Reimagining and Reframing Heart Failure as We Age

A Series of Think Tanks Hosted by the Global Coalition on Aging

In Partnership with

17 April 2018 | New York City

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Aligned with the Heart Failure Policy Network Handbook Launch

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THINK TANK SERIES REPORT:

CONSENSUS TOWARD A GLOBAL HEART FAILURE ALLIANCE

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PART I: SETTING THE STAGE

About the Think Tank Series

The Global Coalition on Aging (GCOA), in partnership with Novartis and Amgen, convened a series of think tanks in North America and Europe throughout 2018, which included a total of roughly 70 global thought leaders across medicine and science, patient advocacy, health and aging policy, cardiovascular diseases, technology, home care, hospital management and administration, and marketing and communications (see APPENDIX). Consensus support was achieved on the goal of the think tanks to connect Heart Failure (HF) to aging as a driver for reframing and reimagining the condition. Over the course of the three roundtables, conversations focused on the HF-aging connection through the lenses of communications, health systems policy, and the economic and societal burdens of hospitalization, readmissions, and caregiving. Think tank participants agreed that the increasing global prevalence of HF, driven by demographic aging, underscores the urgency of raising the visibility and priority of this condition and of addressing it in new ways.

Heart Failure in the Context of Aging

For the first time in the history of humanity, global society has reached the milestone of more old than young. It is in this context that HF's impact on longevity, quality of life, healthcare budgets, as well as social and economic well-being and participation can be better understood, measured and addressed. And, since aging itself is not one point in time but a lifelong process during which interventions at any time can enable people to live healthier, more active, and more productive lives, it also presents a framework to consider new solutions for HF at various stages where intervention can make an impact: from at-risk populations, where wellness and prevention strategies are paramount; to the earliest stage of HF, where early detection, diagnosis and treatment are valued levers; to the later stages of HF, where symptom alleviation joins treatment and lifestyle improvement in improving quality of life for patients and reducing potentially costly hospitalization, readmission, and caregiving burdens.

The global conversation on aging and health holds more potential for achieving transformative change today than ever before, partly as a consequence of the new World Health Organization Ageing and Health Strategy and the Decade of Healthy Ageing: 2021-2030. One of the strategy's top priorities is to address the growing societal and often self-inflicted ageism against older people; the strategy calls for a campaign to change this culture of ageism. In this context, cardiovascular conditions – with their close association with aging – are too often assumed to be a normal part of aging and therefore are not given the priority or urgency that they merit. While cardiovascular conditions like HF do in fact increase in prevalence with age, steps can be taken to prevent and treat and these conditions. By addressing this ageism – and the stigma associated with many of the health conditions that increase with age – we can bring HF out of the shadows, more fully understand its impact, encourage better detection, diagnosis and treatment, and avoid the costly consequences.

Multi-Stakeholder Consensus on Current State and Changes Needed in Heart Failure

Although think tank participants represented various backgrounds and levels of expertise on the topic of HF, consensus was achieved regarding the current framing of HF and barriers that must be overcome in reimagining the condition. Key challenges include:

HF is not prioritized by key stakeholders because it is not well understood by those most affected, including patients themselves. According to think tank participants, HF is currently not given the priority and attention it deserves among cardiovascular diseases for geriatrics/ gerontology, general medicine, nursing, or even the heart-disease-focused organizations, which contributes to it being neglected or misunderstood by many patients. This is due to various factors, including the widespread challenge of clinical inertia in addressing HF, difficulty in identifying and diagnosing HF patients, reluctance of some patients to confront the reality of HF, and challenges of quantifying disease progression and associated symptoms for HF as compared with other cardiovascular conditions, such as hypertension or coronary artery disease.

HF is often dismissed a normal part of aging, which results in patients falling victim to ageism – from society, healthcare providers and themselves. Since HF is a condition of aging, increasing in prevalence with age, it is too often assumed to be a natural part of aging and therefore implicitly accepted. This ageist perception of the condition leads to a fatalism that results in under-recognition, under-reporting – and when it is reported to physicians – a lack of urgency to optimize treatments.

The complexity and progression of HF make communications difficult. HF is implicitly wrongly understood as having one frame when in fact there is a progression starting from the at-risk stage to the earliest stage of HF and on to more advanced HF. And yet, at almost every stage, intervention can help maximize quality of life while living with the condition.

Stakeholders who should be active in today's HF dialogue currently lack information and the tools to motivate action. Healthcare professionals, policymakers, patients, caregivers and the general public need more and better information about (1) risk factors for HF and lifestyle changes that can help delay or prevent the onset of HF; (2) the most effective tools for screening, identifying and diagnosing HF; and (3) ways to ensure effective HF management across the care ecosystem, including access to the best integrated care, adherence to evidence-based care according to clinical guidelines, and efficient care transitions.

