

A black stethoscope is draped over a blue clipboard. The clipboard is open to a white page with text. The background is white with abstract green and orange shapes.

# Patient perspectives on HBV cure

**Milan Mishkovikj**

ELPA Director

11th International ANRS HBV cure  
Workshop 2024

Date  
July 3,  
2024

**ELPA**

European Liver  
Patients' Association

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SOS HÉPATITE



01

**WHY ELPA?**

# EUROPEAN LIVER PATIENTS' ASSOCIATION

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ELPA aims to promote the interests of people with liver disease and, in particular:

- to highlight the size of the problem;
- to promote awareness and prevention;
- to address the low profile of liver disease;
- to share the experience of successful initiatives;
- to work with professional bodies to ensure that treatment and care are harmonised across Europe to the highest standards.

ELPA's vision is that all liver patients

- are diagnosed in time,
- are treated with respect,
- and have equal access to the best standard of medical care – regardless of origin, lifestyle, and type of liver disease.

# OUR VALUES

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Equality



Respect for Diversity



Patient Driven



Commitment



Transparency

**ALBANIA**

Albanian Association  
"Patients with hepatitis"

**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 des Déficiants et Transplantés  
Hépatiques - TRANSHÉPATE  
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

**ITALY**

Italian Association for Research on  
Primary Sclerosing Cholangitis - AIRCS

**KAZAKHSTAN**

Anti Hepatitis C Organisation - AGEP C

**MONTENEGRO**

4Life

**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  
SKLON

**SLOVENIA**

Slovenian Association for patients with  
viral hepatitis - SLOVENIA HEP

**SPAIN**

Catalan Association of Liver Patients -  
ASSCAT

Catalan Federation of Rare Diseases -  
FECAMM

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

**39 MEMBERS**  
**29 COUNTRIES**





Autoimunitná hepatitída (AIH)

Autoimmune Hepatitis

- chronické zápalové ochorenie pečene neznámej etiologie

Ako často sa vyskytuje: 0.1-1.2/na 100.000

U koho sa vyskytuje:

- Ženy /muži 3-4:1
- Dva vrcholy výskytu: vek 10-20 r. a 45-70 r.
- Ojedinele aj u osôb starších ako 70 rokov (muži môžu dominovať nad ženami)

ROYAL PALACE



# Engagement in the framework of Scientific Projects



20

Medical Research Project



+ 150

Million € for liver  
research



+ 200

Partners

Many New Applications





PATIENT  
involvement  
MEDICAL  
RESEARCH  
PROJECTS



ESCALON has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 825510 - GALAXY has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 668031 - DECISION has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847949 - A-TANGO has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 945096 - MICROB-PREDICT has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 825694 - LIVERSCREEN has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847989 - LIVERHOPE has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 73875 - IP-cure-B has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847939 - Artemis Project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 101156299 - Liveration Project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 101104560 - THRIVE Project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 101156222 - GENIAL Project has received funding from the European Union's Erasmus+ programme for education, training, youth and sport under grant agreement No. 101153773



ERASMUS+ LIVERAIM Project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 101152901 - GRIPonMASH Project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 101152946 -

ERASMUS+ FiSPlat has received funding from the EIT Health under grant agreement No. 20508

# Engagement at international organisation level

## ELPA IS PART OF



ECDC  
Advisory Forum

ECDC  
HCV and HBV  
experts group



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

EMA - PCWP  
Patients' and  
Consumers' Working  
Party

EMA - PRAC  
Pharmacovigilance Risk  
Assessment Committee



HERA Agency  
Advisory Forum



WHO EURO Collaborating  
Committee on TB, HIV,  
and viral hepatitis










# Engagement in other organisations



Fatty Liver  
alliance  
du Foie Gras



# ELPA WORKING GROUPS led by patient experts

<b>1</b>	<b>Hepatitis B elimination</b> Leader: <b>Ivana Dragojević</b>  Serbia	<b>6</b>	<b>Prevention</b> Leader: <b>Ivana Dragojević</b>  Serbia
<b>2</b>	<b>Primary Liver Cancer</b> Leader: <b>Dr. Teresa Casanovas T. M.D.</b>  Spain	<b>7</b>	<b>Harm reduction</b> Leader: <b>Aleksey Lakhov</b>  Russia
<b>3</b>	<b>Steatotic liver disease (SLD)</b> Leader: <b>Yiannoula Koulla</b>  Cyprus	<b>8</b>	<b>Cirrhosis</b> Leader: <b>Marko Korenjak</b>  Slovenia
<b>4</b>	<b>Rare Liver Diseases</b> Leader: <b>Sindee Weinbaum</b>  Israel	<b>9</b>	<b>Multicultural</b> Leader: <b>Dr Tove Frisch Ph.D.</b>  Sweden
<b>5</b>	<b>Clinical Trials</b> Leader: <b>Julio Burman</b>  Israel		



