Advocacy initiatives at ESC Congress: focus public & patient

Elisabetta Zanon, ESC Advocacy Director

ESC Congresses Industry Forum
Congresses in an evolving environment

European Heart House, 6 June 2019
Overview

- ESC Advocacy
- ESC Patient Engagement
- Patients at Congress
- Advocacy events during ESC Congress
ESC Advocacy
The burden of CVD is immense, greater than any other condition, yet CVD does not receive the attention decision-makers reserve for other diseases.

ESC Advocacy aims to bring CVD health higher up on decision-makers’ agenda.

Challenge wrong perception that CVD is no longer a public health priority and that it is only a lifestyle disease.

Bridge science and policy: bring scientific knowledge to decision-makers to inform evidence-based policy favorable to CV health.
ESC Advocacy priorities 2019-20

- MEP Heart Group & Call to Action on CVD
- Seek to influence EU Presidencies priorities
- Implementation of new Medical Devices Regulation
- Task Force on CIEDs and GDPR
- Health Technology Assessment at EU level
- Regulatory framework to support clinical trials (ICH-GCP revision)
ESC Patient Engagement
Why Patient Engagement in ESC activities?

✓ Patients as key partners to achieve the ESC mission

✓ Patients are the experts on what it means to experience heart disease

✓ They can offer valuable insight that is different and complementary to that of healthcare professionals

✓ The ambition is to involve patients in all areas of ESC activities, which could benefit from patient input
Mechanism to engage patients across ESC activities

Patient Forum members identified by ESC clinicians, NOT existing patient organisations

Experience of different cardiac conditions: coronary artery disease, heart failure, valvular heart disease, cardiac sarcoidosis, AFib, Open-heart surgery & heart transplantation

Members are involved in personal capacity, not as representatives of a patient group/organisation

Around 30 active members; ensure sufficient capacity and experience in a range of CVD conditions
Patients at ESC Congresses

ESC and subspecialty Associations willing to involve patients in Congresses

BUT...

- Legal restrictions: Directive 2001/83 forbids advertisement to the general public of medicinal products available only on medical prescription
- Different interpretation/implementation of the Directive in the EU Member States
- Sanctions for non compliance are determined individually by each Member State
- Implement stepwise approach with patients at Congresses
- Views of industry partners sought
Patients at ESC Congress 2019

- Ten patients will be invited to participate (not open invitation to patients)
- Access to Plaza and Global Exchange area only
- Easily identifiable badges
Patient Session – Global Exchange area

Patient involvement: unleashing the potential for true excellence in cardiovascular care

Chair: Prof Donna Fitzsimons, ECS Patient Engagement Lead

- Involving patients in professional societies: Evolution or revolution?
- Patients at the table: What are the advantages of engagement?
- I am a patient representing other patients: the challenges I see, the opportunities I want
- A team that works: healthcare professionals, patients and carers
- Q&A
Public Event during ESC Congress
Public Event during ESC Congress 2019

- **DATE**: 31st, August 1st, September
  - From 10am to 5pm
- **PARTICIPANTS**: 10,000 participants expected
- **VENUE**: Paris, Hôtel de Ville
- **OBJECTIVES**: Raise public awareness of cardiovascular disease
The Heart of Paris Beats Stronger
Global View

- Marking barriers covered in the colors of your event
- Entrance arches
- VR Area
- Central covered stage
- Catering Area
- "Living with Cardiovascular Disease" Area
- Area Measure and advice
- Playground with a "heart" toboggan
- Area Sport & Activities
- Ground sticking representing the arteries from the heart to the different areas

Non-contractual view
Activities Area by Area

CATERING AND NUTRITION AREA

A place where participants can eat with a specially adapted choice of healthy drinks and snacks. The space will also include a corner giving nutrition advice.

SPORT & ACTIVITIES AREA

An outdoor area, equipped with sports equipment, and a coach to motivate participants to perform exercises.

“LIVING WITH A CARDIOVASCULAR DISEASE” AREA

This space dedicated to people living with cardiovascular diseases will allow them to be better guided in the management of their disease on a daily basis (how to eat better, lose weight, exercise, etc.).
Under a geodesic dome, your participants are invited to participate in a virtual reality experience plunging them into a human artery.

A space to better detect individual risks of cardiovascular disease and better identify risks.

Equipped with a screen and sound system, the stage will be setup in the middle of the Hôtel de Ville square, and will host conferences, concerts, etc.
Heart Healthy Cities initiative
Heart Healthy Cities initiative: Overview

- Partnering between ESC and Congress host cities
- Capitalise on presence of 30,000+ CVD experts
- Bridge science and policy to address the **URBAN CVD CHALLENGE**
- Urbanised environment (air/noise pollution) & lifestyle (stress, fast food, physical inactivity) are major determinants for CVD

Main objectives:
- **RAISING CV HEALTH HIGH ON THE POLICY AGENDA**
- **CONCRETE ACTION TO REDUCE THE CVD BURDEN**
Heart Healthy Cities - Paris 2019

- Round Table at City Hall, Monday 2 September 14h00-18h00
- Local politicians and scientists to debate CV health challenges in urban areas and identify responses
- Scientific evidence to inform & support local policies in favor of CVD health
- Two topics:
  - Air pollution and CVD
  - Emergency preparedness & first aid (defibrillators, CPR..)
Heart Healthy Cities - Paris 2019

- Broad media and communication activities to complement the round table

- Heart Healthy Cities CALL TO ACTION, signed by CVD scientific community, calling Mayors to take bold and urgent action to address the CVD urban challenge

- Press conference to coincide with the release of the Call to Action

- SYMBOLIC HANDOVER - Passing of “heart shaped testimony” from City of Paris, to City of Amsterdam and London (legacy of the initiative)
Amsterdam 2020 & London 2021

- Programme to be decided in partnership with Amsterdam and London
- Congress Host City to adapt approach and focus in line with their local policy priorities and initiatives