Helping heart patient advocates shape policy

How can cardiovascular patient organisations achieve political impact?

Navigating complex political systems at national and international level can be daunting. Smaller patient advocacy groups may find it challenging to access decision-makers and to persuade them to take action. The policy environment can be highly competitive and is increasingly professional, requiring significant investment of time, energy and resources.

However, patient organisations, large and small, have recorded significant achievements. Taking a long-term approach is key to delivering lasting change. Focusing on a small number of clear and resonant messages, delivered repeatedly to a wide range of audiences, can move a niche issue into the mainstream.

Top tips for driving policy change

1. Understand the levers of power: map decision-makers and stakeholders
2. Identify potential partners and political champions
3. Convince policymakers that they will benefit from supporting you
4. Set achievable milestones towards your ultimate policy goals
5. Build long-term links with politicians and officials across the political spectrum

At the heart of this work is relationship building: coalitions achieve more together than individual organisations can do alone. Making connections with people in power, as well as opposition politicians, helps to ensure progress is not lost if there is a change of government. Whether engaging with political decision-makers or advocacy allies, make your goals meaningful to others. Politicians and coalition partners need publicity and to deliver for their constituents: give them a 'win' in return for support. Above all, political advocacy is about human connection. It is a process that requires patience, persistence and consistency.

Case studies - learning from other advocates

Winning a tobacco policy battle in Jamaica

Jamaica signed the WHO Framework Convention on Tobacco Control in 2003. However, legislation to turn the treaty into national law is still not in place. The Heart Foundation of Jamaica led a sustained campaign to convince lawmakers to implement key elements of the policy, despite resistance from industry. Jamaica amended the Public Health Act to introduce graphic health warnings on tobacco products and laws on smoke-free environments.

‘Our campaign to pass all measures at once was a constant battle,’ says Dr Deborah Chen, Executive Director, The Heart Foundation of Jamaica. ‘So, we decided to push towards a half-way point to give us something to build on.’ This required regular engagement with the media and direct communication with political champions to equip them with data that refuted industry talking points. ‘You need to be credible, to build alliances and to understand the levers of change,’ she says.

Putting rare diseases on the UN agenda

In December 2021, the United Nations adopted the UN Resolution on Addressing the Challenges of Persons Living with Rare Diseases and their Families – the first of its kind to focus on rare health conditions. It was a monumental breakthrough for a policy area which has often been overlooked. More than that, it marked a major achievement for rare diseases advocates because, within the UN system, health is primarily the responsibility of the World Health Organization (WHO).

‘We wanted to have a holistic approach that addressed the broad spectrum of issues facing people affected by rare diseases,’ says Flaminia Macchia, Executive Director, Rare Diseases International. ‘Our challenge was to make rare diseases relevant to the UN.’ This was achieved by linking rare diseases with the UN Sustainable Development Goals, engaging with countries’ permanent missions to the UN in New York, and convincing governments to become sponsors of the proposed Resolution who would advocate on behalf of the rare disease community. ‘It is a big step forward, but the adoption of the UN Resolution is the beginning, not the end,’ says Ms Machia.

Moving gender and ethnicity to the heart of US research funding

In the 1990s, healthcare advocates in the United States set out to tackle a long-standing problem: clinical trials had too few female participants and low inclusion of people from ethnic minority communities. They identified the National Institutes of Health (NIH), largest single public source of health research funding in the US, as a key body that could reshape the clinical trials landscape.

By working together, a broad range of partners, including patients, families, clinicians, employers and others lobbied members of Congress to change federal legislation. As a result, the NIH now requires funding applicants to report data on the gender and ethnicity of people taking part in trials. ‘We found allies, identified the decision-makers, prepared talking points, and we got our message out,’ recalls Gwen Mayes, Health Consultant, Patient Advocate, and Patient Story Coach. ‘There is still much to be done: we achieved a legislative milestone, but this work requires continuous monitoring and follow-up to ensure implementation.’

Changing how the EU collects patient registry data

Data from patient registries can be a powerful tool for assessing the safety and efficacy of medical interventions, as well as providing valuable insights for authorities making reimbursement decisions. However, individual registries sometimes operate in silos rather than pooling data with other registries. Part of the problem is that information is collected and processed in a variety of ways, making it technically challenging to share registry data.

‘We proposed a minimal dataset that would be collected by all registries in a standard way,’ says Christoph Thalheim, Patient Advocate and former Director of External Affairs at European MS Platform. ‘We made the case at the European Medicines Agency (EMA) through its Patient and Consumers Working Party, leading to the Patient Registries Initiative which set out criteria for all registries to follow.’

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