02

**EUROPE'S BEATING  
CANCER PLAN**



European  
Commission

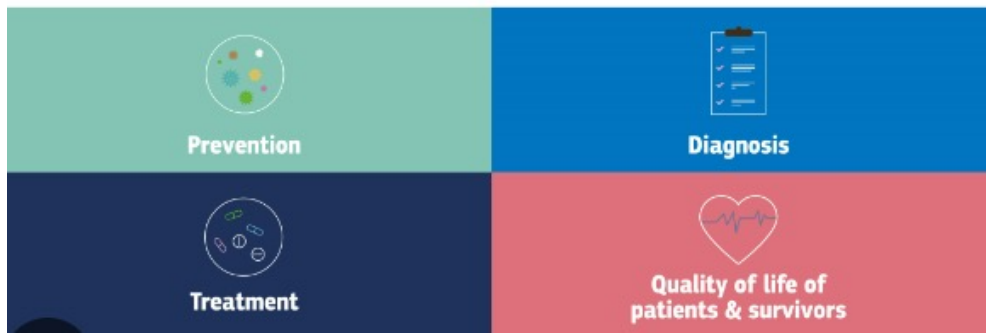


# Europe's Beating Cancer Plan

Communication from the  
commission to the European  
Parliament and the Council



## EUROPE'S BEATING CANCER PLAN STRENGTHENING OUR APPROACH AT EVERY STAGE



## PREVENTING CANCERS CAUSED BY INFECTIONS

ACTION		2021	2022	2023	2024	2025	PROGRESS INDICATOR(S)
20.1	Reduce liver cancer caused by Hepatitis B & C virus	Calls launched	Consortia operational	HBV vaccination, HCV treatment and asymptomatic patients detection events in target Member States			Number of events in target countries, Data on HBV/ HCV asymptomatic patients detection, HBV vaccination coverage, HCV treatment access in target Member States
20.2	Propose a Council Recommendation on vaccine-preventable cancers		Preparatory work, discussions with Member States	Commission proposal			Commission proposal adopted in 2023
	Best Practice Call on Non Communicable Diseases under Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases (SGPP)	Launch implementation of best practices, related to NCDs prevention and health promotion implemented under EU4Health 2021 Work Plan	Joint Action				Number of best practices selected and implemented in Member States

## EUROPE'S BEATING CANCER PLAN

JOIN THE CONSULTATION  
AND HAVE YOUR SAY



#EUCancerPlan



European Commission | Log in | English

Law

### Feedback from: European Liver Patients' Association - ELPA

Have your say > Published initiatives > Cancer Screening Recommendation – update > Feedback from:

Feedback reference	F2886746
Submitted on	21 February 2022
Submitted by	Marko Korenjak

European Commission | Log in | English

Law

### Cancer Screening Recommendation – update

Have your say > Published initiatives > Cancer Screening Recommendation – update > Feedback and statistics: Call

Unique feedback (88) | Statistics

Showing results 41 to 50

21 February 2022 | Non-governmental organisation (NGO)  
**European Liver Patients' Association - ELPA (Belgium)**

HCC is one of the leading causes of cancer-related death. More than 830,000 people died from liver cancer in 2020, making liver cancer the 3rd most common cause of cancer death globally. In Europe, we had 98,787 diagnoses and 89,130 deaths in 2020. Hepatocellular carcinoma (HCC) is the most common type of primary liver cancer and occurs predominantly in patients with underlying chronic liver disease, and continues accounts for 75-90% of...







# 03

## **ELPA IN IP-cure-B PROJECT**



# IP-cure-B website update



HOME

ABOUT US ▾

PROJECT ▾

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IP CURE B

## Our Project



### Context

Hepatitis B virus (HBV) is a major global public health threat with over 257 million people worldwide.



### Strategy

Stimulating innate signaling and inhibiting viral replication in infected hepatocytes.



### Objectives

Perform a proof of concept clinical trial to evaluate novel immune modulators and their combination to boost...



### Expected Results

Improve the functional cure rate in CHB = Chronic Hepatitis B and provide opportunities for finite duration curing therapies...



### ABOUT US

## IP CURE B

IP-cure-B is a five-year project started in January 2020, coordinated by INSERM in France.

