

A black stethoscope is draped over a blue clipboard. A magnifying glass is positioned at the bottom center of the clipboard. The background is white with abstract green and orange shapes.

**The role of international organizations in
the elimination of viral hepatitis in
Europe/Achievements, challenges, and the
way forward**

ELPA experience

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ELPA Vice President

April 5, 2023

ELPA

European Liver
Patients' Association

ELPA MEMBERS

-  **BELGIUM**
VHC – Vlaams Hepatitis Contactpunt
-  **BOSNIA AND HERZEGOVINA**
The Chronic Viral Hepatitis Patients Association, “B18”
-  **CYPRUS**
Cyprus Liver Patients Association
-  **CROATIA**
HUHIV
-  **DENMARK**
Leverforeningen
-  **EGYPT**
Association of Liver Patients' Care – ALPC
-  **FINLAND**
The Finnish Kidney and Liver Association
-  **FRANCE**
Fédération SOS hépatites France
-  **GEORGIA**
Hepatitis C Cured Patient Association
-  **HUNGARY**
Hungarian Association of Chronic Hepatitis Patients – VIMOR
-  **IRELAND**
Hepatitis C Partnership
-  **ISRAEL**
Hetz – Israeli Association For The Health Of the Liver
-  **NORTH MACEDONIA**
Association for health education, prevention and better treatment – HEPTA Hepar Centar – Bitola
-  **NORWAY**
proLAR
-  **POLAND**
Star of Hope Foundation

-  **PORTUGAL**
SOS Hépatites
-  **ROMANIA**
APAH-RO Romania
-  **RUSSIA**
Humanitarian Action United Against Hepatitis
-  **SERBIA**
Liver Patients' Association – HRONOS
-  **SLOVAKIA**
HEP HELP KLUB
Šanca pre pečeň
-  **SLOVENIA**
Slovenian Association for patients with viral hepatitis - SLOVENIA HEP

-  **SPAIN**
Catalan Association of Liver Patients – ASSCAT
National Federation of Liver Patients and Transplanted - FNETH
Spanish Patient Organization Lysosomal Acid Lipase Deficiency - AE LALD
-  **SWEDEN**
Riksföreningen Hepatit C – RHC
-  **TURKEY**
HEPYAŞAM – Living with Hepatitis Association
-  **UNITED KINGDOM**
British Liver Trust
HEP C POSITIVE
Liver4Life



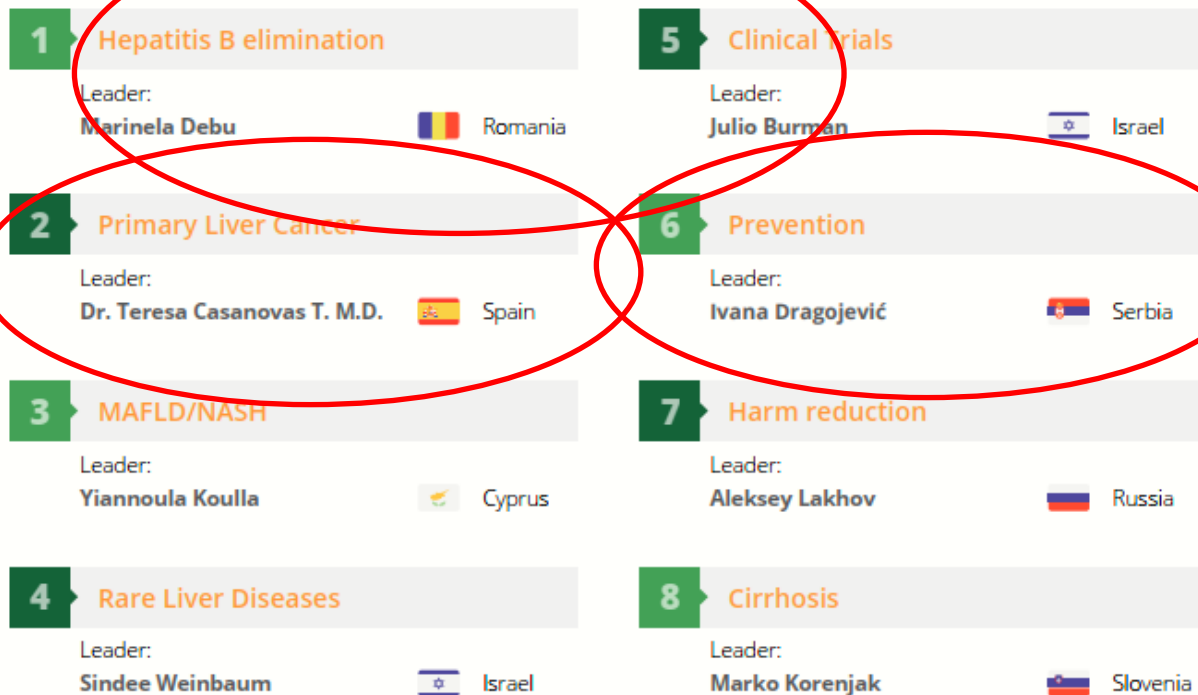
**32 MEMBERS
FROM
25 DIFFERENT COUNTRIES**



