



Together we are  
stronger!

**ELPA MEMBERS'  
PROJECTS SUPPORT  
2022**



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# Our mission

The European Liver Patients' Association - ELPA - emerged in 2005 from a desire amongst European liver patient groups to share their experiences on the different approaches adopted in other countries. Nowadays, ELPA is an umbrella association representing 32 members from 25 countries.

ELPA aims to promote the interests of people with liver disease and, in particular: to highlight the size of the problem; promote awareness and prevention; address the low profile of liver disease; 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.

ELPA's efforts are focused on three main pillars.

## **MEMBER EMPOWERMENT**

ELPA was established by patients, is governed by patients, and represents patients. We put much effort into organising training, promoting capacity building, and stimulating networking. We have eight different working groups to boost expert patients to acquire knowledge in a specific field of liver disease.

## **POLICY AND ADVOCACY**

As an umbrella patients' association, ELPA acts as an intermediary between all the involved stakeholders - the national patients' communities, the scientific community, the industry, and the policymakers. We provide a crucial perspective due to our immediate and direct access to the patients' lives and the best practices in a national and regional context.

ELPA is a member of the following:

- Advisory forum and expert group on HBV and HCV at ECDC.
- Patient and Consumer Working Party and Pharmacovigilance Risk Assessment Committee at EMA.
- Policy and public health committee and Taskforce on Liver Cancer at EASL.
- Advisory Forum at HERA.
- Expert group on HIV, TB, and hepatitis at WHO.
- Expert board at VHPB.

To better communicate with supporters and stakeholders, ELPA obtained the ISO 9001:2015 quality standard in 2021, making it the 1st patients' association in Europe with a quality management system.

## **PARTICIPATION IN MEDICAL RESEARCH PROJECTS**

ELPA is part of 11 EU-funded medical research projects. The participation of patients' associations in these projects is relatively new; nevertheless, being part of them enriches the research field.

## **ELPA VALUES**



**Equality**



**Respect for  
diversity**



**Patient  
driven**



**Commitment**



**Transparency**

# The foreword of the president



In 2022 ELPA continued to collaborate closely with its members on projects developed at the national level. ELPA supported projects of 18 associations in 15 countries.

As the president of the European Liver Patients' Association - ELPA, I am proud to introduce this booklet of best practices at a national level. This booklet is the culmination of efforts from liver patient associations across the European continent and beyond, who have

come together to share their experiences and knowledge. By sharing best practices, we can improve the care and treatment available to liver patients and their families. We recognise that the challenges faced by liver patients can vary widely, depending on factors such as location, resources, and cultural norms. As such, this booklet presents a range of best practices that can be adapted to meet the unique needs of each community.

Furthermore, this booklet serves as a reminder of the importance of interaction between the EU and national levels in different countries. The EU plays a crucial role in setting policies and standards for healthcare across Europe. At the same time, each country has its unique healthcare system and cultural context. By working together, we can ensure that policies and guidelines set at the EU level are implemented in a way that is appropriate and effective for each country. This booklet is an example of how the work of patient associations at the national level can contribute to this broader effort. I hope this booklet will serve as a valuable resource for liver patients, their families,

healthcare providers, and policymakers and inspire further collaboration and innovation in the field of liver disease.

ELPA Members Project Support was not only a mere exercise of funding but also a real engagement from both parties. On one side, it showed the willingness of ELPA members to support their communities. We cannot avoid stressing the effort they put into driving fundamental changes at the local level. Conversely, ELPA had the opportunity to be involved in several local patients' activities for the second year.

Together we are stronger!

*Marko Korenjak*



## The foreword of the ELPA Board of Directors

As the Board of Directors, we are honoured to announce the creation of the new 2022 booklet of good practice, compiled by our members at the national level. This valuable resource offers practical examples based on ELPA members' real-world experiences in their communities; we are proud to have supported them also in 2022 and made it a permanent part of the activities ELPA offers its members.

Our vision is to empower ELPA members by effectively supporting the knowledge and tools they need to advocate for better liver health at the national level. By sharing the collective wisdom of our members, we hope to inspire and raise confidence among other associations but also policy-makers and healthcare representatives facing the challenges of liver disease.

