



# The role and impact of liver patient groups in Europe on the prevention and control of viral hepatitis

*By Nadine Piorkowsky  
President of the  
European Liver Patients Association,  
13 March 2008*

# ELPA at European level



ELPA emerged from a desire amongst European liver patient groups across Europe to share their experiences of the often very different approaches adopted in different countries with regard to viral Hepatitis.

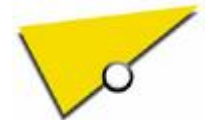
ELPA was formally launched in Paris on April 14th 2005 during the annual conference of the European Association for the Study of the Liver (EASL)

## Aims:

- increase awareness and prevention among healthcare professionals, policymakers and the public at large
- address the low profile of liver disease compared to other disease areas
- share experience of successful case examples as regards the management of the disease

# Our national members

20 members  
from 17  
countries



# ELPA: Successes in 2007



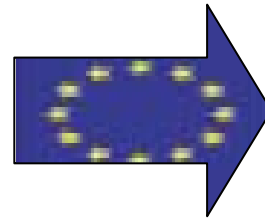
- **Adoption of Written Declaration - 470 MEP signatures, March 07**
- **ELPA Open Discussion Forum on Hepatitis C at the European Parliament as follow up to declaration, May 07**
- **Panel discussion for WHAD in the European parliament took place, co-hosted by ELPA and Stephen Hughes MEP, October 07**
- **Successful inclusion of viral Hepatitis by ECDC in 2008 work programme, December 07**



# ELPA pivotal at EU level



Outreach  
activity by  
national  
ELPA  
members



Written  
declaration  
and Hep C in  
ECDC work  
programme

# 2008: Key objectives



- Adoption of an EU Council Recommendation on targeted Screening for viral Hepatitis across Europe
- Generate reliable and comparable data across the EU, involving the ECDC
- Commitment of EU Member States to implement the future ECDC criteria on surveillance

# 2008: Key activities



- National outreach by ELPA members to secure council recommendation
- WHD 2008 awareness raising activities at national and EU level
- Engagement in dialogue with ECDC – ELPA survey on screening in member states
- Raising support for recommendation at EU level through council presidencies

# 2008: WHD 6 EU Asks



1. Adoption of an EU Council Recommendation on targeted Screening for viral Hepatitis across Europe, ensuring early diagnosis and wider access to treatment and care;
2. Commitment of EU Member States to implement the future European Centre for Disease Prevention and Control (ECDC) criteria for the surveillance of viral Hepatitis;
3. Recognition that targeted Hepatitis Screening of risk groups will effectively prevent complications, such as liver scarring and liver cancer;
4. Commitment to work in partnership with Hepatitis patient groups to ensure a coordinated campaign to raise public awareness;
5. Commitment to a European strategy to protect healthcare workers from blood-borne infections such as Hepatitis due to needlestick injuries by amending Directive 2000/54/EC on risks from biological agents at work;
6. Provision of EU funding for further research on treatment for viral Hepatitis, especially for cases of co-infection with HIV.

# Lessons & opportunities



- Since its foundation, ELPA has devoted its campaigns to **raising awareness** of viral Hepatitis
- ELPA has focused its work on the **promotion of screening** for viral Hepatitis throughout Europe
- **EU initiatives on health matters have proven to have had concrete positive effects in Member States**
- Ultimately, **the key to success is the coordination of campaigns and messages across Europe**

# The role and impact of liver patient groups in Europe



## Thank you!

Nadine Piorkowsky, President of ELPA

<http://www.elpa-info.org>

[elpa-president@t-online.de](mailto:elpa-president@t-online.de)