



Together we are
stronger!

**ELPA MEMBERS'
PROJECTS SUPPORT
2024**

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Our mission

Founded in 2005, the European Liver Patients' Association (ELPA) was born out of a collective aspiration among liver patient groups across Europe to exchange insights about the varying strategies employed in managing liver disease in different nations. Today, ELPA is a comprehensive network representing 39 member organisations from 29 countries.

ELPA's core mission is to advocate for individuals affected by liver conditions by undertaking several key initiatives. These include raising awareness of the substantial impact of liver diseases, promoting preventive measures, increasing the visibility of liver conditions in health discourse, disseminating knowledge from successful health campaigns, and collaborating with healthcare professionals to standardise the quality of care for liver disease across Europe.

Our vision is a future where all patients with liver diseases are diagnosed promptly, treated with dignity, and have equitable access to the highest standard of medical care, irrespective of their background, lifestyle, or the nature of their liver condition.

ELPA's efforts are focused on three main pillars.

MEMBER EMPOWERMENT

ELPA is an organisation of patients, by patients, and for patients. We are devoted to empowering those we represent through comprehensive training programs, capacity-building initiatives, and fostering a supportive network. Our structure includes ten specialised working groups, each designed to enable expert patients to deepen their expertise in distinct areas of liver disease. These groups are instrumental in bolstering our community's knowledge and advocacy.

POLICY AND ADVOCACY

As a leading umbrella patients' association, ELPA serves as a link among key stakeholders in the liver disease community, including national patient groups, researchers, the medical industry, and policymakers. Our unique position allows us to offer essential insights drawn from direct engagement with patient experiences and best practices observed on both national and regional levels.

ELPA proudly holds membership in several influential bodies, which allows us to amplify the patient voice and contribute to shaping health policy.

In our commitment to excellence and effective communication with our supporters and stakeholders, ELPA achieved the ISO 9001:2015 quality standard in 2021. This certification recognised us as the first European patients' association to implement a quality management system, demonstrating our dedication to high standards and continuous improvement. In 2023, ELPA successfully renewed its ISO certification.

PARTICIPATION IN RESEARCH PROJECTS

ELPA is currently involved in more than 20 groundbreaking projects driving innovation in medical research, education, and patient advocacy. Collaborating with more than 300 researchers, policymakers, and industry leaders, ELPA emphasises the crucial role of patient engagement in shaping effective healthcare solutions.

ELPA VALUES



Equality



**Respect for
diversity**



**Patient
driven**



Commitment



Transparency

The foreword of the President



In 2024, ELPA continued to collaborate closely with its members on projects developed at the national level. ELPA supported projects of 18 associations in 14 countries.

I am delighted to present this compilation of exemplary practices at the national level. This compendium represents the collective endeavours of liver patient associations across Europe and beyond, united in their commitment to exchanging experiences and expertise. By disseminating

best practices, we aim to enhance the quality of care and treatment accessible to liver patients and their loved ones. We acknowledge the diverse array of challenges liver patients encounter, influenced by factors such as geographical location, available resources, and cultural contexts. Thus, this compilation offers a spectrum of best practices adaptable to cater to the distinct requirements of each community.

Moreover, this compendium underscores the significance of collaboration between the European Union (EU) and national entities within various countries. The EU is pivotal in formulating healthcare policies and standards throughout Europe. Simultaneously, individual nations possess unique healthcare frameworks and cultural nuances. Through cooperative efforts, we endeavour to ensure that EU-derived policies are implemented in a manner that is suitable and impactful for each one. This booklet exemplifies how the advocacy work of national patient associations contributes to this broader objective. I aspire that this booklet will serve as an asset for liver patients, their

families, healthcare professionals, and policymakers, fostering further synergy and innovation in the field of liver disease.

The support extended through the ELPA Members Project Support transcended mere financial assistance, embodying a genuine commitment from both parties. On the one hand, it demonstrated the dedication of ELPA members to bolster their communities, underscored by their concerted efforts towards effecting significant changes at the grassroots level. Conversely, ELPA seized the opportunity to actively participate in local patient-centric initiatives, further solidifying its engagement with its members for the third year.

Together, we are stronger!

Marko Korenjak



The foreword of the ELPA Board of Directors

As the ELPA governing body, we take great pride in announcing the launch of the new 2024 booklet of ELPA members' projects. This significant publication presents practical examples derived from the real-world experiences of ELPA members within their respective communities. We are privileged to have supported our members throughout 2024, for the fourth year, integrating it as a permanent instrument for supporting members.

The significance of this compendium cannot be overstated. Liver disease afflicts millions globally, yet misconceptions and knowledge gaps persist. By consolidating the insights and expertise of our members, we would like to bridge this gap and furnish a crucial resource to those most in need.

Our overarching vision is to empower ELPA members by furnishing them with the knowledge and tools to effectively advocate for improved liver health on a national scale. By disseminating our members' best practices, we aspire to inspire and bolster confidence among

fellow associations, policymakers, and healthcare stakeholders grappling with the complexities of liver disease.

We extend our heartfelt gratitude to all those who contributed to this booklet through their unwavering commitment at the national level. Your dedication has culminated in creating a valuable tool that will benefit liver patients, inspire fellow patient organisations, and stimulate the inception of novel ideas and initiatives.