Our collaborative network brings together 13 complete including 10 research institutions, 1 pharmaceutical company and 1 private company from 9 different European member states).

[VIEW MORE](#)

### VIDEO

## Hear from the principal investigators

MARIA BUTI



SUSANNA TAN



CARLO FERRARI



FABIEN ZOULIN



MASSIMO LEVRERO



PIETRO LAMPERTO



HÉLÈNE STRICK-MARCHAND



MARKO KORENJAK



This IP-cure-B project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement n°847939.



[https://www.youtube.com/watch?v=D6ou\\_E8GcYY](https://www.youtube.com/watch?v=D6ou_E8GcYY)

# Translation of the flyer – communication material with patients

## La Hepatitis B – Ciencia clínica

Este trabajo ha recibido apoyo del programa de Investigación e Innovación de la Unión Europea, Horizonte 2020 (proyecto de Grant Agreement n° 847939).

### Investigaciones realizadas en cooperación entre el laboratorio de investigación y el hospital

- Personas, que desarrollan una defensa inmunológica, recuperan de la infección del VHB.
- Personas, con una defensa inmunológica débil o insuficiente, no pueden eliminar la infección y desarrollan por consiguiente una infección crónica.

### Vías de infección

A través de la sangre, A través del contacto sexual, De madre a hijo/a

### Diagnóstico y seguimiento

El diagnóstico se realiza mediante análisis de sangre para:

- detectar virus, antígenos o anticuerpos contra la hepatitis B
- medir cantidad del virus (la cantidad de la sangre)
- evaluar el daño hepático (fibrosis, biopsia hepática)

### Tratamientos

Medicamentos antivirales impiden al virus de multiplicarse, la enfermedad de progresar y reducen el riesgo de cirrosis y de muerte. Actualmente estos tratamientos logran no curan completamente la infección. Consecuente estamos examinando nuevos tratamientos.

### El objetivo de la ciencia:

Estos estudios confirman una mejor comprensión de los mecanismos que el virus utiliza para evadir el sistema inmunológico de sus hueros contribuyeron al desarrollo de nuevos tratamientos.

Pacientes, ustedes pueden donar sangre para las investigaciones, una contribución muy importante.

## Hepatitis B – Klinische Forschung

Diese Arbeit ist unterstützt, provided support durch das Forschungs- und Innovationsprogramm Horizon 2020 der Europäischen Union (Projekt Grant Agreement n° 847939).

### Forschung in Zusammenarbeit zwischen dem Forschungslabor und dem Krankenhaus

- Personen, die eine effektive Abwehrkraft entwickeln, erholen sich spontan von der HIV-Infektion.
- Wer wenig oder unzureichende Abwehrkraft hat schafft es nicht, die Infektion zu eliminieren und entwickelt deshalb eine chronische Infektion.

### Übertragung

Durch Blut, Durch sexuellen Kontakt, Von Mutter zu Kind

### Diagnose und Überwachung

Tests erlauben:

- den Nachweis des Virus, Antigenen und Antikörpern gegen HIV zu erkennen
- die Viruskonzentration im Blut (die Menge des Virus im Blut) zu messen
- den Leberschaden zu bewerten (Fibrose, Leberbiopsie)

### Behandlungen

Antivirale Behandlungen ziele darauf ab, die Vermehrung des Virus und somit das Fortschreiten der Krankheit zu verlangsamen. Bisherige Behandlungen können diese Langzeitbehandlungen nicht vollständig beseitigen. Deshalb werden wir neue Behandlungsmethoden in unserer Abteilung entwickeln.

### Ziel der Forschung:

Verstehen, wie HIV und Botschaften (Antigene) auf der Zelle des Immunsystems einwirken.

Diese Untersuchungen werden zu einem besseren Verständnis der Mechanismen beitragen, die das Virus benutzt, um den Immunsystem zu entkommen und somit neue Strategien für Behandlungen zu entwickeln.

Pacientes, Ihre spenden die Blut und helfen Sie damit einen wichtigen Beitrag zur Forschung.

## Epatite B - ricerca clinica

Realizzato con il supporto del Programma quadro dell'Unione Europea per la ricerca e l'innovazione Horizon 2020 (progetto Grant Agreement n° 847939).

### Ricerca eseguita tra il laboratorio di ricerca e l'ospedale

- Le persone che sviluppano una risposta immunitaria efficace guariscono dall'infezione da HIV.
- Le persone con una risposta immunitaria bassa o insufficiente non riescono a eliminare l'infezione e sviluppano un'infezione cronica.

