Community-based organizations' role in global advocacy for hepatitis C therapy

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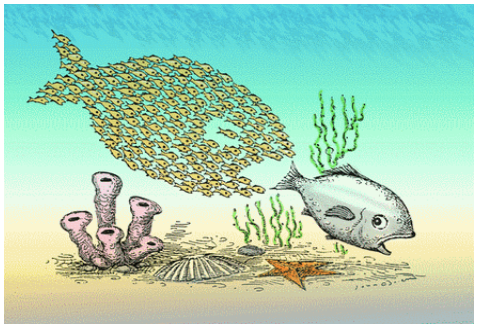
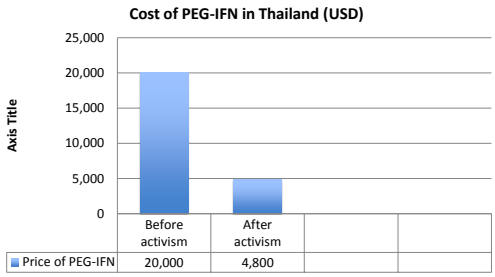
Coinfection Satellite, Melbourne

TAG
Treatment Action Group

Dedicated to Terapol Parmonbutr (1962 – 2008)



No political action without a demand



Thailand: CBOs ensure government commitment to HCV treatment

What did Thai CBOs achieve?

Universal access to healthcare (≅50,000 signatures)

Universal access to antiretroviral therapy

1. HIV and HBV/HCV Coinfection Education and ***Advocacy Manual***; trained 1000s of people with HIV, people who inject drugs, allied NGO staff

2. Provider **survey** to inform policy brief on HCV among people who inject drugs

3. Policy **advocacy** (Ministry of Public Health, National Health Security Office, Thai Liver Association, leading researchers and healthcare providers)

4. Direct action at National Health Security Office (World Hepatitis Day 2011) and letter of demands:

--switch ART regimen to TDF/3TC/EFV for PLHCV

--ensure universal access to harm reduction services

--negotiate an affordable price for treatment

--put PEG-IFN on Thai National Essential Drugs List

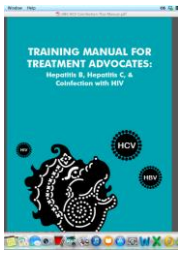
--offer HCV testing and treatment, and HAV/HBV vaccinations, to PLWHA (achieved in 2010 HIV treatment guidelines)

5. Peginterferon on national EDL

6. Peginterferon price reduction

Process

- **Getting diagnosed, talking with peers**
- **Information** – what key questions did community have?
- **Collaboration** – who could provide input, answers, support?
- **Education** – developing tools and materials
- **Outreach** – getting the information to peers
- **Mobilization** – identifying priorities, developing campaigns
- National-level **advocacy**



Key factors for CBO success

Informed and empowered network

Constructive collaborations with local actors

Valuable connections to international networks

Precedent of community organizing around national policy

The *Washington Call* (2012)

We call upon:

- **The pharmaceutical companies** - particularly Roche & Merck - to drastically reduce the price of diagnostics and treatment regimens for the estimated 170 million individuals suffering from chronic hepatitis C, particularly those with HIV co-infection.
- **Political leaders** to mobilize the adequate resources needed now and in the future--in anticipation of new HCV drugs--- to diagnose, monitor and treat high-prevalence populations, such as people living with HIV/AIDS and people who inject drugs.
- The **World Health Organization** (WHO) and other relevant United Nations (UN) agencies to develop treatment guidelines for HCV treatment for HIV/HCV co-infected people and HCV mono-infected persons in low and middle income countries and to develop a prequalification process for bio-similars that facilitates access to pegylated interferon.
- **Researchers** to gather and provide evidence on feasibility and effectiveness of treatment in low and middle income countries, with a focus on disproportionately affected populations, particularly people who inject drugs.
- **International donors** to support community mobilization and treatment preparedness and literacy, as well as treatment cost, which are crucial for access to treatment.