We also must stress how this initiative in 2022 was again not only an opportunity for members to grow in their commitment but also a way to strengthen the European Liver Patients' Association showing what an umbrella organisation should be in synergy with its members.

Additionally, taking part in these national projects was an extraordinary occasion to stay in contact with ELPA members, having regular exchanges about different aspects of the activities there were going to plan. However, these professional communications sometimes gave way to more personal conversations, creating the occasion to feel closer and still 'human' during the pandemic characterised by social distance.

We cannot overstate the importance of this booklet. Liver disease affects millions of people worldwide, and yet there are still many misconceptions and gaps in knowledge surrounding this condition. By bringing together the insights and expertise of our members, we are helping to fill this gap and provide a vital resource for those who need it most.

We would like to extend our heartfelt thanks to everyone who contributed to this booklet with its commitment at the national level. Your hard work and dedication have helped create a valuable tool that will benefit liver patients and be a source of inspiration for other patients' organisations and an opportunity to stimulate new ideas and projects.

Together we are stronger!

*ELPA Board of Directors*



# ELPA Members



## BOSNIA & HERZEGOVINA

- The Chronic Viral Hepatitis Patients Association - B18



## CYPRUS

- Cyprus Liver Patients Association - Promitheas



## EGYPT

- Association of Liver Patients' Care - ALPC



## FINLAND

- The Finnish Kidney and Liver Association



## FRANCE

- SOS Hépatites Fédération



## NORTH MACEDONIA

- Association for health education, prevention and better treatment - HEPTA
- Hepar Centar - Bitola



## NORWAY

- proLAR



## ROMANIA

- Patients with hepatic impairment Association of Romania - APAH-RO



## SERBIA

- Association for helping patients with chronic viral hepatitis - HRONOS



## **SLOVAKIA**

- Šanca pre pečeň



## **SLOVENIA**

- Association - SLOVENIJA HEP



## **SPAIN**

- Catalan Association of Liver Patients - ASSCAT
- National Federation of Liver Patients and Transplanted - FNETH
- Spanish Patient Organization Lysosomal Acid Lipase Deficiency - AELALD



## **SWEDEN**

- Riksföreningen Hepatit C - RHC



## **TURKEY**

- Living with Hepatitis Association - HEPYAŞAM



## **UNITED KINGDOM**

- Liver4Life



# The Chronic Viral Hepatitis Patients Association - B18



## **Info Hep Center B&H**

The project run by B18 aimed to promote the elimination of viral hepatitis in the country by raising awareness using online counselling, including social media and a hotline. The services were run by volunteers who answered by giving peer-to-peer information regarding hepatitis, new treatment options, and health care.

In detail, Info Hep Center activities included:

1. SOS peer-to-peer phone number where the operator was in constant coordination with professional medical staff to provide the users with the best answers to the asked questions.
2. Online counselling: asking questions through the association website and Facebook profile.
3. Printed educational material on hepatitis B and C addressing modes of transmission and availability of therapies.

The COVID-19 pandemic has caused the healthcare system challenges that they have not encountered before. Most hospitals and health care centres have reported delays in screenings, and treatments, pulling away patients. With all these kinds of activities, patient associations can also help people regain trust in the healthcare system.

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# Cyprus Liver Patients Association - Promitheas



## **'I AM WITH YOU!'**

With this project, the Cyprus Liver Patient Association 'PROMITHEAS' wanted to provide psychological support to patients before and after liver transplantation and their smooth integration into their society and families.

Liver transplantation can prolong and improve your quality of life, but waiting for a donor organ can be frustrating and stressful. Unfortunately, in Cyprus, there is no liver clinic or transplant unit. Patients will have to go abroad. These patients often leave their families, homes, jobs, and children to go overseas, waiting for a transplant and the 'right to Life'. That can take months, in some cases years. Coming back home, in addition to the health problems they have to face, many have difficulties in reintegrating into their society.

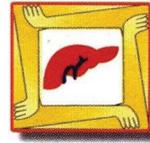
The program aimed to cover the entire island and address all ages and genders.