HF too often results in high hospitalization rates and cost burdens, which could be reduced or altogether avoided with more effective care. Without a committed focus on improving patient education and care, HF has the potential to generate unsustainable costs and care requirements, based on the rising prevalence correlated with aging and the existing high rates of hospitalization.

Clear and powerful messaging is needed to engender support from policy makers at the national and multilateral levels and prioritization of investing in HF prevention and treatment. Although information exists regarding the prevalence of HF and its associated costs, there is a need for compelling, persuasive and evidence-based messaging aimed at motivating action by health policymakers at the national and

multilateral levels to elevate the priority of HF vis-à-vis other health challenges, ensure that it is adequately resourced, and optimize evidence-based patient care, especially in light of the increasing prevalence and costs of HF as societies continue to age.

PART II: KEY ACTIONS AND AUDIENCES

Creation of a Global Heart Failure Alliance

Think tank participants mapped a set of action items to help change the conversation on HF for priority stakeholder audiences and committed themselves to advancing these objectives together through the work of a **Global Heart Failure Alliance**. Participants recognized that the issue of HF is wide-ranging across society and therefore needs wide-reaching, cross-sector, and cross-discipline leadership to begin to change the HF conversation and create a sense of urgency.

Driving a New Conversation on Heart Failure

Think tank participants identified opportunities for reshaping messaging tailored to various key stakeholder perspectives. With the diverse backgrounds and areas of expertise represented, they explored ways to make progress toward reaching each audience. In the end, they identified an explicit set of priority groups toward which to focus the new conversation on HF, as well as several key insights regarding these groups' many connections to HF:

- **Policymakers** were identified as a key stakeholder audience, given their ability to bring about healthcare model transformation to ensure more integrated, multi-disciplinary care delivery. Participants noted that policymakers would be integral in developing strategies at the global, national, and local levels, ensuring policies are tailored to communities, and addressing age discrimination as a barrier to treatment.
    - One gerontologist from the Brussels think tank noted, *"There's an evidence base on effective treatment for heart failure but a lack of uptake. The biggest policy change would be to remove age discrimination-related barriers to heart failure treatment."*
    - One advocacy specialist from the Chicago think tank stipulated, *"As we engage policymakers, we must think about what a plan of action looks like at a global, national, and local stage. The awareness we raise, and the requests we make of public officials, must be actionable and tailored to the needs of their communities."*

- **Healthcare Professionals**, because their communication (or lack of communication) of HF can fundamentally shape how HF is understood, diagnosed, acted upon, and prioritized. For instance, the point of diagnosis provides an important opportunity to properly frame HF as a progressive disease that requires early and ongoing intervention. However, think tank participants pointed out that communication to patients at this time is often unclear and does not spur action.
    - Two New York think tank participants from vastly different industries—nursing and communications—agreed that: *The biggest bang for your buck is getting doctors, NPs, and other healthcare professionals to be as likely to diagnose and talk about heart failure as they would hypertension.*

- **Patients and Patient Advocates** can help to realize the opportunities linked to the aging of society; both for themselves and the wider patient community. HF and healthy, active aging are organically connected with and through patients. Therefore, participants reaffirmed that patients and patient advocates will be essential to the Global Heart Failure Alliance and its implementation.
    - Two Chicago think tank participants representing research and caregivers noted: *Data from studies is lightyears away from the interactions patients are having with clinicians and caregivers, and the emotions that are part of diagnosis and care can provide critical insight into how patients react to HF*.
    - Another Chicago participant highlighted the success of cancer advocates: *"Many fewer patients suffer from cancer than cardiovascular diseases, but cancer has been able to catch the attention of patients as advocates. We don't have enough patient advocates."*

- **Caregivers** can play a critical role at the intersection of HF and aging. Caregivers are essential given their day-to-day responsibilities in managing care, their embodiment of the many rapidly growing societal burdens of HF, and their crucial role in the health system to prevent unnecessary and costly hospitalizations and/or readmissions related to HF.