ELPA

European Liver
Patients' Association

ELPA WORKING GROUPS





02

(lack of)Data do
not lie

hepatitis elimination,
where are we standing?

HEPATITIS B and C burden

WHO. Global progress report on HIV, viral hepatitis and sexually transmitted infections, 2021.
<https://apps.who.int/iris/bitstream/handle/10665/341412/9789240027077-eng.pdf>

GLOBAL

Hepatitis B

New Infection: 1 500 000
 [1 100 000–2 600 000]
 Deaths: 820 000
 [450 000–950 000]

Hepatitis C

New Infection: 1 500 000
 [1 300 000–1 800 000]
 Deaths: 290 000
 [230 000–580 000]

REGION OF THE AMERICAS

Hepatitis B

New infections: 10 000
 [5 100–26 000]
 Deaths: 15 000
 [8 500–23 000]

Hepatitis C

New infections: 67 000
 [63 000–73 000]
 Deaths: 31 000
 [19 000–84 000]

EUROPEAN REGION

Hepatitis B

New infections: 19 000
 [9 400–38 000]
 Deaths: 43 000
 [34 000–51 000]

Hepatitis C

New infections: 300 000
 [240 000–320 000]
 Deaths: 64 000
 [39 000–72 000]

WESTERN PACIFIC REGION

Hepatitis B

New infections: 140 000
 [96 000–210 000]
 Deaths: 470 000
 [200 000–490 000]

Hepatitis C

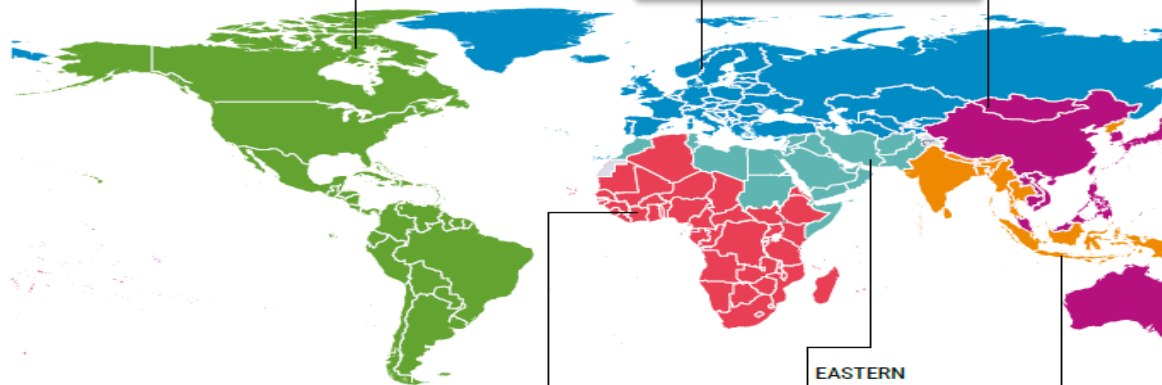
New infections: 230 000
 [220 000–260 000]
 Deaths: 77 000
 [77 000–140 000]

HBV – Europe - 2019:

15 mil. infected
 19 000 new infections
 43 000 deaths

HCV – Europe - 2019 :