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# Association of Liver Patients' Care - ALPC



## **Fatty liver awareness/screening for MAFLD**

From a patient perspective, the use of the name NAFLD has at least three major concerns: confusion, stigmatisation, and trivialisation. Hence, they adopted the acronym MAFLD to increase patients' awareness about fatty liver with compelling messages and non-stigmatising terminology. They arranged to scale up our project with the national health authorities across different Egyptian villages.

The project's steps included the following:

1. An awareness-raising campaign delivered by Egyptian Liver Research Institute and Hospital (ELRIAH) staff (Physicians). This was provided through a series of 60-minute talks that addressed commonly asked questions, together with the distribution of booklets, flyers and posters, to the attendance.
2. They also undertook a scoping visit one week beforehand to identify a suitable location for placement of testing instruments (Portable Fibro scan- Scale) and consultation. All areas were inspected to ensure they met the following criteria: reliable electricity, backup electricity sources and computers.
3. Clinical assessment, screening for NCDs and counselling on treatment: body mass index (BMI) was calculated for each patient (kg/height), and blood pressure and HBA1C were measured to screen for critical NCDs - hypertension and diabetes. Clinical examination and counselling, and guidance about lifestyle and diet were provided.
4. House-to-house visits for those who do not attend the campaigns and the use of promotional materials (e.g. booklets, cartoons, songs) to raise awareness and promote behavioural and lifestyle changes.

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# The Finnish Kidney and Liver Association



## The Liver Week

In 2022 the Finnish Kidney and Liver Association emphasised increasing public knowledge about different liver diseases and the importance of providing early diagnoses for all liver patients. Early diagnoses offer a better choice of care and prognosis. They believed that overall care standards should be reviewed and improved together with people who suffer from these illnesses. Improvements should be ongoing, particularly in Finland, as new care standards in larger well-being areas have been discussed. Patient involvement is crucial to influence healthier life choices, preventative care services, and easier access to diagnosis.

During the week of May 9-13, 2022, 3 press releases were also published. Press releases supported seminar contents and had a named health professional answering further questions for details and scientific facts. They also had active social media marketing for the events, as well as to raise public awareness for liver health. Live seminars were followed by approximately 350 people with more than 350 views on YouTube. The translation of the short version of the ELPA and DiCE White Paper on liver cancer into Finnish was also promoted.

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## CONTACT

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## **NASHletter**

Everything you always wanted to know about NASH but were afraid to ask, well, from now on, SOS Hépatites will try to answer you.

SOS Hépatites was formed in 1996 by patients who wanted to share their experiences and find answers to their questions about hepatitis C. To do this, they created an association, a transmission belt between the world of patients and that of caregivers.

SOS Hépatites has now become “SOS Hépatites and Liver Diseases”. For 15 years, they have seen the NASH epidemic appear and grow; they have heard the concern of patients, their isolation, their stigmatisation and their difficulties in finding information. All this is associated with the impotence of medical professionals and the absence of a political response.

It was, therefore, natural for the association to transfer their experience and skills into the battle against NASH. Today the first right of a patient is to be well informed, and this is the *raison d'être* of this “NASHletter”.

Main objectives of the project:

- Create a space of information for patients and their families.
- Create a space of solidarity, questions and answers for patients and their families. Here is a new experience of health democracy.

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## Association for health education, prevention and better treatment - HEPTA



### **What to Know About Liver Disease and COVID-19, post-COVID Complications, Availability of Therapy for Liver Disease and Vaccination**

Coronavirus disease 2019 (COVID-19) is the illness caused by the SARS-CoV-2 virus. Older adults and people of any age with underlying severe medical conditions, including people with liver disease, might be at higher risk for severe illness from COVID-19. People with chronic liver disease, including hepatitis B and hepatitis C, may have concerns and questions about their risk.

The association organised an interactive workshop for students in the State University of Skopje, Tetovo and Stip to stimulate a discussion around some questions about liver disease and COVID-19, vaccination, availability of therapy for liver disease, and post-COVID complications.

