# Advocacy initiatives at ESC Congress: focus public & patient

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**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**

#### **ADVOCACY, AN ESC STRATEGIC PRIORITY**



- 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 evidencebased 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)

Challenges and Opportunities for Cardiovascular Disease Research Protect Research Agenda for Cardiovascular Disease (BAA CVD)





# **ESC Patient Engagement**

#### Why Patient Engagement in ESC activities?

ESC European Society of Cardiology

- 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



#### **ESC Patient Forum**



- 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**

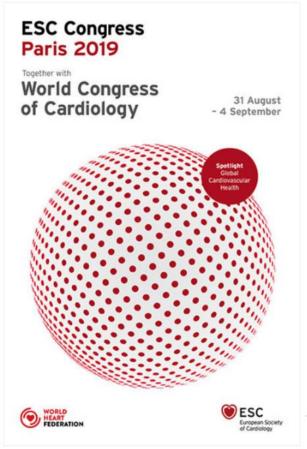


# ESC and subspecialty Associations willing to involve patients in Congresses BUT...

- 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

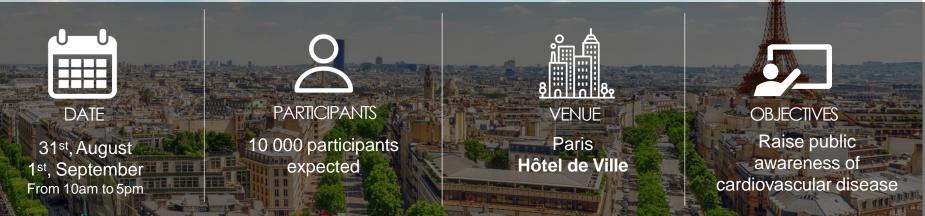
- Involving patients in professional societies: Evolution or revolution?
- Patients at the table: What are the advantages of engagement?
- I am a patient representing other patients: the challenges I see, the opportunities I want
- A team that works: healthcare professionals, patients and carers
- Q&A



# **Public Event during ESC Congress**

### **Public Event during ESC Congress 2019**

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### The Heart of Paris Beats Stronger



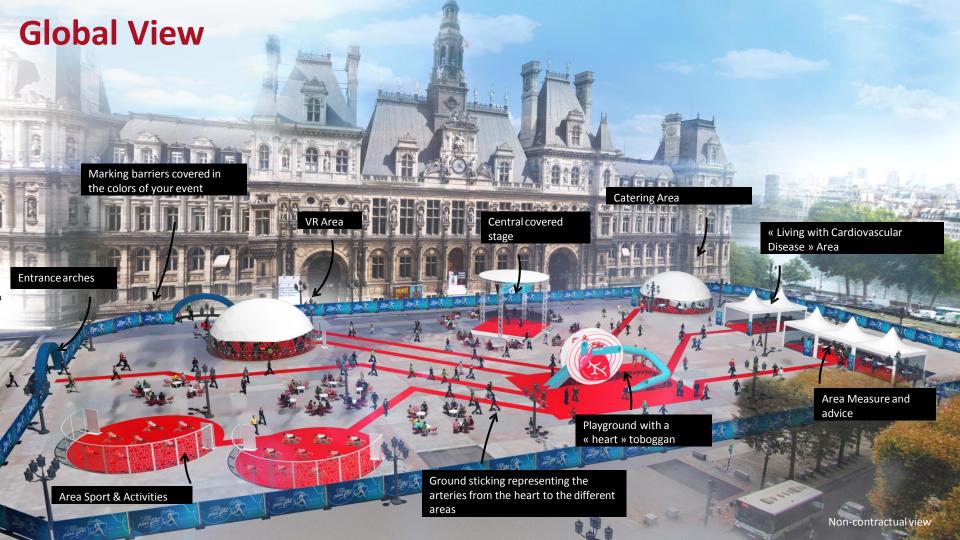
ESC European Society of Cardiology

#### Les 31 août et 1<sup>er</sup> septembre 2019

SUR LE PARVIS DE L'HÔTEL DE VILLEDE PARIS

#### Animations

Conseils santé / Activités sportives Réalité virtuelle /Conférences / Conseil nutrition Détection de maladies cardiovasculaires Course à pied



#### **Activities Area by Area**



CATERING AND NUTRITION AREA

A geodesic tent of 95 sq.m Diameter 11m

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

2 zones of diameter 10m

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



"LIVING WITH A CARDIOVASCULAR DISEASE" AREA

> 2 marquee tents 5m x 5m

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.).



#### **Activities Area by Area**



#### **DISCOVERY AREA**

A geodesic tent of 95 sq.m Diameter 11m

Under a geodesic dome, your participants are invited to participate in a virtual reality experience plunging them into a human artery.



MEASURES AND ADVICE AREA

> 3 marquee tents 5m x 5m

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



#### THE CENTRAL STAGE

Square scene (width of 8m) 64 seats

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