Furthermore, participating in these national endeavours also provided an exceptional opportunity to maintain communication with ELPA members, facilitating regular exchanges on various aspects of ongoing activities. There were occasions for more personal interactions, fostering a sense of closeness.

It is imperative to underscore that this initiative in 2024 was not merely a platform for member growth but also served as a mechanism to fortify the European Liver Patients' Association, exemplifying the symbiotic relationship it shares with its members.

Together, we are stronger!

ELPA Board of Directors

ELPA Members receiving funding in 2024



BOSNIA & HERZEGOVINA

- The Chronic Viral Hepatitis Patients Association - B18



CROATIA

- Croatian Association for HIV and viral hepatitis - HUHIV



EGYPT

- Association of Liver Patients' Care - ALPC



FINLAND

- The Finnish Kidney and Liver Association



FRANCE

- SOS Hépatites & Maladie du foies



NORTH MACEDONIA

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



ROMANIA

- Patients with Hepatic Impairment Association of Romania - APAH-RO



SERBIA

- Association for helping patients with chronic viral hepatitis - HRONOS



SLOVAKIA

- HEP HELP KLUB
- Šanca pre pečej



SLOVENIA

- Association - SLOVENIJA HEP



SPAIN

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



SWEDEN

- Riksföreningen Hepatit C - RHC



TURKEY

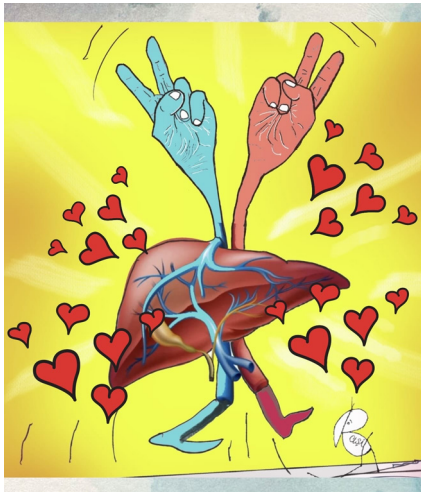
- Living with Hepatitis Association - HEPYAŞAM



UNITED KINGDOM

- British Liver Trust
- Liver4Life





OBELEŽUJEMO SVETOVNI DAN HEPATITISA: Testiranje pri nas brezplačno in povsem anonimno

Slovenija
 Danes obeležujemo svetovni dan hepatitisa, letošnje pod sloganom **Ukrepite se. Zdravite se. Cepite se.** Nevladne organizacije ob dnevno, ki ga obeležujemo 15. leto završni, izpopolnjen projekt Evropske, namenjen izboljšanju zdravstvenih oblik in izboljšanju dostopa do testiranja za nekatere najbolj razširjene skupine v družbi.







The Chronic Viral Hepatitis Patients Association-B18



The Virus Project: Fighting Hepatitis B & C in Bosnia and Herzegovina

The Chronic Viral Hepatitis Patients Association “B18” launched *The Virus* project to combat hepatitis B and C in Bosnia and Herzegovina. From May to December 2024, the initiative focused on raising awareness, offering counseling, and promoting testing through digital platforms, educational materials, and artistic performances.

Key Activities and Achievements

1. Support Services & Awareness Campaigns

- A dedicated SOS telephone line provided essential information and support, ensuring seamless coordination with medical professionals and testing centres.
- Online consultations via the association's website and Facebook page facilitated expert advice in partnership with leading hospitals.
- World Hepatitis Day (July 28, 2024) was marked with an awareness campaign in Banja Luka, where volunteers distributed educational materials and encouraged testing.

2. Strengthening Capacity

- 1,000 brochures detailing transmission, prevention, and treatment were printed and distributed.
- The association's website was updated, and hepatitis B and C tests were procured and used in community screenings.

3. Educational Theater Play “Virus”

- A team of professionals created an engaging educational play, including a director, choreographer, and actors.
- The November 4, 2024, premiere attracted 150 attendees, including healthcare professionals and policymakers.
- Five additional performances for high school students and the public helped spread awareness, with educational materials provided at each event.
- Audience knowledge retention was measured through pre- and post-performance evaluations.

The *Virus* project successfully combined healthcare, education, and the arts to advance hepatitis awareness and prevention in Bosnia and Herzegovina.

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Croatian Association for HIV and viral hepatitis - HUHIV



Elimination of Hepatitis C in the Prison System

The Croatian Association for HIV and Viral Hepatitis launched this initiative to improve hepatitis C detection and treatment in prisons. The project focuses on systematic screening, early treatment, and reducing HCV transmission within correctional facilities. By addressing this high-risk population, the initiative also helps prevent the spread of infections into the broader community and strengthens data collection on infectious diseases among incarcerated individuals.

In collaboration with the Ministry of Justice, the Prison System and Probation Administration, and the Diagnostic Center in Zagreb, rapid oral fluid tests for HCV were procured and administered to prisoners. A dedicated expert was assigned to coordinate testing and healthcare inclusion across multiple prison institutions. Educational sessions were also provided for prison staff and inmates to raise awareness about hepatitis C prevention and treatment.