The main questions were:

1. Does COVID-19 damage the liver?
2. Are people with hepatitis B or C at higher risk for more severe illness from COVID-19?
3. Are people with cancer, like hepatocellular carcinoma (HCC), at increased risk for severe COVID-19?
4. Are people who live in areas that have experienced an outbreak of hepatitis A in the past year still at risk for hepatitis A during the COVID-19 pandemic?
5. What can people with hepatitis B or C do to protect themselves from COVID-19?
6. What can people with substance use disorder and liver disease do to protect themselves from COVID-19?
7. What should I do if I think I might have COVID-19 or have been exposed to a person with COVID-19?

8. What else can people with chronic liver disease do to protect themselves from COVID-19?
9. Can antivirals used to treat hepatitis B or C be used to treat COVID-19?
10. Are shortages of hepatitis B or C medicine expected?
11. Should people with chronic liver disease travel at this time?
12. Do people living with or at risk of viral hepatitis need to take special precautions to prevent COVID-19?
13. What can everyone do to minimise the stigma about COVID-19?
14. Are the COVID vaccines safe and effective for people with liver disease-particularly those who are immunosuppressed or those who had a transplant?
15. The availability of therapy for liver disease during the pandemic.
16. Possible post-COVID complications in patients with liver disease.

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## Hepar Centar – Bitola



### **World Hepatitis Day**

The opening of the liver centre in the country was scheduled for 2022 and approved by the government. Together with the coordination body and the gastroenterology clinic, the association managed to insert the therapy for hepatitis C as regular therapy for patients (No more conditional budgets).

Using essential messages and appropriate graphical designs, the campaign designed by the association was crafted to raise awareness among the decision-makers and to engage patients, clinicians, and policymakers, in this process. The Social Media campaign promoted the liver centre and the possibilities for early detection of Hepatitis C and cure. The focus was not only on prevention, exploring the policy solutions that could best contribute to tackling Hepatitis at the national level to avoid discrimination and stigmatisation, but also on the need for screening, innovation, diagnosis, and treatment.

To summarise, the project's objectives were to heighten awareness of the need to tackle Hepatitis at the policy level among decision-makers to present concrete steps.

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### **CONTACT**

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## **Test and treat**

The project's main objectives were testing people who use drugs for HCV RNA to treat people who are positive with DAA medications as fast as possible and secure awareness in the PWID community.

proLAR Nett run a mobile HCV clinic in urban cities in Norway. The project was limited to one week per month. The association wanted to offer "test and treat" as a low-threshold opportunity for others. At the organisation premises, "open test and treat days" were also organised during these periods when the mobile car was not in use. They used their medical equipment as GeneExpert, and Fibroscan, to perform these tests, and a doctor was available to be called for prescriptions.

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# Patients with hepatic impairment Association of Romania - APAH-RO



## **Round table - post-pandemic Viral Hepatitis - the road to the elimination a challenge**

A round table was carried out in partnership and under the auspices of the Senate Health Commission of the Romanian Parliament as a preamble to the European Testing Week May 16-23, 2022. The event assessed Romania's situation regarding Viral Hepatitis elimination, suggested concrete solutions for Romania to resume its path towards elimination and gave an insight into the steps already taken and how the pandemic impacted the implementation of the National Strategic Plan for the Elimination of Viral Hepatitis three years after its launch in May 2019. A discussion was also opened around the next cost/volume/outcome contract for Hepatitis C and access to new antiviral therapies in hepatitis C and B/D. In addition, the round table wanted to encourage people from all backgrounds to be tested for early detection of Viral Hepatitis and encourage family doctors to get involved in testing.

The project's second part consisted of buying 800 rapid tests for Hepatitis B and C and using them around World Hepatitis Day 2022. Street events were organised in Turda and Campia Turzii, Cluj County and Giurgiu and Comana, Giurgiu County. Informative materials were distributed in various locations in the counties: Brasov, Iasi, Mehedinti, Prahova, Cluj and Giurgiu. The volunteers involved in the APAH-RO actions dedicated to World Hepatitis Day wore white T-shirts, most of them with dedicated messages. 400 tests for infection with virus B and virus C were used, which were used in the street campaign in Campia-Turzii, as well as in the offices of some family doctors with the headquarters of the APAH-RO Cluj branch, respectively the headquarters of ABCH-Giurgiu.

