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/stakenholder 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