14 mill. infected
 300 000 new infections
 64 000 deaths



WHO REGIONS

- African Region
- Region of the Americas
- South-East Asia Region
- European Region
- Eastern Mediterranean Region
- Western Pacific Region
- Not applicable

AFRICAN REGION

Hepatitis B

New infections: 990 000
 [660 000–1 600 000]
 Deaths: 80 000
 [47 000–110 000]

Hepatitis C

New infections: 210 000
 [150 000–370 000]
 Deaths: 45 000
 [23 000–72 000]

EASTERN MEDITERRANEAN REGION

Hepatitis B

New infections: 100 000
 [79 000–140 000]
 Deaths: 33 000
 [26 000–60 000]

Hepatitis C

New infections: 470 000
 [240 000–520 000]
 Deaths: 31 000
 [31 000–74 000]

SOUTH-EAST ASIA REGION

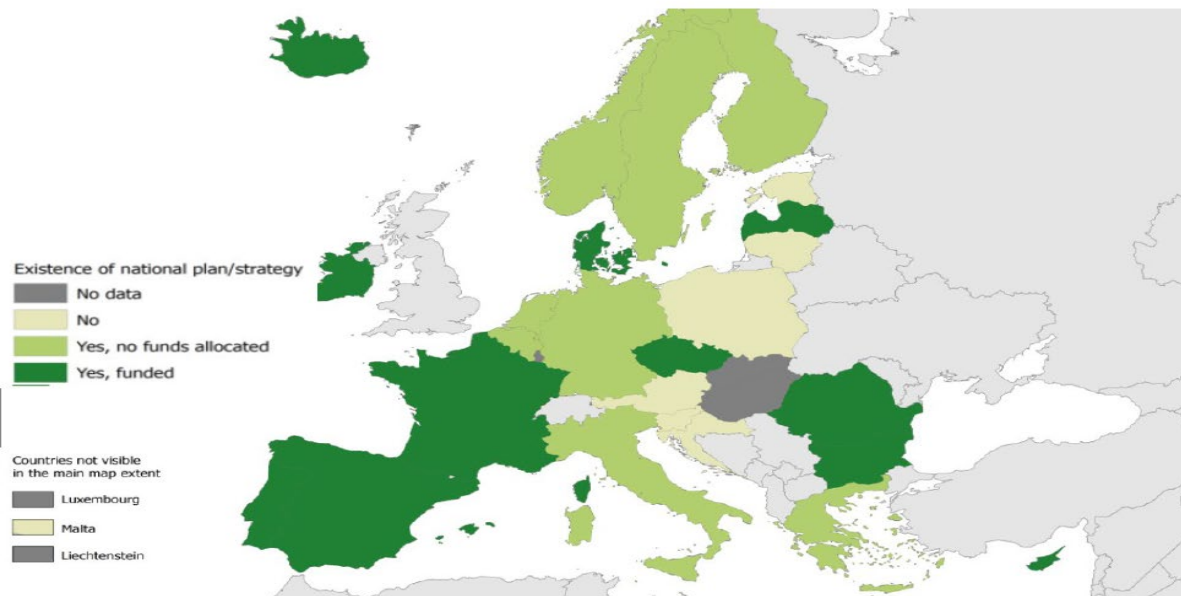
Hepatitis B

New infections: 260 000
 [180 000–590 000]
 Deaths: 180 000
 [140 000–300 000]

