



Together we are
stronger!

**ELPA MEMBERS'
PROJECTS SUPPORT
2023**

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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 serves as a comprehensive network, representing 32 member organizations from 25 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 standardize 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 organization 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 eight specialized working groups, each one 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 policy makers. 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:

- Advisory Forum and Expert Group on Hepatitis B and C at the European Centre for Disease Prevention and Control (ECDC).
- Patient and Consumer Working Party, and the Pharmacovigilance Risk Assessment Committee at the European Medicines Agency (EMA).
- Policy and Public Health Committee and the Taskforce on Liver Cancer at the European Association for the Study of the Liver (EASL).
- Advisory Forum at the Health Emergency Response Authority (HERA).
- Expert Group on HIV, Tuberculosis, and Hepatitis at the World Health Organization (WHO).
- Expert Board at the Viral Hepatitis Prevention Board (VHPB).

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 recognized us as the first European patients' association to implement a quality management system, further demonstrating our dedication to high standards and continuous improvement. In 2023, ELPA successfully renewed ISO certification.

PARTICIPATION IN MEDICAL RESEARCH PROJECTS

ELPA is part of 20 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 2023, ELPA continued to collaborate closely with its members on projects developed at the national level. ELPA supported projects of 20 associations in 15 countries.

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 various local patient-centric initiatives, further solidifying its engagement with its members for the third year.

I am delighted to present this compilation of exemplary practices at the national level. This compendium represents the collective endeavours of liver patient associations spanning across Europe and beyond, united in their commitment to exchanging experiences and expertise. Through the dissemination of 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 encountered by liver patients, 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 assumes a pivotal role in formulating health-care 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. It is my aspiration 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.

Together, we are stronger!

Marko Korenjak



The foreword of the ELPA Board of Directors

As ELPA governing body, we take great pride in announcing the launch of the new 2023 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 2023, for the third 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 requisite knowledge and tools to advocate for improved liver health on a national scale effectively. Through disseminating our members' best practices, we aspire to instil inspiration and bolster

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

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.

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

It is imperative to underscore that this initiative in 2023 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



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



ISRAEL

- Israeli Association for the Health of the Liver - Hetz



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 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

- British Liver Trust
- Liver4Life



Predavanje

Kliničke karakteristike i terapija HCV i HBV

Prof.dr Ivana Milošević

Klinika za infektivne i tropske bolesti, UKC Srbije, zamenica direktora i predsednik Radne grupe Ministarstva zdravlja za virusne hepatitise

10:05-10:25

UDRUZENJE JEKRONOS   

@UDRUZENJEKRONOS @UDRUZENJE_STRUK_MED_ESTET @estetikpro



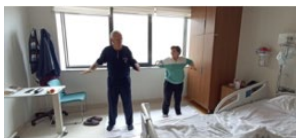
מבט אל העתיד כנס משולב P.S.C-I.P.B.C

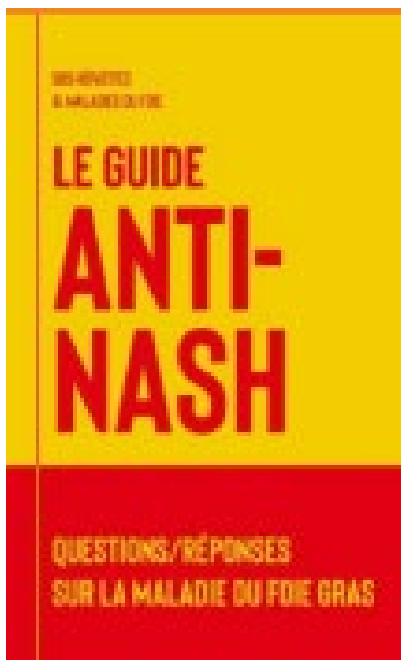
הזדמנויות!
שאלו את הכרופאים הבכירים ביותר בארץ חשערי צדק ללא עלות!
05.07 בשעה 18:00-20:00 המרכז הרפואי שערי צדק

