



WORLD HEART  
FEDERATION®

25



25

## 2<sup>nd</sup> Global Summit on Circulatory Health

Building a civil society  
movement including the  
patient voice

**Tony Duncan** (Heart Foundation of New Zealand)

**Durhane Wong-Reiger** (Canadian Organization for Rare Disorders)

# Panellists

- **Katie Dain**, NCD Alliance
- **Habib Gamra**, African Heart Network
- **John Meiners**, American Heart Association
- **Rajakanth Raman**, Rainbow Across Borders
- **Hung Yong Tay**, Singapore Heart Foundation
- **Maciej Tomaszewski**, International Society of Hypertension

# Setting the Scene

## Where we are now

- Lethargy, dormant diseases, hibernation
- Concerns with workshop title: *'including patient voice'* shows that this is not integral part of our work

## We need to be ready with:

- Arguments backed up with evidence and data.
- Messages for policy makers that speak to the head, heart and pocket.

## Where we want to be

- Urgency & outrage
- Reframe the issue: burning platform of health justice
- Tell the stories of the crisis moments
- Need to galvanize the public & get policy makers' attention

# Action Points

## Reframe the issue as urgent – ‘burning platform’

- Health *justice* (rather than health equity)

## Prominent CVD Champions

- Create a cadre of prominent CVD advocates who can raise awareness

## Invest resources in training patient advocates

- Invest time & money in providing patients with speaker training, the policy framework and the evidence base

# Action Points

## World Heart Day

- Use WHD to create urgency for the UN HLM in 2018

## Build coalitions

- Many CVD organizations exist within one country - build coalitions to unify goals, messages & actions

## Include patients in decision-making processes

- Ensure patients have a voice in setting policies, goals, research

# Key considerations & guiding principles

- Take a holistic approach (psychosocial impact too)
- Understand the whole patient journey
- Look beyond the event, also at management and rehabilitation
- Include families & caregivers
- Include all stakeholders (e.g. incl traditional medicine)