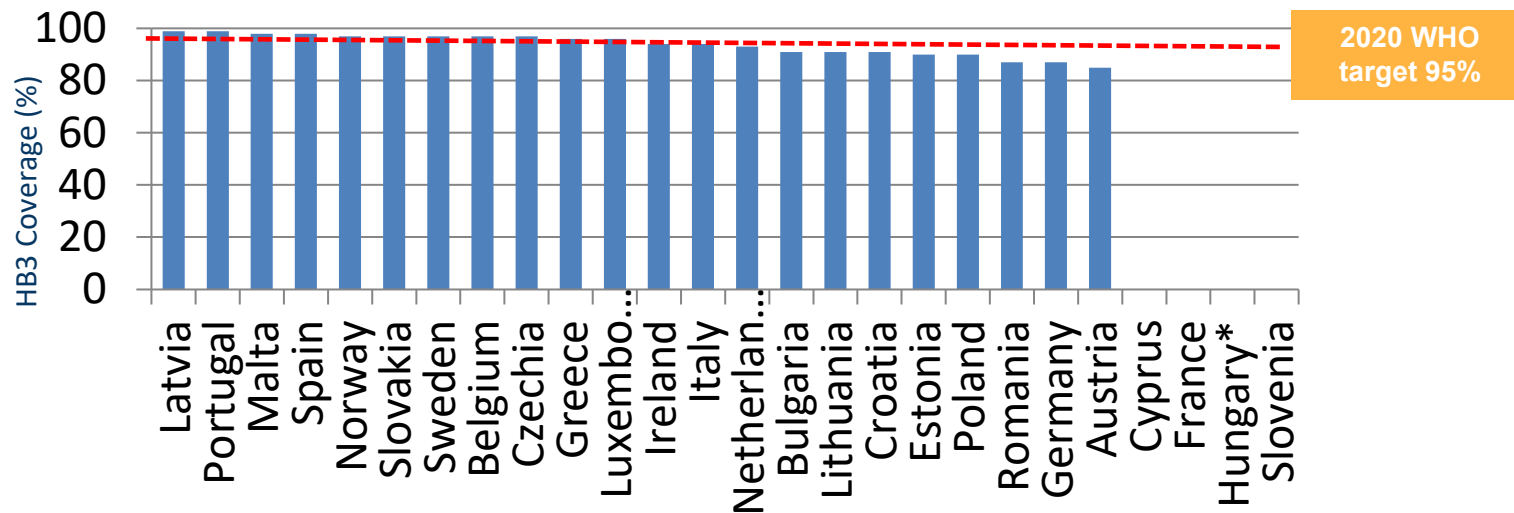
Hepatitis C

New infections: 230 000
 [200 000–430 000]
 Deaths: 38 000
 [37 000–130 000]

Existence of a national strategy for testing and treatment that covers the response to HBV and HCV in EU/EEA, by 2021