The International Day revolved around the central message - Hepatitis can't wait! In this context, all public messages emphasised the importance of updating and financing the National Strategic Plan for the Elimination of Viral Hepatitis as a natural consequence of continuing the actions after the Round Table.

To mark World Hepatitis Day in Romania for the first time after a long time, a press conference was organised by the Ministry of Health with APAH-RO.

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## Association for helping patients with chronic viral hepatitis - HRONOS



### **HEP FREE BADGE - education of professionals in the beauty parlours, the second phase**

In beauty parlours, all procedures leading to skin and mucous membrane damage and bleeding represent the risk of transmitting viral diseases.

HRONOS's project aims to inform employees about infectious diseases, emphasise viral hepatitis, mode of transmission, health complications, and the socio-psychological impact of hepatitis (stigma and discrimination) and inform them also about the correct choice of sterilisation method and adequate procedures, disposal, use, and storage of materials to improve professionalism and protect employees and clients. Standardisation of processes in beauty parlours according to EU standards-sterilization protocol is also advisable.

The project will be implemented with the Association of Aesthetic and Health Professionals EstetikPro from Serbian, the Serbian Institute of public health and the Serbian Health Ministry as an online webinar with 20 beauty parlour representatives. Two questionnaires will be given to the participants at the beginning and end of the workshop. Replies to the questionnaires will be used to develop the topic further. An epidemiologist, a sanitary inspector, an engineer of safety at work, and a patient expert will be giving presentations - a professional beautician will present the cosmetic procedures that can cause injuries - a beauty parlour representative will explain how to sterilise instruments correctly.

After finalising the team and logistic and technical aspects related to the record of the webinars, in 2022, the association filmed two 30-minute tutorials in the Hollywood beauty salon as an example of good practice. They focused

on the sterilisation process and procedures that may cause mucosal abrasion (risk for transmission of viruses).

In 2021 HRONOS just started finalising the team and logistic and technical aspects related to the record of the webinars.

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# Šanca pre pečeň



## **Preventive Actions in liver diseases**

There were several planned activities for the members of the association. They began in May 2022 with the Education Meeting in High Tatra. Gastrologists, hepatologists, and food specialists were invited together with 50 members of the association.

In June, another two activities were organised: "Discussion with a physician", dedicated to the students of the secondary schools in Zvolen regarding the danger of drug abuse, and "Sports weekend" for members, which was held in Dudince. During the entire weekend, members had the opportunity to try many activities such as swimming, cycling, mini golf, throwing cans, bowling, ping pong, billiard, and fast walking.

During the summer, a "Hiking Day" was planned. In September, the association scheduled the meeting "Be health by right food" with the famous Slovak chef Mr Herko, who worked for a long time for Slovak television. He cooked delicious and healthy meals and revealed healthy recipes to increase the knowledge in the health preparation of food, especially for patients with NASH. The last was "Christmas happening", where all the activities previously organised within the year were assessed and discussed.

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## Association - SLOVENIJA HEP



### **Free and anonymous HCV testing for the general public**

The organisation urged people to get tested for hepatitis for free and anonymously. The proposal received support from medical students, who used social media to promote the group. To encourage more people to be tested, free hepatitis screenings were provided. ELPA supported the hepatitis testing kits and the lab work.

Volunteer members of the medical community supported the effort. Medicine students took part to gain practical experience and spread awareness about the importance of hepatitis testing. Students spread awareness about the initiative through various social media platforms, informed the general public and special patient groups, and encouraged participation in the study. The association and hepatitis testing were both boosted by social media promotion efforts.

The project disseminated information regarding testing locations, results, and patient experiences on Facebook, Instagram, and Twitter. The campaign reached more people and engaged new audiences thanks to social media's assistance. The group demonstrated its commitment to the medical community by awarding funds that led to improvements in the treatment of hepatitis. The effort successfully convinced the general population to participate in confidential, free hepatitis screenings. Testing was made more accessible, and better care was provided because of the efforts of medical students, social media, and medical equipment donors. As a result, this was one of the most successful testing years of the decade.

