



Liver patients International is a collaboration of patient associations with heart  
for liver conditions

## **Hepatitis B**

**the very silent and not recognized disease**

**a burden of people with HBV**

**a challenge for patients associations**

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**Liver Patients International** (founded in 2019)

- an umbrella organization providing advocacy and support to liver patient organizations
- share the view that all are seen and heard and have equitable access to healthcare
- focus on all liver diseases: from ultra-rare to not rare
- support colleague liver patient organization is their work for liver patients
- share best practices
- participate in international projects for several liver diseases



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### **What do our members do concerning Hepatitis B**

- provide information on websites, leaflets, social media
- organize Webinars
- organize activities in hospitals and other locations
- organize activities in hepatitis testing week
- have screening programs in prisons
- give presentations at (local) meetings/conferences etc.
- are the spokesperson for people with hepatitis B to the media



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### **Problems that patient organizations face**

1. Lack of interest across countries to spend enough money on screening, campaigns, treatment and preventive measures
2. In some countries: complicated procedure to obtain treatment, or different criteria no matter EASL recommendations
3. Many times even GPs are not familiar with what HBV is-they referred to as jaundice or do not know the difference between different hepatitis viruses



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**And more:**

4. Many patients are non linked to care right on time -> got damaged liver
5. No understanding about the burden to carry a virus through your whole life  
- patients needs also emotional support
6. It is a DNA virus and cannot be easily cleared from the liver cell  
- most clinical trials fail



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## What is urgently needed

- more understanding about the consequences and impact of HBV
- more funds for research concerning diagnosis, treatment and guidance
- more partners/stakeholder at the same page
- de-stigmatization



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## What is urgently needed

- More knowledge about what is happening on a local level
- Policy on global, european or national level
- Attitude to help them so that they don't feel alone
- A long breath, loads of energy and the attitude

**NEVER GIVE UP**



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**Thank you for your attention**