GLOBAL HEART FAILURE AWARENESS PROGRAMME

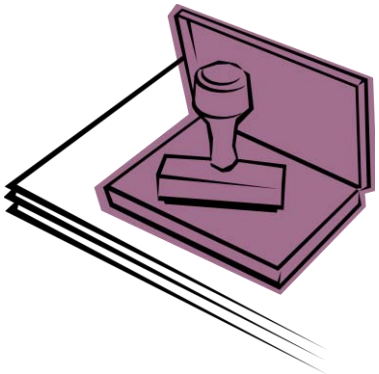
HEART FAILURE ASSOCIATION OF THE ESC

EUROPEAN SOCIETY OF CARDIOLOGY®

Report of the white paper endorsement meeting

Athens, 16 May 2014

15:30–17:30, Divani Caravel Hotel



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Participants

Petros Agathangelou (CY)

Khalid AlHabib (SA)

Laurence Alliot (FR)

Stefan Anker (DE)

Isabel Bardinet (FR)

Christina Boudouri (GR)

Dirk Brutsaert (BE)

Jelena Celutkiene (LT)

Christina Chrysohoou (GR)

Martin Cowie (UK)

Marisa Crespo-Leiro (ES)

Rudolf De Boer (NL)

Kenneth Dickstein (NO)

François Durand (FR)

Gerasimos Filippatos (GR)

Thomas Force (US)

Mihai Gheorghiade (US)

Georgia Giannoulidou (GR)

Stephane Heymans (NL)

Arno Hoes (NL)

Mitja Lainščak (SL)

Ekaterini Lambrinou (CY)

Johan Paul Eric Lassus (FI)

Yury Lopatin (RU)

Theresa McDonagh (UK)

John McMurray (UK)

Alexandre Mebazaa (FR)

Davor Milicic (HR)

Sophie Nisse-Durgeat (FR)

Noémi Nyolczas (HU)

Zoltán Papp (HU)

Massimo Piepoli (IT)

Burkert Pieske (AT)

Vishal Rastogi (IN)

Jillian Riley (UK)

Luis Rohde (BR)

Frank Ruschitzka (CH)

Umesh Samal (IN)

Petar Seferoviuć (RS)

Bambang Budi Siswanto (ID)

Hadi Skouri (LB)

Karen Sliwa (ZA)

Scott Solomon (US)

Sophie Squarta (FR)

Panagiotis Vardas (GR)

Jean Marc Weinstein (IL)

Birhan Yilmaz (TR)

Welcome and introduction

Slides: http://www.escardio.org/congresses/heart-failure-2014/Documents/athens-ghfap-wpendorse-intro-disc-anker.pdf | http://www.escardio.org/congresses/heart-failure-2014/Documents/athens-ghfap-wpendorse-intro-disc-ponikowksi-why-ghap.pdf

Stefan Anker (Berlin, DE) welcomed the delegates to Athens and to the inaugural meeting of the Global Heart Failure Awareness Programme (GHFAP) of the HFA-ESC. Piotr Ponikowski (Wrocław, PL) described how the GHFAP aims to make prevention and treatment of heart failure global health priorities.

Improving care for patients with acute heart failure: before, during and after hospitalization

Slides: http://www.escardio.org/communities/HFA/Documents/athens-GHFAP-endorse-AHF-report.pdf

Martin Cowie (London, UK) presented the policy report on acute heart failure (www.oxfordhealthpolicyforum.org/AHFreport). This report has been endorsed by HFA-ESC and adopted as part of the GHFAP. Professor Cowie stressed the need for a unanimous message and for patient group involvement in influencing policy. Producing a scientifically robust report is just the beginning of a process. Effecting policy change will involve cascading the information to policy-makers, politicians and citizens using a variety of media.

Heart failure: preventing disease and death worldwide

Slides: http://www.escardio.org/communities/HFA/Documents/athens-GHFAP-endorse-main.pdf

Gerasimos Filippatos (Athens, GR) presented the white paper on heart failure (http://www.escardio.org/communities/HFA/Pages/global-heart-failure-awareness-programme.aspx). The realization that heart failure is a problem not only in Europe and the USA, but also globally, led to the initiation of the GHFAP. Policy-makers worldwide must be urged to act on the recommendations of the paper.

16:00 Regional perspectives

Slides: http://www.escardio.org/communities/HFA/Documents/athens-GHFAP-endorse-regional2.pdf

Khalid AlHabib (Riyadh, SA) explained that Saudi Arabia has several different healthcare sectors and that many patients have difficulty accessing healthcare. Although interventional cardiology is

well established, there are few heart failure specialists, nurses or clinics. The recent HEARTS, Gulf CARE and International HF registry studies could be complemented by further international collaboration.

Thomas Force (Philadelphia, PA, US) stressed that a unified front and compelling message are important to drive spending by politicians, who are motivated largely by re-election. Identifying 'champions' in congress could help transform 'lip service' into real service. Making sure that politicians understand the issues is critical for the success of the programme. The Gates Foundation is a potential funder with an interest in health in Africa.

On behalf of Henry Krum (Melbourne, AU), Karen Sliwa (Cape Town, ZA) mentioned that Australia has universal healthcare coverage, but that many people have difficulty accessing services because of education or geography. People from an aboriginal background have high rates of obesity and diabetes, and poor life expectancy. Tackling this problem involves research into understanding the factors driving these inequities, as well as into epidemiology.