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# Catalan Association of Liver Patients - ASSCAT



## **Webinars on Primary Liver Cancer, hepatocellular carcinoma (HCC)**

It is not usual to have the opportunity to know about the entire process of liver cancer, which is complex and involves different specialists and the point of view of patients. This is why these webinars focused on informing patients and families about various issues around liver cancer in an updated way and were presented by specialists who are leaders working in different fields related to HCC. They are available on the ASSCAT Youtube channel.

Titles and topics:

- *Liver cancer.*  
Risk factors. Natural history of chronic liver disease and cirrhosis. Strategies and screening programs in Catalonia. Quality of life health-related in liver patients.
- *I was just diagnosed with liver cancer; now what?*  
Information to the hepatic patient. The role of the liver patient association. How the doctor informs the patient. How to manage the news.
- *A multidisciplinary approach to liver cancer.*  
The management by a multidisciplinary team. Clinical coordination experience: Hepatology-Nursing.
- *Symptoms of liver cancer, the role of nurses.*  
Resource optimisation. Controls by nursing teams. Treatments coordination. Therapeutic advice. Exercise. Nutrition.
- *Medical-surgical treatment options for liver cancer.*  
Surgical treatment. Transplant. Loco-regional treatment: chemo-embolization, ablation.

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## **CONTACT**

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## Catalan Association of Liver Patients - ASSCAT



### **7/24 online support**

In 2022 the association also expanded its service of 7/24 support for patients and families with liver diseases. Active listening focused on updated information and support between pairs.

The telephone service received 1,196 calls in 2022 on the headquarters landline (served by 2-3 Association volunteers) and on the mobile phone for emergencies, answered by an expert volunteer. In addition, 526 inquiries have been answered via WhatsApp and Telegram, more than 60% from outside Spain or residents without a health card. On the other hand, 54 people visited the headquarters by appointment and when the health circumstances caused by COVID-19 allowed it. In 2022, 1,350 emails with inquiries about different aspects of hepatitis B/C, autoimmune hepatitis, hepatic steatosis and hepatocarcinoma (HCC) were received. To guarantee the confidentiality of users and offer better service, the association diverted all inquiries received through social networks, especially Facebook, to phone and email.

Approximately 75% of the queries received by email come mostly from people outside of Spain, especially from South America. They also received 320 emails from patients requesting information about medications. Calls related to hepatitis C have decreased considerably, mainly due to fear of infection. On the contrary, the number of telephone calls and emails referring to HBV, autoimmune hepatitis, fatty liver, primary biliary cholangitis (PBC), and liver involvement due to alcohol consumption have increased exponentially.

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# National Federation of Liver Patients and Transplanted - FNETH



## **No me corto**

FNETH, in collaboration with the federated associations from all the national territory, announces the I Concurso de cortos para jóvenes sobre alcohol y otras drogas hepatotóxicas (1st Short Film Competition For Young People About Alcohol and Other Hepatotoxic Drugs). The competition will be developed during the school term (2022/2023). It is divided into two categories: one dedicated to young people aged 13 to 15 and one to those between 16 and 18. With a maximum length of 20 minutes, the films must be original and can also be an animation.

A jury will be formed, including a representative of the federated associations of the entire national territory, a representative of the National Plan on Drugs and one from the artistic field. The selection of the winners will take place in two phases. Firstly, a pre-selection of 7 shorts will be carried out by popular vote through the page: [www.fneth.org](http://www.fneth.org). Then, the shortlisted shorts will be evaluated by the jury awarding the short film that best reflects the consequences of the consumption of legal and illegal drugs and their relationship with liver diseases, the damage they cause to the liver, the risky practices that derive from their consumption and the behaviours that lead, in many cases, to risky sexual relations, thus favouring the transmission of diseases.

They hope to reach at least 20.000 people through the publication of the short films on social networks and through the award ceremony.

The project's scope is to raise awareness about the consequences of legal and illegal drug use and to make visible the people with these problems' needs and the resources of the associations that work with them.

