100 patient seminars and more than 4000 collaborating heart clinics and health institutions during the Heart Foundation's annual campaign 'Heart Weeks' (Herzwochen) in November.

A scientific advisory board was established in 1982. Headed by Prof. Werner Daniel MD from Erlangen, until 2017, and currently by Prof. Hugo A. Katus MD from Heidelberg, it has more than 500 members, consisting of cardiologists, cardiac surgeons, paediatric cardiologists, psychologists, and pharmacologists. They all provide scientific advice on a voluntary, honorary basis. In 1984, patient volunteers also began to work locally. Today, 600 volunteers and supporters collaborate with hospitals and general practitioners to organize information campaigns. First self-help groups were founded in 1987 in Hannover and Norden, Germany, and there are now more than 90. Also, in 1987 Barbara Genscher, wife of the former Foreign Minister, Hans-Dietrich Genscher, became a patron.

An important international partner of the German Heart Foundation is the European Heart Network (EHN), a Brussels-based alliance of heart Foundations and likeminded non-governmental organizations throughout Europe, with member organizations in 25 countries. Since its beginning and together with its members, EHN has

engaged with EU policy makers to activate and influence policies, which can contribute to promoting cardiovascular health and preventing cardiovascular diseases (CVD). Martin Vestweber, managing director of GHF has been an EHN board member since 2013. Another important partner at an international level is the World Heart Federation. On behalf of the EHN, the German Heart Foundation attended a workshop on pulmonary arterial hypertension hosted by the European Medicines Agency (EMA) and represented the concerns and problems of young patients and their carers.

New challenge: lost to specialist follow-up among grown-up patients with congenital heart disease

In the 1990s, the needs of children with congenital heart disease and their parents became more apparent, therefore *herzblatt*, a magazine dedicated to the parents of children with congenital heart disease was launched in 1992, jointly with the Children's Heart Foundation's set-up. The Children's Heart Foundation also organizes leisure activities such as skiing and sailing under medical supervision for children and grown-up patients with congenital heart disease. 'As the life expectancy for this patient group has improved immensely, adults with congenital heart diseases now form a constantly growing patient group with up to 300 000 patients nationwide, and there is a large number which are lost to follow-up among them: it is a great challenge for us to reach and motivate them to get back into the medical care system', explains Thomas Meinertz. The German Heart Foundation endowed its first GUCH Professorship for a new academic discipline at medical schools in Germany, to improve the clinical management of grown-up patients with congenital heart disease and promote research in this specialty, representing a milestone in the GUCH field. Prof. Tanja Rädle-Hurst, MD, GUCH-certified adult cardiologist at the Saarland University Medical Center at Homburg/Saar, Germany, was nominated for this endowed Professorship and received a grant for the duration of 5 years.



Left: Skipping Hearts: School children in Bavaria improving their physical activity during a rope skipping workshop by the German Heart Foundation. Photograph: Marco Einfeldt. Centre: Patient seminar during the Heart Weeks in 2016 in Germersheim, Germany. Photograph: Ingo Martin/GHF. Right: CPR instruction at the German Football Association/Deutscher Fußball-Bund (DFB); board member Prof. Dietrich Andresen, MD, giving CPR instruction. Photograph: Michael Wichert/GHF.

Further milestones: a single emergency phone number, sports program 'Skipping Hearts', CPR-projects

When lobbying in 1995 for a single emergency telephone number in Germany, the Heart Foundation collected 220 000 signatures. Supported by Barbara Genscher handing over the signatures to the Postmaster General, the idea received enormous media coverage and resulted in 112 becoming the single emergency number throughout Germany, with the exception of two states.

In 2002, the Foundation began hosting expert roundtable discussions between cardiologists and heart surgeons on controversial issues.

In 2005, it launched the Mediterranean diet project in hospitals and state institutions.

A sports program for schools, 'Skipping Hearts', started in 2007, motivating school children by introducing state-wide competitions in rope skipping to do more physical activity. To date, the project has motivated more than 500 000 children in nine federal states to be more physically active.

In 2009, the Foundation campaigned for transparent food labelling in Germany and in the European Union, but the initiative failed as the national and international food industry lobby was too powerful. However, in 2010, successful campaigning led to anti-smoking laws, that were enforced in all German states after a long battle with politicians.

In order to increase first responder rates by bystanders in cases of cardiac arrest, the German Heart Foundation initiated in 2015 the project 'Be a lifesaver', cooperating with the German Football Association [(Deutscher Fußball-Bund (DFB)]. In this project, senior soccer players are offered resuscitation courses, which occur in the clubs of the six participating regional football associations. 'We have noticed that the first responder rate by bystanders in Germany is extremely low, about 30% compared to 70% in other European countries, and that we have to make sure that resuscitation becomes a normal feature of living, for example in family and leisure time activities, schools and job', Prof. Andresen says, who is supervising the project

together with Prof. Tim Meyer MD, Chair of the Sports Medicine Committee of the DFB.

About 65 000 people have a sudden cardiac death per year in Germany.

Cardiac research with patient-related objectives

In 1988, the DSHF was founded with the aim to explicitly support cardiac research, and surpluses are transferred from the German Heart Foundation to the DSHF. Its scientific advisory board is headed by cardiac surgeon Prof. Hellmut Oelert MD. In 2017, the two Foundations funded more than €2.4 million of cardiovascular research in Germany and beyond. This included research projects, annual scholarships, doctoral scholarships, and science awards. With the fall of the Berlin Wall in 1989, the Foundation decided to fund the education and training of young heart specialists in Eastern Germany. The Foundation's research program funds projects that deal with heart failure, cardiac remodelling, cardiac hypertrophy, surgical procedures, valve degeneration, clinical studies, atherosclerosis, imaging procedures, arrhythmia mechanisms and therapy, biomarkers, stroke, haemodynamic, microbiome, and epidemiology.

Managing directors to date have been Eva-Maria Patt, Renate Geus, Martin Vestweber, and Renate Horst (as deputy) and focused strongly on initiating fundraising efforts and campaigning. During his 8-year presidency, Prof. Meinertz has completed his mission to improve the Foundation's performance in all areas, increase the number of members and therefore its ability to fund more initiatives and research projects.

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Conflict of interest: M.W. is Press Officer at the German Heart Foundation.