בתכניה:	19:00 - 18:30
התכנסות וכיכר דג	
ד"ר חמלה - ד"ר לאור - מנהל חידות כבד	
המרכז הרפואי שערי צדק / חמלה מרון -	19:10 - 19:00
מנכ"ל עמותת "חץ"	
P.S.C. - אבחון וסיוע: החמלה מרפי / חמלה	19:25 - 19:10
מואסד - מנהל היחידה האנדוקרית	
P.B.C. - אבחון וטיפול: 2023 ד"ר אנה	19:40 - 19:25
נספח - רופא בכיר בלי הכבד: שער צדק	
החוקים: P.S.C-I.P.B.C ד"ר נדי לאור	20:00 - 19:40
קבוצת המחקר של חץ סניף יוטיוב -	20:10 - 20:00
נחת קבוצת ופניה בינלאומית חסעם חץ	
ELPA-I	
סאנר שאלות ותשובות חץ ושר עם כ"ר	20:30 - 20:10
הדברים	
ד"ר סימון: ד"ר לאור	20:30













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junto a los Pacientes Hepáticos*

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Associació Catalana de Pacients Hepàtics
C/ Pere Vergés 1, planta 8, despacho 11, "Hotel d'Entitats La Pau"
08020 Barcelona
Tels. 93 314 52 09 / 615 052 266
www.asscat-hepatitis.org







The Chronic Viral Hepatitis Patients Association - B18



'End_of_hepatitis.ba'

The 'End_of_hepatitis.ba' project aimed to eliminate hepatitis B and C in Bosnia and Herzegovina by informing citizens about transmission, prevention, and treatment options for viral hepatitis, including new treatments. Additionally, it sought to establish contacts and cooperation with clinical centres treating hepatitis patients to inform them about new drugs. The project involved various activities to raise awareness on viral hepatitis in Bosnia and Herzegovina:

1. SOS telephone line

- Operation of an SOS telephone line for inquiries about viral hepatitis
- Coordination with professional staff and counselling centres in hospitals for optimal responses
- Facilitation of online consultations through the Association B18's website and Facebook page
- Collaboration with Infectious Diseases Clinics to address questions and concerns.

2. Commemoration of World Hepatitis Day on July 28, 2023, at 'Krajina Square' in Banja Luka and on World HIV Day

- Distribution of informative materials
- Offering testing for hepatitis B, C, and HIV
- Volunteers informed citizens and wore promotional t-shirts in line with WHA recommendations
- 37 citizens were tested for hepatitis B and C and HIV at the UKC RS Infectious Disease Clinic with tests provided by the B18 Association
- 20 citizens were tested for hepatitis B and C and HIV at the same clinic with tests obtained through the B18 Association

3. Printing of educational and informative brochures on hepatitis B and C for IHC activities

- Brochures addressed specifics, transmission methods, and therapy availability
- 1000 copies circulated for various project activities

4. Updating of the B18 Association website to incorporate relevant information.

5. Collaboration between Association B18, Clinic for Infectious Diseases UKCRS, and Aleksandrovac Therapeutic Community

- Activities aimed at hepatitis C treatment for IDUs undergoing drug addiction treatment
- Testing for hepatitis B and C and HIV among IDUs undergoing drug addiction treatment

CONTACT

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Cyprus Liver Patients Association - Promitheas



'My name is Alcohol'

The Cyprus Liver Patients' Association has launched a campaign to raise awareness about the health risks associated with alcohol consumption, especially among individuals aged between 15 to 40 in Cyprus. The campaign started on December 5, 2023, and ended on April 5, 2024. The campaign aims to highlight the following points, based on research from reputable sources like the Centers for Disease Control and Prevention (CDC) and Cancer Researchers UK:

1. **Risks to Liver Health:** Long-term alcohol consumption can cause significant damage to liver health, leading to cirrhosis and increasing the likelihood of liver cancer. The damage to liver cell DNA further exacerbates this risk.
2. **Prevalence of Alcohol-Related Liver Cancer:** According to Cancer Researchers UK, 7 out of 100 cases of liver cancer are linked to alcohol consumption.
3. **Additional Health Risks:** Excessive alcohol consumption is associated with a range of other health problems, including cardiovascular diseases, nervous system disorders, and addictive behaviours.

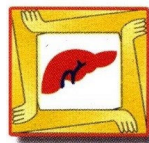
The campaign is conducting surveys within the age group mentioned above to determine the extent of alcohol use among individuals and the underlying reasons behind their alcohol consumption. This information will be used to develop targeted interventions and educational initiatives aimed at promoting healthier behaviours and reducing the incidence of alcohol-related harm among young people in Cyprus.