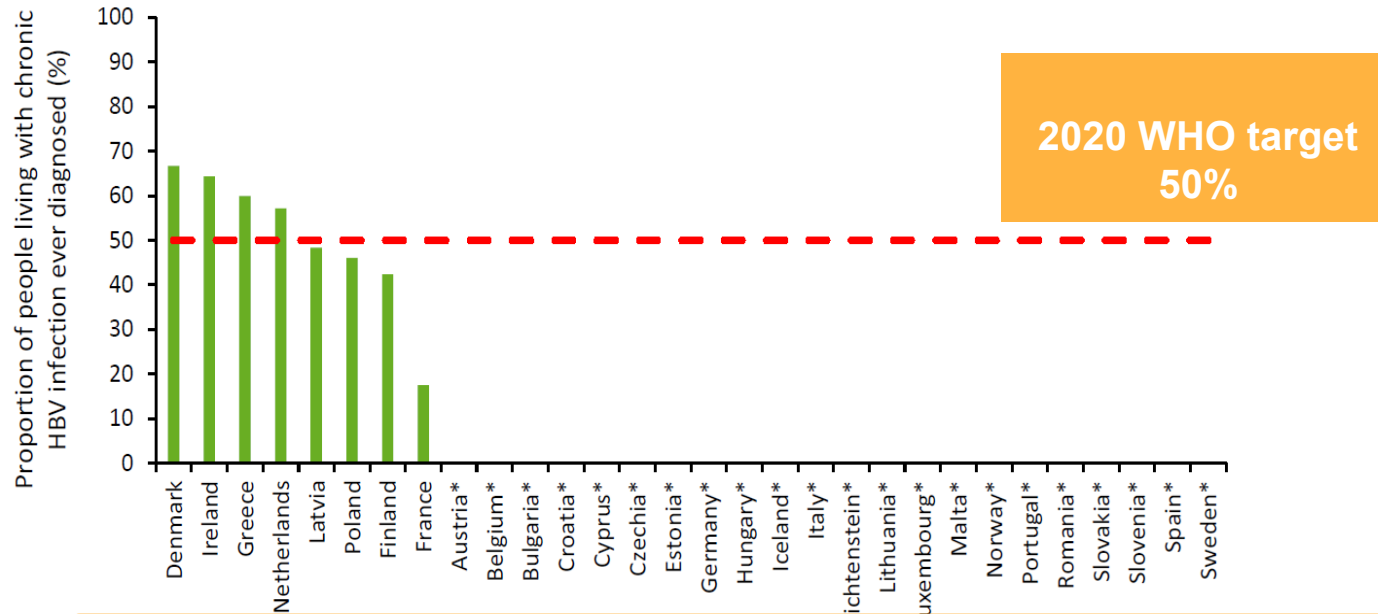


A 3-dose HBV vaccine coverage in EU/EEA countries that implement universal HBV vaccination, 2020



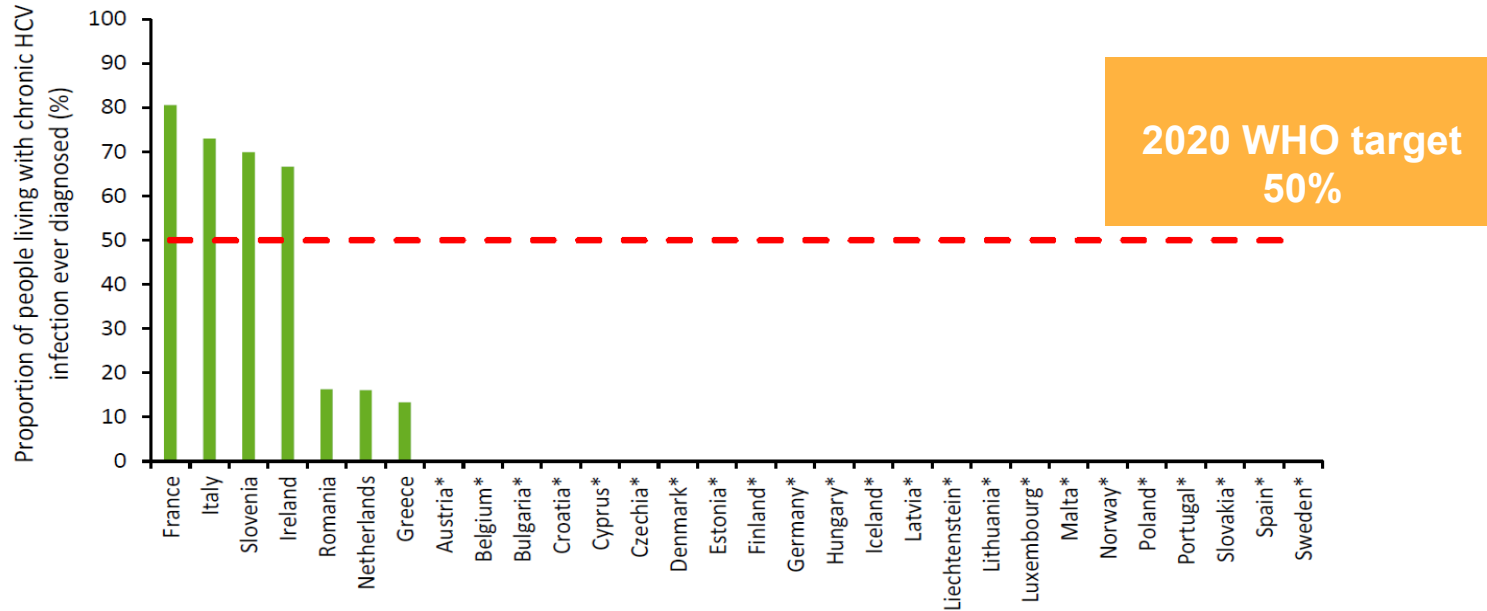
Only 11/22 countries achieved
the WHO target of 95% vaccine coverage by 2020

Proportion of people living with chronic HBV infection and ever diagnosed, EU/EEA countries by 2020



Only 8/22 countries reported data; of them, only 4 countries achieved the WHO target of 50% being HBV diagnosed, by 2020

Proportion of people living with chronic HCV infection and ever diagnosed in the EU/EEA, 2020




Only 7/22 countries reported data; of them, only 4 countries achieved the WHO target of 50% being HCV diagnosed, by 2020



03 Challenges

main obstacles on the way to
elimination from patients
perspective

- 
1. **HBV Adult Vaccination:** the forgotten issue
 2. **HDV:** the unknown issue
 3. **Lack of data:** the missed tool
 4. **Stigma:** the silent disease
 5. **Decentralisation and peer-to-peer services**
 6. Did you say **liver cancer**?



