

European Liver Patients' Association

ELPA

Overview on EU advocacy efforts

*Presentation given by Achim Kautz,
ELPA Vice President Public Affairs*

Sofia, 5 July 2012

Presentation overview

- European Liver Patients' Association (ELPA) – a short introduction
- Hepatitis – only at the fringe of EU policymaking
- Our impact as patient advocates
- Why your initiative is crucial beyond Bulgaria

Who is ELPA & what do we do?

- An umbrella organization for patient groups, launched in April 2005, now 23 members in 19 European countries
- ELPA promotes the interests of liver patients (with a focus on hepatitis) at EU and national level, by
 - ✧ raising the low profile of the liver in relevant EU programmes and initiatives
 - ✧ identifying and disseminating best practice
- Close cooperation with medical specialists, i.e. EASL

ELPA Objectives

- Short-term: further the early diagnosis of hepatitis (currently, up to 90% of the patients do not know of their infection)
- Long-term: promote a fair access to care for all patients and eradicate health inequalities.

Hepatitis– only at the fringe of EU policymaking

➤ 2006: beginning of ELPA's EU advocacy activities with an “inventory” of relevant EU policies.

Results:

- Hepatitis only the “poor cousin” of more prominent infectious diseases;
- Focus largely on primary prevention only.

Our impact as patient advocates

➤ On the plus side

- ✧ European Parliament Written Declaration on Hepatitis C;
- ✧ Hepatitis has become an ECDC priority
- ✧ Various ELPA events in the EP on the occasion of World Hepatitis Day highlighting good practice;
- ✧ EU funding for hepatitis projects;

➤ On the down side

- ✧ European Commission and Council have not yet moved politically;

ELPA – specific projects

In cooperation with relevant experts, ELPA seeks to broaden the disease knowledge base

- Euro Hepatitis Index: doing a “hepatitis inventory” in EU 27 plus Croatia, Norway and Switzerland, using 32 indicators.
- White Paper project to assess the economic and social burden of liver disease in general (including e.g. hepatitis, cirrhosis, cancer) in selected EU Member States

ELPA's request for your support

- Help us ensure that other governments become “infected” and develop the same commitment “bug” in the fight against hepatitis as you have!
- Raise the issue of hepatitis case-finding with the European Commission and at Council level!
- Become an Ambassador for hepatitis in the EU!



ELPA's offer to you

- ELPA would be delighted to share our experience and expertise with you, providing independent advice when you are developing your national hepatitis plan;
- We would also be pleased to provide you with a forum to showcase your plan, document progress and share your future insights with EU and national policymakers.

Thank you for your attention