The 'My name is Alcohol' has collected 48 responses in English and 261 in Greek by April 2024. The initiative aims to empower individuals to make informed decisions regarding their alcohol intake and overall well-being by raising awareness of the health risks associated with alcohol consumption.

CONTACT

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Association of Liver Patients' Care - ALPC



'Educate-test and treat for HBV'

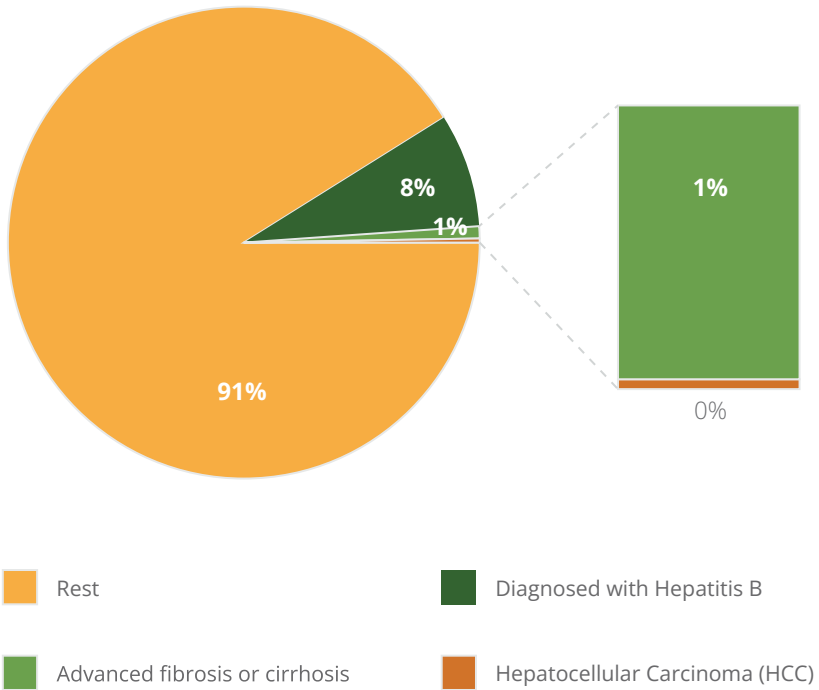
The project aimed to address hepatitis B virus (HBV) infection, a significant global health issue, by scaling up testing and treatment interventions to achieve WHO's goal of HBV elimination by 2030. This goal involves a 90% reduction in incidence and a 65% reduction in mortality compared to a 2015 baseline. The project aimed to identify undiagnosed HBV-infected patients and improve the cascade of care for HBV patients.

The main steps of the project included the following:

1. **An awareness-raising campaign about HBV infection** was conducted by staff from the Egyptian Liver Research Institute and Hospital (ELRIAH), comprising physicians. This involved delivering talks addressing transmission routes, signs of infection, and treatment criteria, accompanied by the distribution of booklets, flyers, and posters to attendees.
2. **A preliminary visit** was conducted one week before to identify suitable locations for testing instrument placement and patient consultation. All locations were assessed for reliable electricity, backup power sources, and computer availability.
3. **Serological screening for HCV-Ab and HBsAg** using RDTs was carried out. HBV viral load measurement was conducted for those testing positive for HBsAg.
4. Patients confirmed to have positive **HBV DNA levels** underwent further investigations at the Egyptian Liver Research Institute and Hospital and were initiated on treatment.

During the project, a total of **6,714 patients** were screened for Hepatitis B, resulting in **570 individuals** being diagnosed with the virus. Among them, **72 patients** were identified to have advanced fibrosis or cirrhosis, while only **2 patients** were diagnosed with Hepatocellular Carcinoma (HCC) related to Hepatitis B.