04

Patients'
associations in
action

good practice from civil
society at different levels

Europe's Beating Cancer Plan

3.7. Preventing cancers caused by infections

Many cancers can be prevented and lives saved by vaccination.

Flagship 3: With dedicated funds under the EU4Health programme and other funding instruments, Europe's Beating Cancer Plan will support Member States' efforts to extend routine vaccination against human papillomaviruses of girls and boys – in order to **eliminate cervical cancer and other cancers caused by human papillomaviruses**. The objective is to vaccinate at least 90% of the EU target population of girls and to significantly increase the vaccination of boys by 2030⁴⁸. Member States will play a critical role in meeting this target

Furthermore, the Commission will help ensure access to vaccination against Hepatitis B and to treatments to prevent liver and gastric cancers associated with the Hepatitis C virus and Helicobacter pylori infections. It will also propose a **Council Recommendation on vaccine-preventable cancers** to help address cancer risks associated with Hepatitis B and Human papilloma virus infections. In parallel, as announced by the EU Pharmaceutical Strategy, the Commission will examine the system of incentives and obligations to boost innovation and ensure better access to first-line medicines and vaccines.

Preventing cancers caused by infections (3.7)

20	<p>(1) Reduce liver cancer caused by Hepatitis B virus (by vaccination and investment in related infrastructures) and prevention of liver cancer caused by Hepatitis C virus and gastric cancer caused by Helicobacter pylori (by treatment with antivirals and antimicrobials respectively);</p> <p>(2) Propose a Council Recommendation on vaccine preventable cancers.</p>	2021-2030
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Other actions

- ▶ Improve health literacy on cancer risk by updating the European Code against Cancer – 2021-2025.
- ▶ Create a 'Tobacco-Free Generation', including reviewing the Tobacco Products and the Tobacco Taxation Directives and the legal framework on cross-border purchases of tobacco; update the Council Recommendation on Smoke-Free Environments, and support implementing the Framework Convention on Tobacco Control – 2021-2025.
- ▶ Review EU legislation on alcohol taxation and cross-border purchases of alcohol products, and propose mandatory labelling of ingredients and nutrient content, along with health warnings on alcoholic beverages – 2021-2023.

ELPA-DiCE Launch of *White Paper Liver Cancer: No Patient Left Behind*



LIVER CANCER: NO PATIENT LEFT BEHIND

White paper calling for increased equality of best practice implementation in the prevention, diagnosis and management of liver cancer across Europe

WHAT IS LIVER DISEASE? CAUSES, PROGRESSION INTO CHRONIC LIVER DISEASE AND CIRRHOSIS

There are many different causes of liver disease, which may be linked with liver cancer. Some of the most common include:



Alcohol-related liver disease: Caused by regularly drinking too much alcohol.



Non-alcoholic fatty liver disease: Frequently linked to being overweight, which may cause fat to build up in the liver and might lead to liver inflammation.



Hepatitis: Infection of the liver caused by a virus.



Cirrhosis: a late-stage liver disease in which healthy liver tissue is replaced with scar tissue and the liver is permanently damaged.



