

How patient organizations can be an influential factor for HCV policies

Are drug users part of the picture?

Opportunities and ways to collaborate with PWID community

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SOME KEY FACTS:

- Current estimates are that between 7.3 and 8.8 million persons are infected with HCV in the European Union, i.e. twice as many as an estimate made in 1997 [1].
- An annual average incidence rate of 6.19 per 100,000 inhabitants (95% CI 4.90-7.48) can be estimated, based on rates reported from the European region to the WHO [2].
- Intravenous drug users are particularly exposed to the risk of HCV infection, with prevalence rates of up to 50% in Cyprus [3], 59.8% (95% CI 50.7-68.3) in France [4], 75% for those admitted for opiate detoxification in Germany and 83.2% in Italy [5].

1: Hepatitis C. Wkly Epidemiol Rec 1997;72:65–69


2: Muhlberger N, et al BMC, Public Health, 2009;9:34.

3: Demetriou VL et al J Med Virol 2010;82:263-270.

4: Jauffret-Roustide M et al BMC Infect Dis 2009;9:113.

5: Camoni L et al Ann Ist Super Sanita 2010;46:59-65.


Findings out of the European Hepatitis Index (www.hep-index.eu)

- Significant shortcomings in all categories across all countries
 - High prevalence of viral hepatitis
 - Low detection rate due to lack of consistent screening programmes, especially among high risk groups
 - Significant increase in end-stage complications of viral hepatitis (cirrhosis & HCC)
 - High inequality with regard to access to treatment within and among countries and EU regions
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How to influence policies?

Step 1 - Provide policy decision makers with high level key facts:

EASL is in all EU 28 countries accepted as the highest scientific level for facts in hepatitis. Their review of available epidemiological data published in 2013 in “The Burden of liver disease in Europe“ provides an incontestable database to confront politicians. Out of this report it is clear that the highest incidence of HCV is among PWID in EU 28.



How to influence policies?

Step 2 - Provide policy decision makers with high level screening and treatment recommendations:

Geert Robaey et al has published in 2013 the first international „Recommendations for the Management of Hepatitis C Virus Infection Among People Who Inject Drugs“ in Clin. Infect Dis.

Part of this paper is now content of the latest update of the EASL HCV guidelines.



How to influence policies?

Step 3 - Provide policy decision makers with real life and successful strategies:

The Scottish national hepatitis action plan demonstrates that after implementation of a targeted program especially for PWID, can eradicate HCV in this high risk group.



How to influence policies?

After step 1 - 3 there is no longer an excuse for policy decision makers not to care holistic for PWID.

It's time now for:

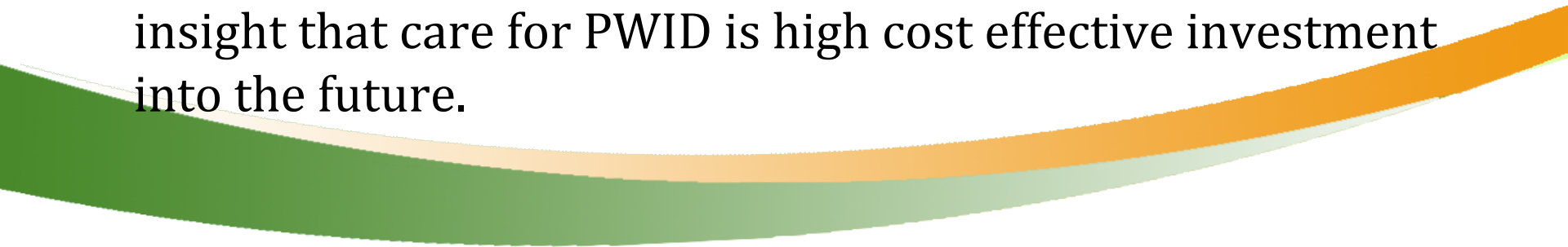
- awareness
- case finding
- access to treatment

How to influence policies?

Step 4: direct contact with national decision makers to establish holistic HCV strategy plan, which includes the biggest incidence group: PWID

ELPA has established in the last years to build up permanent negotiations with representatives from different governments and has helped to write national strategy plans.

A stable continuation of this discussions can lead to the insight that care for PWID is high cost effective investment into the future.



How to influence policies?

Step 5: all NGOs (scientific and patient organizations) has to work close together with harmonised

- **strategies**
- **messages**
- **arguments**

ELPA is more than happy to be part of this correlation networks and invites all to participate in the national activities.

ELPA

European Liver
Patients Association



THANK
YOU!