Vishal Rastogi (New Delhi, IN) described the ongoing epidemiological transition in India, where heart diseases are taking over from infectious diseases as the major killer. The wide income gap and the high cost of healthcare are the main drivers of inequity, with the majority of the population living in villages with poor access to services. There is a need for new heart failure clinics and for specialists to collaborate with and educate general practitioners.

Luis Rohde (Porto Alegre, BR) commented that heart failure is not a defined priority within the Brazilian public healthcare system set up in 1988. Heterogeneity in this system is the main driver of inequity, making improving access to primary and secondary care the main tool available for effecting change. The number of specialist centres also needs to increase. Local prevention campaigns should include measures focused on Chagas disease.

Bambang Budi Siswanto (Jakarta, IN) stressed the wide geographic scope of the Asia-Pacific region. As an archipelago, Indonesia experiences significant geographical inequities and is covered by only 500 cardiologists. Educating patients about medication adherence is important, and there is a need for more community heart failure nurses.

Karen Sliwa (Cape Town, ZA) explained that improved funding for research is producing African epidemiological and clinical data on heart failure. Africa is highly heterogeneous: the recognized huge burden of infectious disease is paralleled by a poorly reported and under-researched burden of heart disease. Many African countries do not train cardiologists, and there are no specialist heart failure nurses, programs or clinics. There is an opportunity to integrate these with infectious disease care. Because policy-makers do not read academic journals, there is a need to supply them with appropriate summaries of research findings.

Future plans

Slides: http://www.escardio.org/congresses/heart-failure-2014/Documents/athens-ghfap-wpendorse-intro-disc-ponikowski-future-plans.pdf

Piotr Ponikowski encouraged representatives from national societies to endorse both the documents. Endorsement from patient and advocacy groups will also be sought. HFA-ESC will be in touch with individual organizations by email.

Over the next four years, these documents will be widely disseminated and a more detailed white book will be written. The European Heart Failure Awareness Day will be broadened as part of the GHFAP, and epidemiological and guideline studies will be undertaken to provide an evidence base for improving care.

Discussion

Patient groups and public awareness

Petros Agathangelou (CY) opened the discussion by stressing that policy-makers need to understand the global and local burden of heart failure, and the costs of treatment. More awareness of the severity of the disease could stimulate investment. In Cyprus, there are associations for patients with specific heart conditions, but not for patients with heart failure.

Davor Milicic (HR) suggested that the heterogeneity of heart failure might deter patients from joining together in an association. Rather, organizing specific groups of patients (e.g. those with implanted devices or transplants) would be more feasible.

A straw poll of the participants revealed that only the USA was known to have a patient association devoted specifically to heart failure. Stefan Anker suggested a future brainstorming session on patient groups.

Kenneth Dickstein (NO) framed the importance of patient awareness campaigns in political terms. Patients are ultimately represented by voters, who re-elect policy-makers and politicians.

Karen Sliwa suggested that the group could be involved in developing very short video clips as part of an awareness program for the public. Thomas Force mentioned that many thousands of patients do use online disease resources. The Heart Failure Society of America has produced video modules which could be shared with the GHFAP.

Mortality due to heart failure

Mihai Gheorghiade (US) mentioned that age is an important factor in the perception of heart failure: death may be seen as natural in someone aged 75 years, but heart failure is not just a disease of the elderly. Furthermore, heart failure is not perceived as serious or fatal (unlike cancer), and

patients feel better with available treatments. Yet, in half of patients, implementing all interventions does not improve outcomes after hospitalization and does not affect the course of disease.

John McMurray (UK) mentioned that most countries do not allow heart failure as a primary cause of death on a death certificate (rather, the underlying disease has to be stated). In the Russian Federation, this is also true for discharge diagnoses. Government statistics in many countries therefore tell politicians that hardly anybody dies from heart failure. This is something the group could try to change. Karen Sliwa voiced her agreement.

Burkert Pieske (AT) suggested that heart failure with preserved ejection fraction (HFPEF) should form a core part of the GHFAP, and asked what worldwide data exist on incidence and prevalence of HFPEF. Once hospitalized for worsening heart failure, the outcome for a patient with HFPEF is as poor as for patients with reduced ejection fraction.

Funding and ideas for global scope

Stefan Anker described the intention of the HFA to submit grant proposals to secure funding from three to five sponsors to the value of EUR 250 000 to 400 000 each per year for a number of years. Piotr Ponikowski welcomed innovative and globally relevant ideas for these proposals.

Luis Rohde queried how the group could adopt a global scope. In Brazil there is no awareness day for heart failure (unlike for smoking and hypertension): one idea would be a global awareness day. Gerasimos Filippatos mentioned that, even in Europe, the awareness day is spread across a week in different countries. A global awareness day could be a very important part of the initiative.

Khalid AlHabib stressed the need for grants to train competent heart failure specialists, nurses and allied professionals. Gerasimos Filippatos mentioned that the HFA-ESC has training grants, and suggested that a global grant programme would be beneficial.

Translations

Luis Rohde recommended that the white paper be translated. François Durand (FR) and Stefan Anker supported the proposal for translation into 4–6 different languages.

Stefan Anker concluded the meeting by thanking the presenters, the participants and the support staff from Translational Medicine Academy (CH) and Oxford PharmaGenesis™ (UK).