ELPA @EuropeLiver · 26 Oct

John Ryan, Deputy Director DG SANTE: High-Level meeting: Launch of #WhitePaper in Europe
#livercancer High on the agenda of @EU_Health @EU_Commission
#EUCancerPlan @SKYriakidesEU @WHO_Europe @vonderleyen
#livercancerawarenessmonth multi-stakeholder engagement on the 1st place



RECOMMENDATIONS



OPTIMISE PREVENTION

Viral hepatitis

- Adhere to the Action plan for the health sector response to viral hepatitis in the WHO European Region, ensuring equitable access to recommended prevention, testing, care and treatment services for all, including:
 - Implement mass HBV immunisation (for all newborns and high-risk groups)
 - Control HCV transmission (including raising awareness of link with unprotected sex and needle-sharing)/ improve screening of high-risk populations, and offer treatment
 - Ensure equitable access to therapies for HBV and HCV infections

Lifestyle risk factors – alcohol smoking and obesity

- Implement the EU Beating Cancer Plan (BECA) to reduce the harmful consequences of chronic alcohol consumption, smoking and obesity, and promote healthy lifestyles from an early age.

RECOMMENDATIONS



OPTIMISE EARLY DIAGNOSIS

Screening

- Improve implementation of screening programmes to identify at-risk populations, following the [EASL guidelines](#) and/ or [ESMO guidelines](#). Patients at high risk of developing HCC should be entered into surveillance/ screening programmes. All individuals at high risk should be screened by use of abdominal ultrasound examinations every 6 months.
- Monitor the outcomes of the [LiverScreen initiative](#) to understand if detection of advanced liver fibrosis in high-risk groups within the general population, using transient elastography as screening tool, is a valid screening approach.

RECOMMENDATIONS



OPTIMISE PATIENT INVOLVEMENT AND EMPOWERMENT

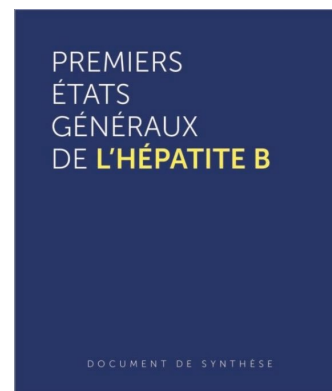
Patient health literacy and support

- Utilise standardised nomenclature around liver cancer across Europe.
- Ensure liver cancer patients and carers/ families are informed about patient organisations in their country immediately after diagnosis. If there are no organisations in the country, direct them to DiCE/ ELPA.
- Raise awareness of increased risk of liver cancer among family members and encourage sharing this information with HCPs.

Patient involvement in research

- Ensure liver cancer research incorporates the patient perspective e.g. endpoints that reflect the most meaningful outcomes for patients.
- Ensure there is a systematic approach to collecting real-world patient experiences and needs throughout the patient pathway.

SOS Hépatites Fédération



Estates General of Hepatitis B

Initiated in mid-2019, the Estates General of Hepatitis B, in French “États Généraux de l’Hépatite B”, wanted to highlight the consequences of hepatitis B in France. At the end of an unprecedented mobilisation lasting more than a year, the participants gave public authorities a series of concrete proposals in December 2020.

The proposals issued by the Estates General of Hepatitis B included content from a variety of stakeholders within society. Patients, nurses, the medical profession and social figures to name a few, all with the purpose and intention to raise awareness and better inform the public, health practitioners and political authorities.

The Estates General of hepatitis B represents an unprecedented enterprise for health-related democracy, initiated by patients fully justifying their designation in French as “hépatants”, which means patients with liver disease but also amazing (in French “épatants”) patients.

En collaboration avec SOS hépatites et la ville de Prades, la première table ronde régionale sur l'hépatite B a eu lieu le 13 décembre 2019 à Prades.

SANTÉ. La commune a lancé une série de réflexions.

Première table ronde régionale sur l'hépatite B



À Au Foirail, Prades a ouvert la 1^{re} des 6 tables rondes régionales.

Dernièrement, le maire Jean Costes accueillait à la salle du Foirail l'équipe mobile hépatites du centre hospitalier de Perpignan et l'association de patients SOS hépatites pour la tenue d'une table ronde régionale organisée dans le cadre des premiers États généraux de l'hépatite B, lancés à l'échelle nationale en juillet 2019. Une trentaine de participants, acteurs de santé et usagers du

système concerné par l'hépatite B, ont travaillé en atelier avec les représentants du CCAS (Centre communal d'action sociale) et de la municipalité sur les parcours de soins des personnes avec l'hépatite B, le dépistage et la vaccination en dehors des centres urbains. Les objectifs du projet États généraux de l'hépatite B sont de mieux rendre visibles les véritables conséquences de l'hépatite B, d'optimiser la