Key Issues

- Stigma and discrimination, criminalization, exclusion of PWID, PLWHA
- Lack of awareness, HCV knowledge among at-risk, high-risk groups TARGET: PWID, PLWHA, NGOs, GOVERNMENT
- Lack of treatment guidelines TARGET: WHO, GOVERNMENT
- Health care capacity – budgets, provider knowledge, attitudes, availability of drugs/diagnostics TARGET: GOVERNMENT, PHARMA
- Drug (and diagnostic) prices – TARGET: PHARMA, UNITAID
- Lack of adequate epi data/surveillance systems –TARGET: WHO, GOVERNMENTS
- Lack of national plans, funding – TARGET: GOVERNMENTS, DONORS (GFATM, etc.)
- Lack of biosimilar prequalification framework– TARGET: WHO
- PEG-IFN not on WHO EML – TARGET: WHO
- Lack of data on drugs and drug interactions in PWID, PLWHCV, cirrhotics, other groups frequently excluded from clinical trials TARGET: PHARMA

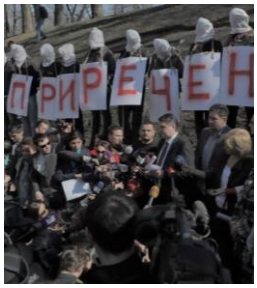
Campaigns and Activities

- PEG-IFN on WHO EML campaign
- "Have a heart, Save my Liver" Price Reduction Campaign
- 1st HCV World Community Advisory Board (CAB) meeting and report
- MISSING (WHO leadership) campaign
- World Health Assembly advocacy and briefing paper

Today, the world faces a '1996 moment' in the fight against hepatitis C…As in 1996, highly effective new therapies are coming online. Regimens containing sofosbuvir, in particular, have the potential to cure 90% of patients…after just 12 to 24 weeks of once-daily pills. But is there a plan that can link funding to delivery for those living in poverty?

– Dr. Paul Farmer, Feb. 2014

Eastern Europe



Asia

Global

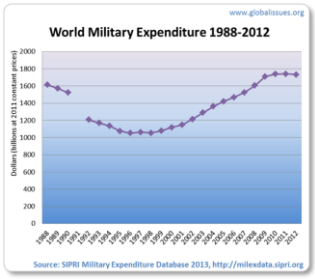
Lessons from HIV

- community mobilization – key role of civil society
- peer-led, evidence-based, rights-based
- focus on price of treatment – must have access to quality, affordable generics
- addressing underlying IP and structural barriers
- need to fight same Pharma arguments (gov. commitment, funding, infrastructure prerequisites)
- Prioritize high-prevalence/KAPs
- Build political will and secure resources (governments, others)
- nvolvement of/leadership by most affected/marginalized, and
- diverse campaign strategies including translating cutting-edge science for community use in high-level policy advocacy; alliance-building and street-based direct action/demos

Conclusion

- Engage other activists in advocating for access to HCV treatment and care (intellectual property expertise, effective networking and advocacy).
- Lessons from HIV: We need an evidence-based, community-driven, human rights approach that focuses on key affected populations
- Hold governments and institutions accountable to obligations, ethics, moral and legal imperatives
- Demand transparency and participation of communities
- Speak out against pressures on governments from external influences that try to dissuade them from exercising certain rights
- Can utilize some HIV strategies to lower the cost of HCV course of care, increasing access to quality, safe, effective and affordable HCV treatment (generics, TRIPs flexibilities, harm reduction and drug reform, structural barriers)

Global military expenditure stands at over $1.7 trillion in annual expenditure at current prices for 2012



NGOs…can support, empower and vocalize. As Paul Farmer so rightly said, 'the community is part of the infrastructure.'

-Joep Lange

www.hepcoalition.org
www.treatmentactiongroup.org