Screenings focused on prisoners with a history of drug use, as they represent a key at-risk group. Those who tested positive were further evaluated for HCV RNA to confirm infection and initiate treatment. Continuous efforts ensured that diagnosed individuals were adequately integrated into the healthcare system, even if detected before the project's official launch.

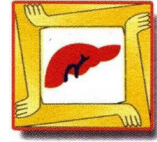
In 2024, 159 prisoners were tested, with 36 identified as anti-HCV positive. Among them, 18 were confirmed as HCV RNA positive, while 22 individuals completed treatment. However, challenges remain, as some prisoners were unavailable for treatment due to release, refusal, or relapse.

The project aims to establish permanent HCV testing and treatment programs in prisons, improve data collection on substance abuse-related infections, and reduce the overall spread of hepatitis C within correctional facilities and beyond. Continued collaboration with penitentiaries, healthcare institutions, and policy-makers will ensure long-term impact and sustainability.

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Association of Liver Patients' Care-ALPC



Evaluate the extent of liver fibrosis & Steatosis among diabetic patients using FibroScan

This project aimed to educate diabetic patients and their families about the importance of liver health monitoring, early detection of complications, and the benefits of non-invasive assessments such as FibroScan. By combining awareness campaigns with advanced screening techniques, the initiative sought to improve patient outcomes and enhance overall healthcare management.

A series of educational sessions were conducted by healthcare professionals, focusing on the link between diabetes and liver disease. These sessions provided valuable information on liver fibrosis, steatosis, and hepatocellular carcinoma (HCC) risk, emphasizing the role of regular monitoring. Attendees received booklets, flyers, and posters to reinforce key messages.

To further support patient care, FibroScan examinations were carried out to assess liver fibrosis and steatosis. Data collection included patient demographics, diabetes history, and test results, helping to establish correlations between diabetes severity and liver health. The results guided risk stratification, clinical management strategies, and recommendations for lifestyle modifications or medical interventions.

The project established a framework for longitudinal monitoring, with follow-up FibroScan assessments scheduled every six months. This approach ensures continuous tracking of liver health changes in diabetic patients, allowing for early intervention and better disease management. Additionally, HCC surveillance was introduced for high-risk individuals, enhancing early detection efforts.

By combining education, screening, and ongoing monitoring, this initiative strengthened liver health awareness and improved healthcare strategies for diabetic individuals. Moving forward, expanding access to non-invasive liver assessments and fostering continued education will remain priorities to enhance patient care and long-term health outcomes.

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The Finnish Kidney and Liver Association



Liver Week 2024

In Finland there are still a large population in working age people, who consume alcohol regularly. In some cases, alcohol consumption is high, and it has become an ordinary everyday product with meals as well as ever-growing recreational goods. Both events aimed at understanding what alcohol does to liver health, how addictive it may get and what can be done about it.

Short description of the project:

1st event: Broadcast from the studio: Professor Perttu Arkkila Liver health and alcohol, Dr. Kaarlo Simojoki; How addiction is formed and its consequences to our health, Mr Antti Nisula; How I became addicted and cured.

2nd event: Helsinki University open forum and Streamed event: Member of EU parliament Sirpa Pietikäinen; How Europe is talking about Liver Health, Dr. Kimmo Salminen; Am I in danger to get a liver disease, Physiotherapist Jaana Ahoranta; It is possible to change old habits.

Several press releases as well as social media inputs were produced. Both events were broadcasted to a wider audience and recorded as well as stored in the association's YouTube channel.

Educational peer day for Rare Disease patients

The main objective of the project was to bring together rare disease patients from different parts of Finland to share knowledge and experience. This event was for AIH, PBC and PSC patients and patient with PCS and IBS.

Short description of the project:

The event was composed by an online lecture: Effect of over-the-counter medicine combined with prescribed medicine - How to succeed with medication in a safe way; Mika Wallin, pharmacists and trainer, Kauhava Pharmacy. An on-site lecture: Rising costs for patients with long term liver illnesses; Elisa Arvola, health and social care expert, IBS association (after the lecture questions about support services was asked individually and privately). The day was wrapped up with an on-site activity: Pilates and gentle movement; Marjo Äärelä, physiotherapist. Dinner and networking followed.

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Fédération SOS hépatites & Maladies du Foie



June Without Added Sugars 2nd edition - 2024

The “*Juin Sans Sucres Ajoutés*” (June Without Added Sugars) challenge, launched by SOS Hépatites & Maladies du Foie, encouraged participants to reduce or eliminate added sugars for a month. The initiative aimed to raise awareness about the impact of excessive sugar consumption on health, particularly in relation to metabolic dysfunction-associated steatohepatitis (MASH) and fatty liver disease. The 2024 edition, supported by ELPA and other partners, sought to expand participation and enhance public engagement.

Building on the success of 2023, the 2024 challenge introduced a dedicated website and strengthened partnerships to reach a broader audience. Participants joined different engagement levels, from casual observers to ambassadors promoting the challenge within their communities. The initiative emphasised the collective aspect, creating an interactive space for sharing recipes, tips, and support. A structured online survey helped track participant experiences and long-term dietary changes.

