# **European Liver Patients' Association**

ELPA

Overview on EU advocacy efforts

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#### 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
- 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.

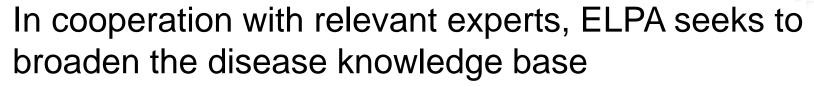
#### Our impact as patient advocates



- ≫n 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



- ➤ 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