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## **CONTACT**

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# Spanish Patient Organization Lysosomal Acid Lipase Deficiency - AELALD



## **IV Meeting of Experts and Families Affected by Lysosomal Acid Lipase Deficiency (LAL-D)**

LAL-D is considered ultra-rare, only affects 45 people in Spain, and is also known as Wolman's Disease or Cholesterol Ester Storage Disease (CESD).

The association that brings together families affected by LAL-D organised the IV Meeting of Experts and Affected Families in Madrid on November 25-26, 2022. During the meeting, the activities carried out by the association during the year and the news regarding the research projects carried out by a committee of experts were presented. In addition, the association brought together many experts intending to advance the research's projects.

Dr Maria Mercadal, Assistant Physician Pediatrics | Paediatric Hepatology and Liver Transplantation Unit at Vall d'Hebron Hospital in Barcelona, spoke about the critical aspects of Lysosomal Acid Lipase Deficiency in the transition to adults. Júlia Pijuan and Cèlia Rodríguez, both dietitians and nutritionists of the Unit of Vascular Medicine and Metabolism UVASMET and the Unit of Research in Lipids and Arteriosclerosis (URLA) of the Hospital Sant Joan de Reus., presented about Healthy Nutrition for LAL-D and the Website LAL-D your way which helps affected patients manage the disease nutritionally. Félix de la Fuente, Medical Science Liaison - Alexion, explained what the International Alexion Registry is, in which doctors enter patient data anonymously. Francesc Cayuela, IT consultant linked to hospital centres, and Andrea Lisbona presented the Patient 73 Project, which aims to be a platform to be used by patients, families, health professionals and researchers internationally. Julio Burman, ELPA Vice-President, explained to the attendees

the function of ELPA that brings together associations of patients with liver diseases in Europe, showing the families that AELALD has initiated an international process as a patient organisation.

Parallel to this meeting, the day before the IV Meeting of Families, a meeting of experts in the disease was held, gathering health professionals from different disciplines: medicine, biology, nutrition, information technology, etc.

The importance of this congress lay in having the possibility of putting all affected patients and their families in contact to create a compact and coordinated group to achieve greater dissemination of knowledge about this severe disease and, of course, try to achieve sufficient economic support to initiate lines of research that allow the cure of the disease in the coming years. The current and only existing pharmacological treatment delays the progression of the disease to those affected, so it is vital to continue researching this pathology to learn more about it and, in the future, to be able to find a cure.

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# Riksföreningen Hepatit C – RHC



## **Transplantation and stakeholder cooperation in Sweden**

Thanks to many contacts with other NGOs active in different fields and many areas of the country, the Swedish organisation found out that there are many urgent unmet needs related to transplantation, and they can make a difference working together, tackling different aspects: economic, psycho-social, legal, pre-and post-surgery, research.

The project had the following objectives:

1. How can cooperation between representatives of different diseases and patients at risk of transplantation be improved?
2. More support than before for pre- and post-transplanted patients.
3. Broaden the picture of transplantation, facilitate the collaboration between patients and caretakers, and researchers and the industry to get more information and know more about the patient's perspective.
4. Get more information thanks to MOD (More Organ Donation), an organisation started in 2012.

Two meetings were organised to coordinate the work of this multistakeholder initiative with people coming from all parts of Sweden to reach patients all over the country, also because organs have to be shared between different geographical regions of Sweden.

1. Patient security and transplantation in Stockholm.
2. The Public Health Authority meeting on improving help to and cooperation with NGOs, HIV and hepatitis in focus.
3. Catch-up-meeting for patients not able to attend.

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### **CONTACT**

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# Living with Hepatitis Association - HEPYAŞAM



## HEPAVISION - learning hepatitis from students' cameras

The association came up with the idea of organising a competition of short videos about hepatitis dedicated to students enrolled in Turkish universities' cinema and television departments.

The aim was to raise awareness of hepatitis because, during the COVID-19 pandemic, hepatitis was somehow neglected. Due to the pandemic, many patients refrained from going to health institutions or delayed their treatment. They wanted to draw attention to hepatitis again. and inform society about it.

Announcement posters were sent to universities. In addition, announcements were made regularly on social media. A separate web page dedicated to the competition also included information about hepatitis. The participants could choose one or two subjects related to hepatitis, such as vaccination, stigma, access to treatment, transmission routes, and discrimination, to be tackled in a 90-second video. The deadline for submission was on July 28, 2022, World Hepatitis Day.