The 2024 edition saw a significant rise in participation, growing from 500 to over 3,500 registered participants. Among respondents, 88% reported reducing their sugar intake, while 76% became more mindful of food choices. A key finding was the link between sugar reduction and decreased consumption of ultra-processed foods. Additionally, 52% of participants who previously consumed industrial meals reported stopping entirely, and 40% eliminated industrial desserts.

The challenge is set to continue in 2025 with an expanded focus on research, collaborating with Inserm UMR 1252 SESSTIM for a scientific study on the long-term effects of sugar reduction. By fostering awareness, advocacy, and healthier dietary habits, “*Juin Sans Sucres Ajoutés*” aims to create lasting change in sugar consumption behaviours and public health.

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Association for health education, prevention and better treatment-HEPTA



It's time for action! Viral hepatitis B and C in North Macedonia

This initiative aimed to increase awareness and knowledge about viral hepatitis B and C, focusing on transmission, prevention, diagnosis, and therapy. It also seeks to introduce advocacy and lobbying skills to the general population, highlighting the urgent need for action against hepatitis-related health risks. Given that the liver performs over 500 vital functions daily, early detection, treatment, and prevention of viral hepatitis are crucial in reducing increasing mortality rates. The project aligned with World Hepatitis Day 2024 on July 28 under the theme *"It's Time for Action."*

The project emphasised improving treatment standards for those infected with hepatitis B and C by providing essential medical knowledge. Public awareness efforts focused on reducing stigma, supporting affected individuals and their families, and advocating for policy changes that improve healthcare accessibility. Professional consultation services ensured that patients received accurate information on their rights and treatment options.

To address gaps in testing and treatment coverage, interactive workshops were held for general practitioners, as they play a key role in early diagnosis and patient support. These workshops and educational lectures were conducted in collaboration with healthcare and social institutions, NGOs, and local authorities. Printed materials were distributed to support public education and reinforce key messages about hepatitis prevention and management.

By promoting collaboration between medical professionals, social workers, and the broader community, this initiative aimed to enhance advocacy and awareness. Expanding hepatitis testing, improving healthcare access, and fostering a supportive environment for those affected will contribute to a long-term national strategy for hepatitis elimination. The project's goal is to ensure that more individuals receive timely diagnosis, treatment, and support, leading to improved public health outcomes.

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Hepar Centar Bitola



World Hepatitis Day 2024: A Landmark in Public Health

Hepar Centar Bitola led the most extensive national campaign against hepatitis in North Macedonia, collaborating with the Ministry of Health, WHO Office Skopje, the EU Embassy, University Clinics, and other key stakeholders. Spanning 10 cities, 2 jails, and 3 harm reduction services, the campaign combined education, awareness, and free screenings to combat hepatitis and liver cancer.

Key Activities and Achievements

1. Nationwide Awareness Campaign

- A high-impact social media campaign launched alongside a concert at Heraclea Bitola featuring Nokaut.
- Press conferences in Skopje, Bitola, Kumanovo, and Shtip engaged media, healthcare leaders, and policymakers.
- Extensive media coverage through TV, radio, and digital platforms amplified public awareness.

2. Free Testing and Screening Initiatives

- Free and anonymous hepatitis B, C, and HIV testing in 10 major cities.
- Advanced screening with FibroScan technology for early liver disease detection.
- Targeted testing campaigns in prisons and harm reduction centers.

3. Educational Outreach

- Distribution of thousands of educational brochures and promotional materials.
- Public workshops and interactive sessions with medical professionals to promote prevention, vaccination, and treatment options.

4. Community Engagement and Policy Advocacy

- Meetings with WHO and Ministry of Health officials to advance a national hepatitis elimination strategy.
- The campaign culminated in the White Night Event in Bitola, reinforcing public commitment to liver health.

Impact and Legacy

- 1,500 individuals screened, 4,500 tests conducted, and 800 FibroScans performed.
- Strengthened public awareness and policy engagement for long-term hepatitis elimination.

This campaign demonstrated the power of collaboration in driving impactful public health initiatives and setting the foundation for a hepatitis-free future.

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Patients with hepatic impairment Association of Romania-APAH-RO



Viral Hepatitis in Romania: Stages on the Road to Eradication

The APAH-RO initiative, supported by ELPA, focused on advancing the eradication of viral hepatitis in Romania through high-level discussions, policy advocacy, and public health initiatives. Central to this effort was a hybrid roundtable discussion in the Romanian Parliament, where key officials, medical experts, and policymakers convened to address the challenges and opportunities in hepatitis detection and treatment. The event emphasized the importance of ensuring continuous access to medical care, particularly for uninsured patients, and explored ways to integrate innovative therapies into the national healthcare system. A position paper summarizing these discussions was developed and widely disseminated to reinforce the need for policy changes.

In parallel, Romania successfully completed the European Union's largest hepatitis B, C, and D screening program, marking a significant milestone in public health. A new contract for HCV treatment was initiated in May 2024, ensuring that patients have ongoing access to essential therapies. Additionally, the approval of new Delta virus treatments positioned Romania as a leader in the region, providing patients with cutting-edge medical options.

