

# Patient advocacy – working together to get what you want



**Tamsin  
Rose,  
Tamarack  
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Two impatient boys find a solution to one spoon with chocolate cake mix

# The key elements for advocacy

The problem (What is happening/when/why)

What do you want to achieve

The audience (stakeholders)

The information/evidence/data

Your key messages (what you want)

Personal stories (how it affects you, why it matters)

Actions

Communication tools

# Successful advocates communicate

- Why change is needed and why now.
- What you want to happen and how things will be different.
- Who will benefit and who will lose out.
- What it will cost and who will pay for it.
- What you want someone to do and when they should do it.
- How you will help them.

# The framework for action

- ❖ Understand the potential winners and losers of a change.
- ❖ Identify appropriate windows of opportunity for advocacy.
- ❖ Build coalitions and alliances to multiply the impact of messages.
- ❖ Develop arguments appropriate to target audiences.

# Fire safe cigarettes

2006 EU RIP cigarette alliance – modelled on national fire-safe cigarette alliances.

Brings together fire safety, children's rights campaigners, anti-tobacco groups, family and women's groups, health and housing NGOs.

2008, European Commission defines the safety requirements and asks CEN to develop relevant standards for national implementation under the General Product Safety Directive

November 2011 New standards published – saving an estimated 500 deaths per year in EU

# Creating space for all voices for be heard

A global network 90 international and local NGO, advocates for effective, sustainable local solutions on improving access to water and sanitation and water resource management.

The network speaks not on behalf but rather supports its members to voice the views of the sector in strategic water-related international fora (World Water Forum, Agenda 2030, climate change conferences, etc.) in order to influence consistently the political agendas of water-related issues



# IFOAM – a decade of advocacy for organic food and farming

**Preventing the acceptance of GMO traces in non-GMO seed** together with civil society and environmental NGOs in 2005. The fight to make Europe GMO-free continues.

**Avoiding an EU Ecolabel for food in 2012** which would have caused consumer confusion and unfair competition for the organic label. Maintaining recognition of the most environmentally friendly and sustainable food system available was key to this success.

**Founding a research & innovation platform, and obtaining official recognition:** Year 2007 marked the start of what has become an influential advocacy platform for organic research & innovation, TP Organics, with more than 70 organisations involved.

**Keeping private standards alive** by ensuring EU Organic Regulation (EC) No 834/2007 agreed in 2007 allowed private standards to continue to be the frontrunners they are.

**Presenting almost 200 common positions** to decision-makers, founded on the diversity of organic producers and operators. This is the movement's and IFOAM EU's strength!

**European organic congresses and conferences** attended by high-level policy makers and authorities, and recognised as key events for being informed of Europe-wide developments, for providing input to IFOAM EU positions and for networking.

**Giving organic processors and farmers a voice** within IFOAM EU, and making sure that they have space to form positions on issues relevant to their unique needs, by setting up interest groups for organic processors (2006) and farmers (2012).

**Leading organic processing** by calling for environmental performance standards to be introduced for organic processing and trade, and pushing for stricter definition of additives used in organic production, e.g., by asking for the revision of the requirements and specific standards for organic flavours.

# Getting an Anti Discrimination Directive at EU level

After waiting 10 years for change, in 2009 the European Social Platform decided to take action:

Their campaign achieved this:

- Getting all the European NGO stakeholders to agree on the same messages through the lobbying process
- Getting the Commission to draft a Directive
- Getting some of their messages reflected in the draft Directive
- Getting a vote in the European Parliament on the Directive to go in the same direction as the NGOs thinking



# How did they do it?

- Build an alliance of social NGOs (in the broad sense) to put pressure on the Commission to prepare a draft Directive.
- Work with MEPs to gain their support and help to put pressure on Commission.
- Work with national Ministers of Social Affairs where possible
- Work with all the NGOs to build arguments, facilitate agreement on actions and key messages, building trust among to ensure maximum information sharing.
- Personal meetings with prominent social affairs attaches in Brussels, meeting Ministers where possible.
- Create a pool of anti-discrimination legal experts who worked pro bono to help develop legal arguments. The NGOs and legal experts shared any leaked drafts of the Directive that they received.

# Endocrine Disruptor Chemicals (EDC)

The Endocrine Disrupting Chemical (EDC) Alliance features > 70 health and environment NGOs.

The Commission has published criteria to identify EDC in regulations on pesticides and biocides.. But Member States and NGOs want the Commission to have a consistent approach to **EDC across all EU regulations.**

What is not properly covered yet:

- toys;
- cosmetics;
- food contact materials; and
- construction products.

The Alliance has set out 8 'essential elements' that must be in an EU Strategy on EDC.

# Gearing up for the European Parliament 2019 elections

NGOs coming together to support victim's rights, including women, children, migrants, older people. Their plans to collaborate include:

- Create coalitions, engaging young people, creating a manifesto (ex. European week of action for girls)
- Address issues of framing, bringing together research on framing and messaging, especially in certain countries.
- Establish women in politics working group in all member states requesting that all countries have parity.
- Launch a tool kit to help members' campaigns (to support victims, human rights, etc.)
- Launch a training session with the European investment bank on gender budgeting. Get it onto the manifestos of parties.
- Explore how can NGOs support their grassroots members on the field.

# What do you want to advocate for?