    - As a healthcare quality specialist from the Chicago think tank argued, *"Caregivers have to feel empowered, and must be educated sufficiently on HF in order to reduce unnecessary and costly trips to the ER."*
    - A home care provider from the New York think tank noted, *"Somebody with heart failure might spend an hour a day on strictly medical care—a doctor's appointment, or medication management, for example. Home care asks, 'What happens during the remaining 23 hours? How do we prevent social isolation or other conditions that might lead to deteriorating health in people with heart failure?'"*

- **Non-traditional Partners**, which were represented among participants in the three 2018 roundtable discussions, would be valuable for helping to share new messaging on HF. For instance, leveraging potential technology partners and others would help build bigger, more complete data sets to better understand what people at all stages of HF are experiencing. Innovative technology solutions are also important in helping HCPs detect and diagnose HF and in monitoring HF patients at a distance. Also, employers as a constituency to bring attention and awareness to HF could help those at risk identify signs early on and be a partner in helping their employees with or at risk of HF (and their caregivers) access the most effective and appropriate interventions.

    - As a participant from the technology sector explained in New York: *"We can expand current systems to incorporate value-based design. We can use telemedicine to ease the burden around medication adherence, for example. With a little bit of policy and a little bit of tech, we can save system costs and increase the 'health span.'"*

PART III: VISION AND OBJECTIVES

The think tanks led to the creation of a Global Heart Failure Alliance, a platform for cross-sector and cross-disciplinary action, and set out a long-term vision for reframing HF. This vision seeks to highlight the urgency of addressing HF and serves as a guide for the strategic planning that will map out the actions and collaboration of the Alliance.

Vision

To change the conversation on Heart Failure (HF) so that patients, caregivers, medical professionals, policymakers and the general public recognize the burden that HF imposes on patient quality of life, family and caregiver well-being, and healthcare budgets; the vast unmet clinical need relating to HF; and the urgency of diagnosing patients as early as possible and ensuring their access to the best available treatments.

Objectives

1. **Context of Active Aging:** HF, because of its increasing prevalence and impact as a consequence of 21st-century longevity, must occupy a prominent position in the public health conversations on healthy and active aging. To advance the dialogue and action, the connection between HF and aging must be illuminated as an opportunity to improve patient quality of life, quality care and cost reduction. And, to achieve success, the ageism that assumes HF is a natural part of aging must be acknowledged and tackled.

2. **More Effective Monitoring, Earlier Diagnosis and Action:** Earlier detection and diagnosis of HF, which includes better monitoring and analytics, must become priorities in order to encourage action from HCPs and patients and improve outcomes. Further, once a diagnosis is achieved, it is imperative that HCPs and patients alike take action toward more effective management of HF – both through care integration and the growing number of medical and technological advances available for the treatment and care of HF.

3. **Aligned and More Powerful Communications:** There must be a set of aligned communications aimed at HCPs, patients and their advocacy organizations, policymakers and the general public to increase awareness of and action on HF. This should be based upon concise, powerful messages that are understandable, persuasive, and aimed at motivating behavior change. The think tanks helped identify new key messages aligned to priority audiences.

4. **Priority for Key Stakeholder Audiences:** HF must be elevated by making it the focus of a major communications and policy platform, creating urgency due to the rapid aging of our global population. These efforts will be aimed at building awareness of HF and stimulating specific policy action to tackle it; this platform should encompass the cardiovascular health community, as well as for broader healthcare, aging, economic, and public policy leadership.

5. **Impact of HF on Social Engagement and Productivity:** The full costs and impact (both direct and indirect) of HF should be persuasively identified, described, and quantified – including direct economic costs to patients, families and health systems, and indirect costs in terms of lost productivity, presenteeism, impaired patient quality of life, the burdens on working caregivers of patients with HF, and the like. Further, we must communicate that appropriately addressing HF

can be a cost-saver in healthcare (e.g., by reducing hospitalization and readmissions rates, as well as health costs related to caregiving) and a driver of economic growth.

Next Steps for Think Tank Participants

Bringing together a new cross-section of interested parties, the think tanks led to a new multi-stakeholder consensus, to be embodied through a Global Heart Failure Alliance. The groups noted a number of next steps upon which to advance with GCOA's leadership of the effort to reimagine HF. These are actions that could be taken immediately to continue momentum from the think tanks and offer quick and progressive wins toward meeting the groups' long-term vision for HF.

1. **Fully activate the alliance**, adding new participants as we reach new audiences, to rapidly begin moving the needle on HF. We will confirm participation in the Alliance effort from all think tank participants and grow awareness to new audiences, leveraging the positioning of the issue as now a focus of GCOA's agenda.

   GCOA will convene a core group of GCOA members, led by Novartis and Amgen, to set and approve a 12-month strategy that focuses on short-term wins, bringing together more key stakeholders, and crafting GCOA's position and recommendations for policy action on HF. We would also engage key leaders in this space including World Heart Federation, European Society of Cardiology, American Heart Association, American Association of Heart Failure Nurses, Preventive Cardiovascular Nurses Association, etc., as well as non-traditional partners as identified through the think tanks, including employers, the tech sector, economists, psychologists and others.

