VHPB BALKAN MEETING
SESSION 4
LITERATURE SESSION

ROLE OF PATIENT ASSOCIATIONS
DIFFERENT PATIENTS – DIFFERENT EXPECTATIONS – DIFFERENT LEVEL OF ENGAGEMENT

- Acute, interested
- Chronic, interested
- Acute, not interested
- Chronic, not interested
ROLE OF PATIENT ASSOCIATIONS

- Building a Patient Movement
- Partnerships with Decision makers and Influencers
- Generation and Disseminating Patient Priorities
- Advocating for Change on Patient Priorities
Involving patients in the communication with general public

Re-shaping Institutions to be more open to patient advocacy

A multi-stakeholders approach

Increasing funding for Patients’ Associations
A more cohesive and harmonious society
EXAMPLE OF PATIENT ACTIVITIES – QUALITY OF ADR AT EMA

EEA and non-EEA ADR reports received

Total 2021: 3,525,827


Number of reports from patients

- 2021: 781,632
- 2020: 143,958
- 2019: 159,860
- 2018: 172,762
- 2017: 90,385

Note: Following the launch of the new EudraVigilance system in November 2017, figures in 2017, 2018, 2019, 2020 and 2021 include reports of non-serious suspected adverse drug reactions.
ELPA has 8 Working Groups.

Headed by a leader, each Group can count up to 5 members.

ELPA Working Groups are a way to create Expert Patients in a specific fields of liver disease.

1. **Hepatitis B elimination**
   - Leader: Marinela Debu
   - Romania

2. **Primary Liver Cancer**
   - Leader: Dr. Teresa Casanovas T. M.D.
   - Spain

3. **MAFLD/NASH**
   - Leader: Yiannoula Koulla
   - Cyprus

4. **Rare Liver Diseases**
   - Leader: Sindee Weinbaum
   - Israel

5. **Clinical Trials**
   - Leader: Julio Burman
   - Israel

6. **Prevention**
   - Leader: Ivana Dragojević
   - Serbia

7. **Harm reduction**
   - Leader: Aleksey Lakhov
   - Russia

8. **Cirrhosis**
   - Leader: Marko Korenjak
   - Slovenia
EUROPEAN LIVER PATIENT ASSOCIATION

- 10
  - Medical Research Project

- +72
  - Million € for liver research

- +140
  - Partners

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New Application
ELPA AND EU STAKEHOLDERS
ELPA AND EU STAKEHOLDERS

**Member of VHPB**
Member of Advisory Forum at ECDC
Member of expert group on HBV and HCV at ECDC
Member of Advisory Forum at Health Emergency Preparedness and Response Authority – HERA
Member of Patient and Consumer Working Party at European Medicine Agency
Member of Pharmacovigilance Committee at European Medicine Agency
Member of Policy and Public Health Committee at European Association for the Study of the Liver
Member of Task force on Liver Cancer at European Association for the Study of the Liver
Member of association ACHIEVE
Member of WHO committee on HIV, TB and viral hepatitis in WHO European region

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