Public engagement played a vital role in the project's success. During European Testing Week, a press release in collaboration with the Romanian National Society of Family Doctors helped amplify awareness. The initiative benefited from extensive media coverage and live-streamed discussions, which reached a broad audience and facilitated greater public participation.

Looking ahead, legislative amendments have been proposed to allow uninsured individuals to access free hepatitis testing. Efforts are also underway to integrate screening into national healthcare strategies, ensuring long-term sustainability in the fight against viral hepatitis. This project demonstrated Romania's commitment to eradicating viral hepatitis through collaboration, innovation, and policy reform, setting a strong foundation for a healthier future.

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Association for helping patients with chronic viral hepatitis-HRONOS

UDRUŽENJE PACIJENATA SA BOLESTIMA JETRE



HepFree Badge- Spring seminar of cosmetologists “Infection prevention in modern cosmetic procedures”

This initiative focuses on reducing the risk of viral hepatitis transmission in beauty salons while combating stigma and discrimination. According to WHO, unhygienic manicures and pedicures can contribute to the spread of hepatitis B and C, yet this risk remains significantly understudied. By educating beauty professionals and promoting safe practices, this project aims to improve hygiene standards and protect clients and workers in personal care settings.

Experts, including a professor of infectious diseases, an epidemiologist, a professional beautician-esthetician, and the head of the Ministry of Health inspection department, conducted a series of lectures. Topics covered the epidemiological and clinical aspects of hepatitis B and C, best practices in beauty parlours, regulatory requirements for salon hygiene, and strategies to reduce the stigma surrounding hepatitis.

This project aims to minimise the risk of infection transmission and create a safer working environment by educating beauty professionals. The initiative will also contribute to breaking down misconceptions about hepatitis, reducing stigma, and promoting public awareness. Expanding outreach efforts and incorporating more beauty industry professionals into training programs will ensure broader and more sustainable improvements in salon hygiene and safety practices.

Ask the Doctor

This initiative aims to bridge the communication gap between patients and medical professionals by providing a structured platform where individuals can ask questions directly to infectious disease specialists and oncologists. Given the time constraints many doctors face, this service ensures that patients receive the medical guidance they need in a timely and organized manner.

A dedicated online form allows patients and citizens to submit their questions through a specially created email system. Before submitting a question, individuals will complete a structured form that includes essential medical details. Additionally, they have the option to attach supporting documents in PDF or JPEG format for better case evaluation.

Responses are provided within 48 hours, with the possibility of further follow-up if needed. Each participating doctor is assigned a separate email address, and communications are systematically tracked. Statistical reports on inquiries and responses are generated every fifteen days to monitor engagement and efficiency.

To maximize accessibility, posters featuring QR codes linking to the platform will be placed in public transportation across Serbia's four largest cities. Simultaneously, a strong social media presence will ensure continuous promotion and awareness. With this approach, the project expects to reach a broad audience, offering reliable medical information to those who need it most.

CONTACT

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Šanca pre pečeň



Preventive action in liver diseases

From April 2024 to December 2024, the association planned activities for its members to Increase their knowledge of a healthy life by meeting with gastroenterologists.

They started with an Educational Meeting in the BRUSNO, which about 50 members of the association attended. At the meeting, they celebrated the 15th anniversary of the establishment of the patient association. Specialist doctors in the field of gastroenterology were also invited. Among the participant there was also the president of the AOPP (umbrella organization for patient associations in Slovakia).

As usual, in June 2024, they organised a “Weekend sports meeting” in Dudince, where sports competitions took place among the members of the association both outdoors and indoor.

In August, a meeting was organised with the members of the Social Centre of Seniors ELIM in Zvolen. The association was presented, including its mission and vision, what benefits it offers to the members and information about the increase in liver diseases.

In September 2024, they organised an educational meeting for members in the GOTHAL area in Liptovská osada.

A meeting was also organised in October at the Spa Lúčky, where members could enjoy the Spa, rest, exercise, and do sports (hiking, cycling, swimming). Invited speakers: Doc. MUDr. Skladaný Ľubomír PhD., MUDr. Rác Marek, PhD., MUDr. Havaj Daniel, MUDr. Žilincánová Daniela.

Before Christmas, they had the last meeting of the year, during which they evaluated the activities done in 2024.

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Educational Activities and Reaching Out – Hep Help Klub 2024

The HepHelpKlub initiative focused on rebuilding and enhancing its online presence, developing new educational and promotional materials, and restarting its patient brochure series. These efforts aimed to improve visibility, boost membership, and strengthen communication with stakeholders, including healthcare professionals and the general public.

A crucial aspect of the project was the creation of a new, secure website at hep-helpklub.sk after the previous site was compromised. A mirror English version was also developed to extend accessibility. In alignment with GDPR regulations, a new contact email was established.

Updated promotional materials were designed to expand outreach and engagement, including a membership application form (print and online), an informational leaflet, and a new office address. Necessary statutory changes were implemented, and an archive of previous materials was secured.

The project also marked the revival of the HepHelpKlub educational brochure series. The 2011 patient education materials were digitized and archived, providing continued access to essential information on viral hepatitis and liver health. Additionally, new brochures were introduced, covering topics such as transient elastography of the liver and metabolic dysfunction-associated steatohepatitis (MASH), ensuring patients and healthcare providers have up-to-date resources.