### Cos'è l'epatite B?

L'epatite B è una malattia del fegato causata dal virus dell'epatite B (HBV). L'infezione può diventare cronica e comportare delle complicazioni gravi (come cirrosi e cancro al fegato).

### Trasmissione

Tramite sangue, Tramite contatto sessuale, Da madre a figlio/a

### Diagnosi e controllo

I test consentono di:

- Scoprire il virus, gli antigeni o gli anticorpi contro l'epatite B
- Misurare la carica virale (la quantità del virus nel sangue)
- Valutare il danno epatico (fibrosi, biopsia del fegato)

### Trattamenti

I farmaci antivirali mirano a ridurre la moltiplicazione del virus e quindi la progressione della malattia, riducendo il rischio di cirrosi e di morte. Attualmente questi lunghi trattamenti non curano completamente l'infezione, perciò stiamo nuovi metodi di trattamento.

### Obiettivo della ricerca:

Capire come il virus e i suoi componenti (antigeni) infettano nelle cellule del sistema immunitario.

Questi studi forniranno una migliore comprensione dei meccanismi utilizzati dal virus per sfuggire al sistema immunitario e in questo modo contribuiranno anche allo sviluppo di nuovi trattamenti.

Pacienti, potete donare i vostri campioni di sangue per la ricerca, il vostro contributo è molto importante!

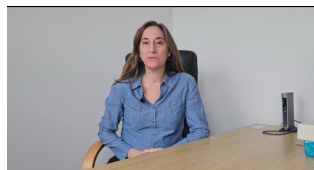
Prepared by Lucile Dumolard

- German
- Spanish
- Italian
- Swedish



# Myth busters

This IP-cure-B project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement n°847939.



# More dissemination and the future



- Second laymen event – EASL ILC 2025
- EU Projects Booklet 2024
- ELPA Annual report 2023 and 2024
- Monthly Newsletters
- Active presence on social media
- Press releases
- Updates on the project timeline and progress
- Update about upcoming conferences





04

**ELPA'S UPCOMING ACTIVITIES  
ON WORLD HEPATITIS DAY  
2024**

# Myth busters' dissemination

ELPA European Liver Patients' Association present IP-cure-B

## Hepatitis & Liver, debunking some myths

**FACTS** **MYTHS**

# Social media campaign

**DID YOU KNOW?**

ELPA World Hepatitis Day 28 July

ELPA World Hepatitis Day 28 July

Hepatitis A virus can cause inflammation of the liver. In children, hepatitis A virus infection is often asymptomatic or mild. However, in older people or in patients with co-morbidities, it can be life-threatening. Hepatitis A never progresses to chronicity.



# Hepatitis B flyers dissemination

## Hepatitis B - Clinical Research

Research conducted in collaboration between the research laboratory and the hospital

**What is hepatitis B?**  
Hepatitis B is a liver disease caused by hepatitis B virus (HBV). Infection can become chronic and cause serious complications (cirrhosis and liver cancer).

**Transmission**  
By blood, By sexual contact, From mother to child

**Diagnosis and monitoring**  
• detect the presence of virus, antigens or antibodies (blood and/or urine)  
• measure the viral load (amount of virus present in the blood)  
• measure liver damage (transaminase levels)

**Treatments**  
Antiviral treatments aim to reduce the multiplication of the virus and, thus, the progression of the disease. At present, these long-term treatments do not fully cure the infection. Therefore, new therapy methods are being tested in our unit.

**Research objective**  
• Understand how HBV and liver cells interact  
• Patients, you can donate your blood samples for research, your contribution is very important!

# Joint work of all ELPA members across Europe





05

ELPA

European Liver  
Patients' Association

**SOS** hépatites  
Fédération

*Hépatites & Maladies du foie*



# SOS hépatite – working on hepatitis B

-In June 2022, SOS hépatite network promoted ANRS HB07 IP-cure-B recruitment, <https://soshepatites.org/le-premier-patient-recrute-dans-lessai-clinique-ip-cure-b/>.

-In February 2024, the European Project Manager - IP-cure-B shared with SOS hépatite the Informational **poster on Hepatitis B**

IN ADDITION:

- JE VIS AVEC L'HÉPATITE B : MON MÉMO ! (I LIVE WITH HEPATITIS B: MY MEMO!),  
December 2023

- L'HÉPATITE B, M'AIDER À LA COMPRENDRE, SAVOIR CE QU'IL FAUT FAIRE,  
(HEPATITIS B, HELP ME TO UNDERSTAND IT, TO KNOW WHAT TO DO) February 2024

## Je vis avec l'hépatite B, une maladie potentiellement grave : mon mémo !



**Je réalise** au moins une fois le dépistage de l'hépatite D, de l'hépatite C et du VIH.



**Je prends soin de mon foie** : mon suivi médical est régulier tout au long de ma vie, mon alimentation est équilibrée, et je fais régulièrement de l'exercice physique adapté.