2. **Communicate on key messages that leverage HF** as a powerful example of aging's impact on society. For instance, we will utilize a mix of data and emotive content to call for maximizing strategies to prevent hospitalizations and readmissions in HF patients and therefore reduce the burden on individual patients and health care systems. In addition, we can show HF as a powerful example of self-inflicted and societal ageism as it relates to current levels of incidence and prevalence; effective detection and diagnosis; and pick-up as a priority in national health systems. This aligns with the "ageism" focus of the WHO Ageing and Health Strategy.

3. **Launch a series of targeted and sequenced think tanks, gatherings and communications for 2019 and beyond** to strengthen the alliance, further develop messaging tailored to key audiences, and elevate HF as a priority within the aging and cardiovascular health communities. We'll expand our reach and pursue a truly global effort with a focus in LATAM and Asia, in addition to Europe and North America.

4. **Explore potential partnerships between and among various think tank participants**, including technology players, medical community, survey researchers, and employer community.

5. **Ensure all Alliance work builds on existing materials and progress** from the experts across the HF ecosystem, whether at ESC, WHF, AHA, the European Parliament or other such bodies.

CONCLUSION

The think tanks held throughout 2018 across North America and Europe defined a major opportunity to coalesce a new HF community comprised of multi-sector and multi-disciplinary thought leaders. Participants agreed to pursue an ongoing effort with global influence to include communications between and among the groups to facilitate partnerships and execute upon these key actions for reimagining and reframing HF.

APPENDIX: THINK TANK PARTICIPANTS

17 April 2018 | New York City

- Emmanuel Akpakwu, Practice Lead for Value Based Healthcare and Healthcare Strategy, **World Economic Forum**
- Holly Andersen, Director of Education and Outreach, Ronald O. Perelman Heart Institute, **NewYork Presbyterian Hospital—Weill Cornell Medical Center**
- Christine Beer, Program Director, Health Leadership Council, **The Conference Board**
- Cynthia Bither, Immediate Past President, **American Association of Heart Failure Nurses**
- Sandra Blum, Global Head Patient Advocacy—CardioMetabolic Franchise, **Novartis**
- Carlos Castro, President, **Ale Association, I.A.P.**; President, **International Heart Hub (iHHub)**
- Colleen Conway-Welch, Dean Emerita, **Vanderbilt University School of Nursing**
- Allyse Depenbrock, Campaign Director, **Ad Council**
- Jean-Luc Eiselé, CEO, **World Heart Federation**
- Mark Farnworth, Worldwide Associate Director, Digital & Social Media, **Novartis**
- Greg Fulton, Industry, Policy & Content Lead, **Philips Wellcentive**
- Maciej Gajewski, Director, Global Franchise Public Affairs, **Novartis**
- Alex Gallafent, Design Director, **IDEO**
- Michael Hodin, CEO, **Global Coalition on Aging**
- Neil Johnson, CEO, **Croí—The West of Ireland Cardiac & Stroke Foundation;** Board of Trustees, **International Heart Hub (iHHub)**
- Sue Koob, CEO, **Preventive Cardiovascular Nurses Association**
- Norm Linsky, Executive Director, **Mended Hearts/Mended Little Hearts**
- Philip McNamara, Director, US Cardiovascular Communications, **Novartis**
- Melissa Mitchell, Executive Director, **Global Coalition on Aging**
- Nick Padula, Vice President Strategic Solutions, **Philips Healthcare**
- Bob Perkins, CEO, **Sharp Arrow Consulting**
- John Rowe, Chair, **International Association of Gerontology and Geriatrics;** Julius B. Richmond Professor of Health Policy and Aging, **Columbia University Mailman School of Public Health**
- Dave Ryan, General Manager, Health & Life Sciences Sector, Internet of Things Group, **Intel Corporation**
- Ilse van Hensbeek, Global Medical Director for Cardiovascular Disease, **Amgen**
- Jeff Watson, Senior Consultant, Clinical and Integrated Networks, **Home Instead Senior Care**
- Durhane Wong-Rieger, Chair, **Rare Disease International;** President & CEO, **Canadian Organization for Rare Disorders**