A Jury was also elected to evaluate the submissions and announce the winners who will have visibility on social media and in health-related TV programs.

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## CONTACT

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Liver4Life



## Helpline Support

The Liver4Life free Helpline is dedicated to providing support to all people affected by a liver condition. In 2022 Liver4Life strengthened this service which has proved to be crucial for the community.

The calls received in 2022 showed a slight decrease overall from 2021 when support was provided to more than 1,000 people, but the average time spent on each individual call rose to over 30 minutes.

In the previous year, the number one reason for calling had been mainly around COVID-19; however, in the last year, questions were primarily related to GP blood results and travel insurance. This suggests that people affected by liver conditions are now becoming less concerned about the effects of COVID-19 and more about how they can move on with their lives. There was also a higher proportion of people who requested dietary advice than usual.

The team leader's ability to share his knowledge and experience of living with a liver transplant and a liver condition has been invaluable.

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## CONTACT

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ZDRAVJE > AKTUALNO

# Na UKC Ljubljana anonimna brezplačna testiranja na hiv ter hepatitis B in C

AVTOR: S. H. H. | 23. NOVEMBER 2016, OB 12:00



ZURNAL24 MAIN

100% SLOVENIJE



CREATE INSTANT FLIPBOOKS & EBOOKS



VEČ S SPLETA

Ročno žile izginjajo za vedno. Pred spanjem morate le...





# Ste prepričani, da ste zdravi?

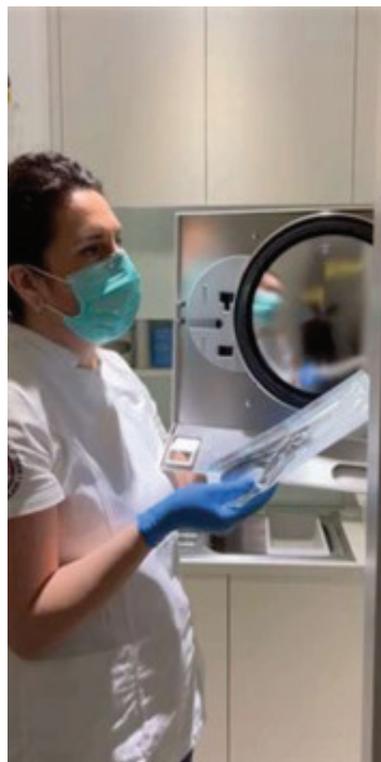
4 od 5 žensk, ki imajo hepatitis C, se tega ne zaveda. Pravočasno odkrivanje in zdravljenje preprečujeta kronično bolezen jeter, cirozo in raka jeter.

Poiščimo (vse) okužene. Testirajte se!













SUPA ENETH



CICLO DE WEBINARS SOBRE HCC – 2022

Roche

Obra Social  
Fundación de la Roche

ELPA

ASSCAT

**MI 02.11/  
de 17h a 18h**

**EL TRATAMIENTO MÉDICO-QUIRÚRGICO DEL CÁNCER DE HÍGADO**

Ponentes: Joana Ferrer, consultora del Servicio de Cirugía General y Digestiva y miembro de la Unidad de Oncología Hepática del Hospital Clinic de Barcelona; Marc Pulgarri, hepatólogo y responsable del tratamiento médico del HCC en el Hospital del Mar (Barcelona).

Webinar 1 Aspecto epidemiológico del hepatocarcinoma

- La incidencia es 2-4 veces mayor en hombres que en mujeres
- La edad media de aparición en nuestro medio está sobre los 60 años (etiología por VHC, alcohol, Enfermedad por hígado graso no alcohólica). En Africa y sudeste asiático aparece sobre 30-40 años (el principal factor etiológico es la infección por VHB adquirida al nacer por transmisión materno-fetal)
- Distribución de la mortalidad por hepatocarcinoma

Rate
> 12.0
10.0 - 12.0
8.0 - 10.0
6.0 - 8.0
4.0 - 6.0
2.0 - 4.0
< 2.0









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