The project significantly improved HepHelpKlub's ability to disseminate reliable liver health information, engage with patients, and support healthcare professionals. By modernizing its digital infrastructure and reviving educational initiatives, HepHelpKlub reinforced its commitment to providing accessible, high-quality information for individuals affected by liver diseases. Future efforts will continue to expand educational resources and strengthen community engagement.

CONTACT

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Association Slovenia HEP



World Hepatitis Day 2024

The activities organized by the Slovenian Association for Patients with Viral Hepatitis on World Hepatitis Day 2024 were crucial to raising awareness and mobilizing people.

Through these activities, we exceeded expectations and achieved significant success in raising public awareness of critical issues related to hepatitis, liver cancer, and other related health conditions. With a strategic and comprehensive approach, the awareness project reached a broad audience. The campaign lasted almost a month on social media, garnering an impressive 110,000 views, contributing to spreading knowledge and encouraging public engagement.

The ELPA support enabled the association to raise awareness and provide essential health services. More than 100 individuals received anonymous, free testing without referrals at the University Medical Centre (UKC) Ljubljana, giving them access to crucial healthcare services that significantly improve their health and well-being.

The success of this initiative would not have been possible without the collective efforts of organizations and institutions. The project was led by the Clinic for Infectious Diseases and Febrile Illnesses at UKC Ljubljana, in collaboration with the Institute of Microbiology and Immunology of the Faculty of Medicine at the University of Ljubljana, the Medical Students' Association of Slovenia – VIRUS PROJECT, and the Slovenian Association for Patients with Hepatitis.

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National Federation of Liver Patients and Transplanted - FNETH



#YoCuidoMiHígado: Raising Awareness for Liver Cancer

The #YoCuidoMiHígado campaign, organized by FNETH in collaboration with the Spanish Association for the Study of the Liver (AEEH), aimed to increase awareness of liver cancer and break the stigma surrounding the disease.

A central component of the campaign was the dissemination of information through social media, utilizing the hashtags #YoCuidoMiHígado and #PonLuzAlCáncerDeHígado. Additionally, the campaign included participation-driven activities such as healthy recipe contests, fitness initiatives, and the symbolic illumination of prominent buildings across Spain to reinforce awareness efforts.

The campaign spanned five weeks, with each focusing on a distinct theme:

- **Week 1:** Basic facts about hepatocellular carcinoma (HCC), covering risk factors, prevalence, treatment, and symptoms. Informational content was shared widely on social media to educate the public.
- **Week 2:** The importance of adopting healthy lifestyle habits. FNETH encouraged its associations to share nutritious recipes and practical tips for liver-friendly diets.
- **Week 3:** The impact of alcohol consumption on liver health. During this week, FNETH hosted training sessions and a gala event celebrating its 20th anniversary and the 40th anniversary of Spain's first liver transplant. These sessions featured expert discussions on liver health and patient experiences.

- **Week 4:** The role of physical activity in liver health. Renowned Spanish athlete Fátima Gálvez endorsed the campaign, and various associations organized sporting activities to encourage participation.
- **Week 5:** The final week featured the culmination of activities, including the illumination of over 50 landmarks, such as city halls, hospitals, and cultural sites, in green to symbolize liver cancer awareness. FNETH also published key findings and campaign results.

The campaign generated significant engagement, with FNETH's social media seeing substantial growth in impressions and interactions. Over 9,800 impressions and 1,733 interactions were recorded, with a notable increase in post engagements. Additionally, FNETH strengthened collaborations with healthcare professionals, institutions, and patient organizations, expanding its influence within the liver health community.

The recipe contest and fitness challenges were particularly successful in engaging the public, promoting both awareness and actionable lifestyle changes. Interviews with medical professionals were shared to provide expert insights, and media outreach efforts helped extend the campaign's reach beyond social media.

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Spanish Patient Organization Lysosomal Acid Lipase Deficiency - AELALD



Family Congress 2024

The 6th AELALD Family Meeting, held on November 23, 2024, in Zaragoza, brought together patients, families, and experts to share experiences and knowledge about LAL-D. Eduardo López, AELALD's president, presented the association's achievements, while key presentations covered topics such as the importance of research in rare diseases, coping strategies for patients and caregivers, and early diagnosis alongside the transition to adult care.

This year, ELPA was presented at the meeting to show the families that AELALD has initiated an international process as a patient organisation.

The event featured an interactive Mentimeter activity, highlighting families' main concerns, with a strong focus on finding a cure and improving treatments. The meeting concluded with the announcement of the creation of a European LAL-D association, aiming to enhance international collaboration and patient support across Europe.

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Riksföreningen Hepatit C – RHC



‘Organisation, Cooperation, and Research with and Among the Swedish Members of the Multicultural Group’

The project commenced its journey on January 1st, 2023, with thorough preparations including interviews, discussions, and the identification of suitable members with diverse cross-cultural experiences and professional backgrounds. Throughout the year, the project delved into the multifaceted aspects of hepatitis, patient perspectives, and diseases, exploring not only cultural and ethical dimensions but also professional and patient-oriented viewpoints. This holistic approach was made possible by the inclusion of members representing various countries, professions, and healthcare roles, fostering a rich tapestry of perspectives.