6 September 2018 | Brussels (Aligned with the Heart Failure Policy Network Handbook Launch)

- Esko Aho, Executive Chairman of the Board, **East Office of Finnish Industries**; former Prime Minister of Finland
- Paola Antonini, Head, Clinical Research, **Italian Association of Heart Failure Patients (AISC)**
- Sandra Blum, Global Head Patient Advocacy—CardioMetabolic Franchise, **Novartis**
- Sabina Brennan, Principal Investigator, **ADAPT Centre Trinity College Dublin**
- Emmanuele Degortes, Global Head of Patient, Innovation and Access Policy, **Vifor Pharma**

- Salvatore Di Somma, Professor of Internal Medicine, Cardiologist and Internist, **Sapienza University of Rome**
- Andras Fehervary, Executive Director of Advocacy Relations Europe, **Amgen**
- Maciej Gajewski, Director, Global Franchise Public Affairs, **Novartis**
- Manfred Gogol, Treasurer, **Geriatric Medicines Society**
- José Ramón González-Juanatey, Director, Cardiology and Intensive Cardiac Care Department, **University Hospital, Santiago de Compostela;** Past-President, **Spanish Society of Cardiology**
- Hans Groth, Chairman of the Board, **World Demographic & Ageing Forum, St. Gallen/Switzerland**
- Michael Hodin, CEO, **Global Coalition on Aging**
- Neil Johnson, CEO, **Croí—The West of Ireland Cardiac & Stroke Foundation;** Board of Trustees, **International Heart Hub (iHHub)**
- Annekatrin Krause, Global Patient Engagement Manager Pharma, **Novartis**
- Steven Macari, President, **Association Vie Et Coeur**
- Sara Marques, Senior Researcher, **The Health Policy Partnership**
- Tijs Neutens, Senior Manager, Corporate & Public Affairs Belgium, **Amgen**
- Ian Philp, CEO, **EasyCare Group;** Professor of Global Ageing, **University of Stirling**
- Mario Romao, Global Director, Health and Data Policy, **Intel**
- Marieke van der Waal, Director, **International Longevity Center—The Netherlands**
- Patricia Vlasman, President, **Let the Beat Go On**
- Marc Wortmann, CEO, **Marc Wortmann Consultancy**; former Executive Director, Alzheimer's Disease International
- Faiez Zannad, Professor of Therapeutics, **University of Lorraine;** Head of the Division of Heart Failure and Hypertension, **Institut Lorrain du Coeur et des Vaisseaux**

11 November 2018 | Chicago (Aligned with the American Heart Association's Scientific Sessions)

- Geri Lynn Baumblatt, Health Communication and Engagement Consultant, **Articulations Consulting**
- Sandra Blum, Global Head Patient Advocacy—CardioMetabolic Franchise, **Novartis**
- Michele Bolles, National Vice President, Programs and Operations, Quality and Health Information Technology, **American Heart Association**
- Carlos Castro, President, **Ale Association, I.A.P.** President, **International Heart Hub (iHHub)**
- Stephen Dentel, National Director, Field Programs and Integration, **American Heart Association**
- Daniel Forman, Chair, Section of Geriatric Cardiology, Divisions of Geriatrics and the Heart and Vascular Institute, **University of Pittsburgh Medical Center**
- Maciej Gajewski, Director, Global Franchise Public Affairs, **Novartis**
- Tim Goodman, Director of Global Advocacy Relations for Cardiovascular and Metabolic Disease, **Amgen**
- Michael Hargrett, Director, Strategic Engagement, **American College of Cardiology**
- Michael Hodin, CEO, **Global Coalition on Aging**
- Sue Koob, CEO, **Preventive Cardiovascular Nurses Association**
- Philip McNamara, Director, US Cardiovascular Communications, **Novartis**
- David Meltzer, Fanny L. Pritzker Professor in the Department of Medicine, the Harris School of Public Policy Studies and the Department of Economics, **University of Chicago**
- Melissa Mitchell, Executive Director, **Global Coalition on Aging**
- Peter Murray, Founder and CEO, **EmotionInc**

- Kim Newlin, Director of Cardiovascular Services, Cath Lab, Interventional Radiology, and Specialty Clinics, **Sutter Roseville Medical Center**
- Nick Padula, Vice President Strategic Solutions, **Philips Healthcare**
- Simona Sappia, Global Head of Communications, Commercial and Medical Affairs, **Novartis**
- Mark Schoeberl, Executive Vice President, Advocacy, **American Heart Association**
- Michael Springer, Chief, Executive Relations, **Philips Healthcare**
- Jacqueline Tomei, Quality Programs Manager, National Center, **American Heart Association**
- Andrea Vassalotti, Director, Partnerships and Programmes, **World Heart Federation**
- Jeff Watson, Senior Consultant, Clinical Integrated Networks, **Home Instead Senior Care**