**Je ne consomme pas d'alcool** et je bois au minimum 1,5 L d'eau par jour.



**Je protège mes proches** : ils sont dépistés et vaccinés selon le résultat du dépistage.



**Si j'ai un traitement**, je le prends tous les jours à la même heure. Je m'organise pour ne pas oublier sa prise.



**Je mérite une vie sexuelle épanouie** : j'utilise les préservatifs et autres dispositifs qui protègent des Infections Sexuellement Transmissibles (IST).



**Je mérite une vie professionnelle épanouie** : en France, vivre avec l'hépatite B ne doit pas être un frein pour exercer le métier de mon choix. Je me renseigne.



**Emploi** : depuis décembre 2014 et sous réserve de certaines conditions, le Haut Conseil de la Santé Publique (HCSPP) a émis un avis relatif à la conduite à tenir concernant les personnes ayant une infection chronique par le virus de l'hépatite B et voulant intégrer des filières de formation en santé listées dans la version du 21 avril 2015 de l'arrêté du 6 mars 2007.



**Je n'hésite pas à contacter SOS hépatites** & maladies du foie [www.soshepatites.org](http://www.soshepatites.org)

**N° Vert 0 800 004 372**

www.marsat.france.fr

**sos hépatites**  
Hépatites & Maladies du foie



## Je vis avec l'hépatite B, une maladie potentiellement grave : mon mémo !



**Don de sang** : je vis avec l'hépatite B, je ne peux pas donner mon sang. Néanmoins, je peux demander à l'Établissement Français du Sang (EFS), de m'inscrire sur la liste du don de sang pour la recherche.



**Don d'organes** : je vis avec l'hépatite B, je ne peux pas être donneur d'organes. Néanmoins, les transplantations de foie entre les personnes vivant avec l'hépatite B sont possibles.



**Je peux fonder une famille** mais ma ou mon partenaire doit être dépisté.e, voire vacciné.e. L'hépatite B n'est pas dangereuse pour la mère et son enfant au cours de la grossesse. Si je suis une femme, mon bébé doit être sérovacciné (injection de gammaglobulines anti-HBs + injection du vaccin contre l'hépatite B) à la naissance. Si je suis un homme, mon bébé doit être vacciné (cette vaccination peut être commencée à la naissance).



**Procréation Médicalement Assistée (PMA)** : seuls les centres de PMA agréés peuvent accompagner des personnes vivant avec toute infection virale. Ils proposent une activité spécifique avec un circuit séparé pour le recueil et le traitement des gamètes.



**Office National d'Indemnisation des Accidents Médicaux (ONIAM)** : pour l'hépatite B, comme pour l'hépatite C, les personnes contaminées par transfusion sanguine peuvent être indemnisées à condition de pouvoir prouver cette contamination.



**Je n'hésite pas à contacter Santé Info Droits** au 01 53 62 40 30 pour toutes questions juridiques et sociales en lien avec le droit de la santé.



**Je n'hésite pas à me rendre sur** [www.soshepatites.org](http://www.soshepatites.org), sur la plateforme hépatante pour tous renseignements sur l'hépatite B, C, la NASH, la cirrhose et le cancer...  
[@https://twitter.com/soshepatites](https://twitter.com/soshepatites) et à contacter SOS hépatites & maladies du foie.

**N° Vert 0 800 004 372**

www.marsat.france.fr

**sos hépatites**  
Hépatites & Maladies du foie



# L'HÉPATITE B

M'AIDER à LA COMPRENDRE  
SAVOIR CE QU'IL FAUT FAIRE

**sos hépatites**  
Hépatites & Maladies du foie

# SOS hépatite – working on hepatitis B – THE FUTURE

Prepare a flyer and possibly a short video interview of a patient to describe the experience with Fine Needle Aspirate. The idea with the flyer would be to describe briefly the procedure, give the personal experience of a couple of patients with a couple of statements, and the arguments supporting FNA for HBV cure research.

# Conclusions

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## What ELPA is calling for...THE FUTURE

1. More funding, resources, research
2. More volunteers, more work power for better and faster results
3. More awareness of Hepatitis D
4. More awareness of Hepatitis B vaccination

# TOGETHER, WE ARE STRONGER!

Do you have questions?

## European Liver Patients' Association

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