Amidst the diverse array of project proposals put forth by members, the consensus gravitated towards initiating the first project focusing on immigrants affected by hepatitis B and D, prompted by the emergence of a new medicine targeting hepatitis D, particularly relevant for immigrant communities hailing from endemic regions who often face significant neglect in healthcare discourse.

The project cast its net wide, targeting a broad spectrum of individuals and groups across multiple countries. The primary focus remained on Sweden, with additional involvement from Norway, Iran, Togo, Benin, Ghana, Spain (Cataluna), Turkey, Israel, Egypt, as well as patients and professionals from diverse healthcare disciplines such as doctors, dentists, therapists, and beyond.

Throughout 2024, extensive interviews were conducted to analyse healthcare interactions, focusing on how meetings between patients, healthcare staff, and organisers take place. The goal was to identify differences between countries, cultures, and professional perspectives while finding ways to prevent negative or missed interactions.

A majority of interviews have been completed in Sweden, engaging individuals from diverse ethnic backgrounds. Additionally, interviews have been carried out across multiple member countries, with two remaining nations scheduled for early 2025. To complement the interviews, visits to clinics and medical offices were conducted to observe practical implementations of patient care strategies.

By addressing these challenges, this initiative aims to foster better communication, mutual understanding, and more effective healthcare meetings, ultimately benefiting both patients and medical professionals alike.

CONTACT

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Living with Hepatitis Association - HEPYAŞAM



Cartoon Workshops on the Liver

The association organised the workshops to raise social awareness of liver-related health problems through cartoons and drawings.

Vaccination, liver transplantation, some information about Hepatitis A, B, C, D and E, hygiene, water shortage, numerical rates related to liver diseases, events in the world, and social structure in approaching the disease were addressed in the drawings.

Experienced cartoonist-journalist Raşit Yakali and his team, as well as some students and art teachers, also participated in this project. The first activity was the meeting between Raşit Yakali and his team and the association's President Hilal Ünalmiş Duda. In this first meeting, Duda informed the cartoonists about the liver and especially hepatitis. Then the work and drawings started. In addition, mini-information about liver diseases was given to students who were interested in drawings and cartoons. The drawings from them also reached the association. This project is not a competition. Therefore, every received drawing is very valuable. The cartoons and drawings that reached in the association in November were classified and divided into their own subjects. For example, hygiene, transmission routes, vaccination, liver health, hepatitis, transplantation, stigma, discrimination, treatment, and right to work.

Drawings mostly came from students and young people about vaccination. Our art teacher discussed topics such as the right to work, especially the celebration of the inclusion of hepatitis C drugs in the scope of reimbursement among the public, and hygiene. The fact that some people in society are constantly obsessed with football and some people are constantly obsessed with the disease was drawn. The black market and thoughts that are compatible with or contrary to human rights regarding liver transplantation were discussed. There is also a nice cartoon about a tradition of families in rural areas, such as covering hepatitis patients with yellow blankets.

All cartoons and drawings were prepared to be exhibited as a result of the “Cartoon Workshops on the Liver” project. With this project, society is provided with a little more information about the liver.

CONTACT

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British Liver Trust



British Liver Trust Patient support groups

With the support of ELPA, the British Liver Trust expanded its patient support groups, providing vital assistance to individuals with liver conditions. These groups aim to reduce isolation, improve mental well-being, and enhance self-management by offering both virtual and in-person sessions. A variety of support groups were established, including sessions for young patients, liver cancer support, pre- and post-transplant patients, and caregivers. The initiative ensures that individuals living with liver disease have a platform to share experiences, seek advice, and receive emotional support from both professionals and peers.

In 2024, the Trust conducted 120 online support sessions, reaching 172 participants across England. A milestone was achieved with the launch of an in-person pre- and post-transplant support group at Freeman Hospital in Newcastle, attended by 17 individuals. The average session attendance was 12 people, highlighting the demand for structured support systems. Surveys revealed that 81.4% of participants felt less isolated, 79% reported a stronger support system, and 52% experienced improved mental well-being. Additionally, 75% of respondents noted that the support groups were their only source of emotional and social support.

Patient feedback underscored the importance of peer support, with 95.3% of respondents stating they gained valuable knowledge about managing liver conditions. Many patients described feeling uninformed before joining the Trust's network, often stuck in a limbo between medical appointments. Additionally, 67.4% felt more confident in coping with their illness, while 77.3% of those attending six or more sessions reported an increased ability to advocate for their healthcare needs. Several individuals also expressed a desire to influence policies, workplace accommodations, and public awareness of liver disease.

In 2025, the Trust aims to expand face-to-face meetings in the Midlands, Northwest, and London through hospital partnerships. Outreach efforts will target at-risk individuals, including those with type 2 diabetes and high alcohol consumption, ensuring that more people access essential liver health support services. Furthermore, the Trust plans to introduce additional guest speaker

sessions on specific topics, as survey responses highlighted a strong interest in more educational content.