Overview of Hepatitis B Screening results



CONTACT

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The Finnish Kidney and Liver Association



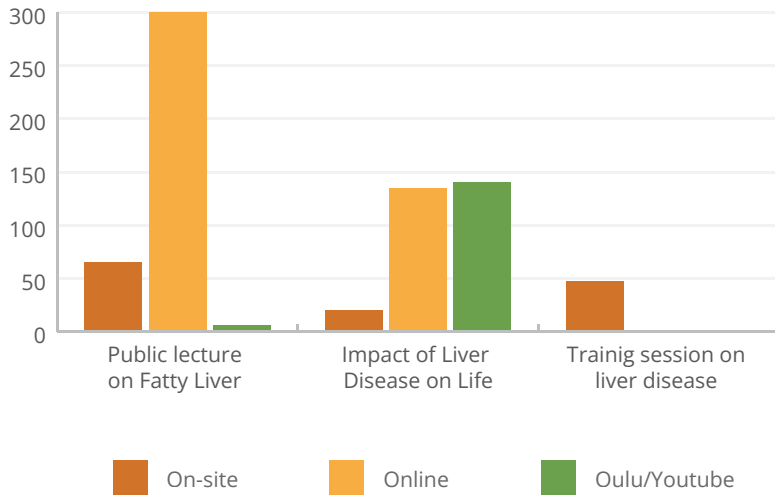
Liver Week

Project, held from 8th to 12th May 2023 by The Finnish Kidney and Liver Association in Helsinki, Finland, aimed to raise awareness about Fatty Liver (NAFLD) and rare liver diseases. Through seminars and events, featuring talks on NAFLD diagnosis, treatment options, dietary management, and patient experiences, the project successfully educated the public and advocated for improved liver care standards in Finland's healthcare system. The main events of the project included:

1. **Public lecture on Fatty Liver and its treatments on 8th May in Helsinki** included presentations of Dr. Fredrik Åberg, a gastroenterologist and associate professor, discussed the prevalence, progression, diagnostics, and treatments of NAFLD, while licensed nutritionist Reijo Laatikainen addressed dietary. Petra Saarinen shared her personal experiences with fatty liver disease.
2. **Online event "Impact of Liver Disease on Life" on 10th May** included panel discussions led by Kaj Kunnas, featuring liver disease patients. Remote studios were set up in the cities of Hyvinkää, Jyväskylä, Oulu, Raahe. The event aimed to raise awareness of liver disease's impacts and received a 4.4 rating from viewers, who found it informative and supportive.
3. **Online training session on liver disease care and guidance on 12th May in Tampere** covered topics such as early recognition of liver disease, complications of liver cirrhosis, substance-dependent patient care, treatment plans, hepatitis C treatment, medication effects on liver health, and fatty liver.

Press releases throughout the Liver Week highlighted the importance of liver health, addressing issues such as the fatty liver epidemic in Finland and promoting lifestyle modifications for prevention. Media responses emphasized the significance of exercise, weight control, and lifestyle changes in preventing and managing fatty liver disease.

Overview of participants



CONTACT

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Publication of Anti-NASH guide

The project involved the publication of a comprehensive guide titled 'ANTI-NASH', aimed at addressing common questions and concerns among patients and their families regarding non-alcoholic steatohepatitis (NASH). The Guide, released on **June 8, 2023**, on World NASH Day, was a collective effort initiated by the association to defend patients SOS hépatites & maladies du foie. It aimed to provide accessible and concrete answers on various aspects of the disease, including detection, prevention of complications, relationship with diabetes, available treatments, dietary recommendations, and prohibited foods.

The Guide was based on discussions with patients, including those on social networks, ensuring that it addressed the most relevant issues raised by those affected by NASH. The target audience included patients, their families, health system users, and health professionals nationwide.

During the French Hepatologists Association for the Study of the Liver (AEEF) congress from **October 4 to 7th, 2023**, the Guide was promoted through digital communication and the congress briefcase. Additionally, the Guide was promoted during the SOS Hépatites & Maladies du Foie National Forum on **November 23rd and 24th, 2023**.

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Israeli Association for the Health of the Liver - Hetz



Congresses about PSC/PBC

The HETZ association led a project called 'Congresses about PSC/PBC' that took place in the second, **third, and fourth quarters of 2023**. The congresses were held at two healthcare institutions: Share Tzedek Hospital in Jerusalem and Belinson Hospital in Petah Tikva. These venues provided an excellent setting for the gatherings, offering an environment conducive to learning, discussion, and community engagement. The primary objective of the congresses was to raise awareness about Primary Sclerosing Cholangitis (PSC) and Primary Biliary Cholangitis (PBC). Through three face-to-face congresses hosted in hospital settings, the project aimed to directly engage patients and their families, fostering a deeper understanding of these often-overlooked conditions. By bringing together patients, families, and healthcare professionals, the project aimed to disseminate crucial information about these diseases and provide a supportive network for all those affected.