prise en charge, le suivi des patients souffrant d'hépatite B chronique, et d'obtenir une juste reconnaissance de la part des autorités de santé et de l'opinion publique, face aux réelles difficultés des patients. Les États généraux de l'hépatite B comptent 6 tables rondes régionales travaillant sur différents thèmes : en Gascogne, à Bordeaux, à Lyon, à Strasbourg, à Rennes et Prades qui a ouvert la première table ronde avec des échanges qui seront synthétisés au sein du comité de pilotage national des premiers États généraux de l'hépatite B dont les propositions seront rendues publiques en mai 2020.

Émile Claverie

HEPATITIS B THROUGH THE EYES OF PATIENTS: TEN LESSONS TO REMEMBER

- 2 Once screened, the illness creates strong fears, both for one's self as well as for others. When they are asked what is the most difficult thing to live with, among the repercussions of hepatitis B, 59% of people cited the uncertainty regarding the illness's evolution, while 57% answered the fear of cancer. Right behind that was the fear of contaminating other people at 56%.
- 8 Trust in the vaccine is not absolute, even in people with hepatitis B. The most effective prevention against hepatitis B is the vaccine. A sign of the times, defiance against this vaccine has even infiltrated people with hepatitis B: 24% of people said "that they did not trust it" and 7% preferred not to say.

AU FIL DU TEMPS

● **Information paroissiale.** Messe, adoration en l'église à 9 h 30.
● **Médiathèque.** Pour les fêtes de fin d'année, la médiathèque sera fermée du

mercredi 25 décembre au jeudi 2 janvier inclus.
● **Sur l'écran du Lido.** À 15 h, *Pat et Matt en hiver* ; à 18 h 15, *Stars Wars l'ascension des Skywalker*.

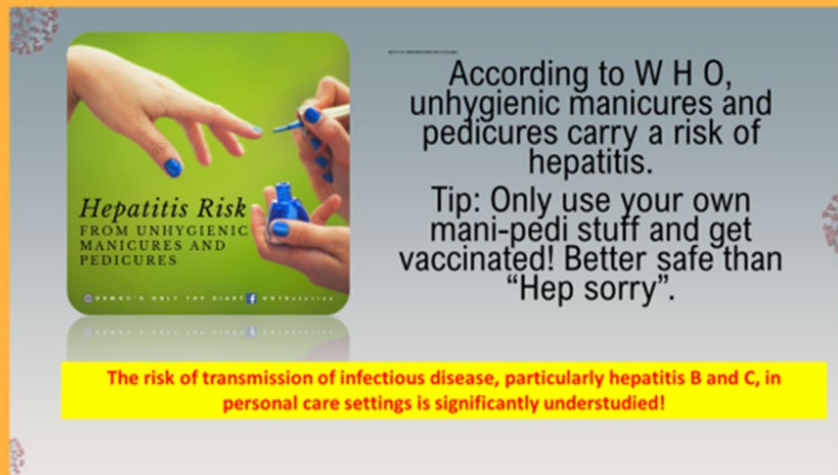
Patients with hepatic
impairment Association
of Romania - APAH-RO



The national Campaign "Mother's Day with Hepatitis"



HEP FREE BADGE – education of Professionals in the beauty parlors



 SERBIA

Association for helping patients with chronic viral hepatitis, "HRONOS"

UDRUŽENJE PACIJENATA SA BOLESTIMA JETRE
 **HRONOS**

Data related to risk assessment in Eastern EU countries in cosmetic parlors lacking. In beauty parlors, the risk of transmitting viral diseases is represented by all procedures that can damage the skin and mucous membranes, and bleeding, which is carried out with unsterilized or improperly sterilized instruments, namely: manicures, pedicures, and permanent makeup.

Cosmetology spring seminar

"Infection prevention and modern cosmetic procedures"

Was held in Belgrade on March 6. 36 salon representatives and 19 medical school students participated in the seminar. The lecturers were an epidemiologist from the Institute of Public Health, an infectious disease specialist, and a sanitary inspector from the Ministry of Health.





TOGETHER, WE ARE STRONGER!

Do you have questions?

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