With continued advocacy, education, and support, the British Liver Trust remains dedicated to improving the lives of individuals affected by liver disease. By fostering connections, increasing knowledge, and promoting patient confidence, this initiative continues to make a meaningful difference in the lives of those navigating liver health challenges.

CONTACT

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Liver4Life



Freephone Helpline Support

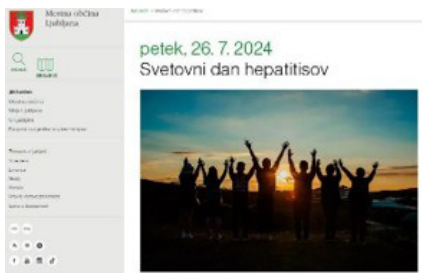
The calls received by the Helpline increase year-on-year, and our team leader's (Kelvin) ability to share his knowledge and experience of living with a liver transplant, and with a liver condition is invaluable. They provided information and support to more than 1,000 people in 2023 and asked for ELPA's support to guarantee this service for another year.

The calls received by our Helpline in 2024 showed an increase overall from 2023, and the average time spent on each individual call rose to over 34 minutes. In the previous year, it was questions regarding GP blood results and Travel Insurance that topped the list. This year, Travel Insurance was still high, but the number of different conditions that Kelvin and his team discussed was much more varied.

There was also a higher proportion than normal of people who requested dietary advice and how they can manage to measure their alcohol intake more accurately.

CONTACT

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1
Odpovede na Vaše otázky Vám poskytnú Váš alergický lekár, ktorý Vám vyšetrenie odporučí a vyhodnotí výsledkové znaky pri samostatnej vyhodnotení.

Tranziéntna elastografia pečene (TELP)

Fibroscan® Echosens®

Základné informácie a odpovede na najčastejšie otázky

HEPHELP KLUB

Áko sú odpovede na Vaše výšetrenie?
Záverom pečene je veľmi dôležitá pre zdravie a život celého organizmu. Vyšetrenie TELP pomôže zistiť, či Vaša pečeň robí alebo zvládne požadovanú prácu, či zmeny fibrozy spôsobujú dôsledky celého pečene. Vyšetrenie indikuje Váš deň odmietajúceho pečene – špeciálne na ochorenia pečene.

Áko sa môže prejavovať ako sa dá zistiť poškodenie pečene?
Ochorenie ochorenia pečene často prebieha bez príznakov a dospelci z domov odmietajú pečeň.

Áko sa môže prejavovať ako sa dá zistiť poškodenie pečene?
Môže to spôsobiť ochorenie pečene alebo náhodou látky v nebezpečnom ochoreni pečene, u ktorých nie je možné zistiť príčinu choroby (Lupus erythematosus) pečene. V niektorých prípadoch ochorenia dochádza k úplnej poškodeniu a následne normálnej funkcii pečene.

Áko sa fibroza prejavuje?
Ide o prírastok pečene, ktorá pečene, zmenou vlákn, jeho zväčšenie, a to na šír zväzok pečene. Prípad sa zvyšuje tuhosťou („Lupus“) pečene. Pečeň môže byť ochorenia 4 stupňa fibrozy pečene. Pečeň môže byť ochorenia ochorenia alebo ochorenia.

Áko prebieha vyšetrenie?
Vyšetrenie vykoná vyšetrenie, ktoré vyšetrenie vyšetrenie.

Áko sa môže prejavovať ako sa dá zistiť poškodenie pečene?
Môže to spôsobiť ochorenie pečene alebo náhodou látky v nebezpečnom ochoreni pečene, u ktorých nie je možné zistiť príčinu choroby (Lupus erythematosus) pečene. V niektorých prípadoch ochorenia dochádza k úplnej poškodeniu a následne normálnej funkcii pečene.

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HEPHELP KLUB

Welcome to our webpage!

We are an organization of patients with liver diseases, their relatives and other concerned persons. In collaboration with medical specialists we aim at improving their quality of life, raising public awareness, and providing medical, emotional, support, and possibilities of various beneficial activities. We organize patient educational events and other events. We want to build a strong and patient patient organization in Slovakia and abroad. Please, feel free to have a look, and join our membership!

POZNANIE PRE PACIENTOV A ICH RODINNÝCH PRÍSLUŠNÍKOV

VÝSKUM O STIGME OCHORENIA PEČENE

• Pacienti s Váš v štádiu na medikamentózne vyšetrenie, ktorý do nemôže medikamentózne štádiu pre pacientov a ich rodinných príslušníkov aj dospelci (prírodné ochorenia pečene).

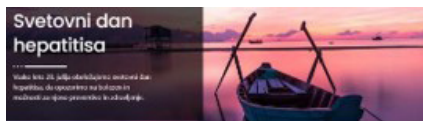


Pacientul20

Hepatite virale în România

Etapă în drumul spre eradicare





Bolezen, ki jo povzroča virus hepatitisa, je ena od najpogostejših vzrokov za kronično bolezen jeter. Čeprav je bolezen, ki jo povzroča virus hepatitisa, je ena od najpogostejših vzrokov za kronično bolezen jeter, je bolezen, ki jo povzroča virus hepatitisa, je ena od najpogostejših vzrokov za kronično bolezen jeter.

Zadnje novice







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