The estimated reach of these congresses extended across the national landscape, aiming to touch the lives of individuals grappling with these conditions and their loved ones. Through interactive sessions, informative presentations, and shared experiences, the project endeavoured to catalyse a broader dialogue surrounding PSC and PBC within the community.

CONTACT

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Association for health education, prevention and better treatment - HEPTA



‘Is elimination of viral hepatitis possible in the world?’

The project, ‘Elimination of Viral Hepatitis: A Global Endeavor,’ took place from **April 1st to November 30th, 2023**. The primary objectives of the project were to increase awareness and knowledge about viral hepatitis, advocate for easier access to health services, provide training in patient advocacy, conduct peer education sessions for students and raise public awareness about health-related issues associated with viral hepatitis. The project included an interactive workshop held for students at the International Balkan University, with participation from a multinational student body. Professors from various faculties contributed diverse perspectives on the topic. The workshops aimed to equip students with skills and knowledge to advocate for improved health service access and prevention efforts in their communities, contributing to the global goal of eliminating viral hepatitis.

The workshop was attended by more than 500 participants showing up and displaying a keen interest in the event. Discussions during the workshop hours were productive, with moderators answering questions regularly. Participants exhibited impressive knowledge and thoughtfulness, leaving moderators pleasantly surprised. Although the workshops were initially planned for a maximum of 3 hours each, some were extended to 5 hours due to enthusiastic engagement and discussion participation. To enhance their knowledge during the workshop sessions, participants were provided with materials such as scientific papers from journals, TV shows featuring medical experts, flyers, and slides from moderators.

CONTACT

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Hepar Centar - Bitola



World Hepatitis Day

On World Hepatitis Day 2023, Hepar Centar Bitola led a national campaign in collaboration with key stakeholders such as the Ministry of Health, University Clinics, health insurers, and international organizations like ELPA, WHA, and WHO. The campaign consisted of four stages: preparation, announcement through social media, impactful events in eight cities, and reflection on outcomes. The campaign aimed at raising awareness about hepatitis and liver cancer prevention, diagnosis, and treatment. Through free screenings, educational workshops, and awareness rallies, thousands of individuals across North Macedonia were reached, leading to early diagnoses and increased awareness about hepatitis and liver cancer. The campaign proved to be successful in strengthening partnerships and laying the groundwork for ongoing initiatives against these diseases.

As part of the campaign, various events were organized. This included **three press conferences and numerous interviews across various media platforms such as TV, radio, web portals, newspapers, and digital media**. Free and anonymous testing for HCV-HBV-HIV was conducted in eight cities in the Republic of North Macedonia (RNM) along with free and anonymous screening with FibroScan, and distribution of materials. In addition, awareness and screening campaigns were carried out in jails and harm reduction centers in Bitola and Skopje, as well as in regional centers. The campaign also involved a public awareness and screening campaign for the general population and policy activation initiatives.

CONTACT

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Patients with hepatic impairment Association of Romania - APAH-RO



‘Hepatitis in vulnerable communities’

The ‘Hepatitis in Vulnerable Communities’ campaign aimed to promote ongoing testing and access to medical services and therapies for diagnosed patients during European Testing Week campaign, dedicated to the European Testing Week, aimed to highlight the importance of ongoing testing, and ensuring access to specialized medical services and therapies for diagnosed patients.

1. Hepatitis B and C testing

At Sacele Municipal Hospital, 121 tests for hepatitis B and C were conducted, identifying one hepatitis B case. In Giurgiu, 67 individuals were tested, with plans to continue testing in June. In Turda, 55 tests during a first aid course revealed one hepatitis B case and one hepatitis C case.

2. Press conference with Romanian Journalists

A press conference and event for Romanian journalists featured representatives from various organizations, addressing challenges faced by hepatitis patients despite elimination efforts. Discussions focused on access to innovative medicines, free investigations, and drug availability.

3. Scientific Council event

During a Scientific Council event, topics included advocating for access to medicines and investigations, improving drug availability, and implementing laws for uninsured patients. The importance of nationwide testing campaigns and the impact of hepatitis on Romanian patients were emphasized.

A project highlighted patients' struggles due to medication unavailability and treatment discontinuity. Advocacy efforts continue to achieve Romania's goal of eliminating viral hepatitis by 2030-2035, with data from the study informing messaging for World Hepatitis Day 2023.

CONTACT

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Association for helping patients with chronic viral hepatitis - HRONOS



‘Infection prevention and modern cosmetic procedures’

The ‘Spring Seminar for Cosmetologists: Infection Prevention and Modern Cosmetic Procedures’ in Belgrade on **March 6th** aimed to address the crucial issue of preventing viral hepatitis transmission in beauty parlors. With a lineup of five distinguished speakers including an infectious diseases professor, an epidemiologist, a professional beautician-esthetician, the head of the Ministry of Health inspection department, and myself, we will delve into key topics. These include the epidemiology of viral hepatitis B and C globally and in Serbia, clinical characteristics and therapies for HCV and HBV, best practices in beauty parlors, and the essential conditions for safe salon operations. Moreover, the seminar tackled the important issue of stigma and discrimination surrounding hepatitis.

The event aimed primarily to educate those engaged in procedures with infection transmission risks, such as medical pedicures and permanent makeup application. Anticipating 30 participants representing beauty parlors nationwide, the seminar impacted national beauty practices and standards.

CONTACT

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Šanca pre pečeň



'Preventive actions on liver disease'

A project highlighted the challenges faced by patients due to lack of medication and treatment continuity. Advocacy efforts continue to eliminate viral hepatitis in Romania by 2030-2035 with the study's data informing messaging for World Hepatitis Day in 2023.

1. **Prevention Actions Project**

The Preventive Actions Project had the goal of improving health knowledge through meetings with gastroenterologists, promoting physical activity, increasing awareness about World Hepatitis Day via social media, educating young people about the dangers of substance abuse, and providing guidance on how to write successful projects. The project included various activities such as meetings with healthcare professionals and patient organization representatives, a sports day in Dudince, an event to raise awareness about drug use in Zvolen, and a training session on fundraising. **The project targeted individuals aged 15 to 70 and took place from February 6th to December 1st, 2023.**

2. **Sport Weekend**

Over the weekend of June 16th to 18th, 2023, members of the Šanca pre pečeň organization participated in a sports weekend held in Dudince. The event featured a range of competitions aimed at promoting physical activity and building camaraderie among participants. The activities included swimming, cycling, dart throwing, target practice, tug-of-war, and concluded with a friendly bowling competition.

3. **Weekend Stay and General Meeting**
In October 2023, a Weekend Stay and General Meeting took place in Sliač, featuring presentations and discussions on various aspects of liver health. Attendees received reports on the activities and finances of Šanca pre pečej in 2022, along with insights from specialists on factors influencing hepatic diseases, patient management strategies, and the role of microbiome in health. Cooperation with ELPA was also highlighted, and plans for future activities were discussed.

CONTACT

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HEP HELP KLUB



'Educational and promotional aides'

Four-month project, 'Educational and Promotional Aids of the HepHelpKlub, encompasses several key initiatives:

1. **Website Development:** The project involves the creation of a new website to serve as a comprehensive platform for information, resources, and support related to hepatitis awareness, prevention, and treatment.
2. **English Website Mirror:** A mirrored version of the website will be developed to cater specifically to English-speaking users, ensuring accessibility and inclusivity across diverse linguistic backgrounds.
3. **Publication of Promotional materials:** HepHelpKlub Slovakia will design and produce new promotional materials in both printed and online formats. These materials, including application and registration forms, as well as informative leaflets, aim to effectively communicate the organization's objectives, services, and benefits to potential participants and stakeholders.
4. **Development of Patient Educational Materials:** Special focus will be placed on creating educational resources tailored to patients. This includes detailed materials explaining complex procedures such as transient elastography, along with the production of the MASH patient brochure. Additionally, the HepHelpKlub brochure series will be revitalized to offer comprehensive educational support to patients and their caregivers.

The project targets multiple groups and individuals on a national level, including the general population of all ages seeking information on liver health and diseases, patients with liver diseases and their family members who require comprehensive educational resources and support, and healthcare

providers such as general practitioners, hepatologists, and other professionals involved in diagnosing, treating, and managing liver diseases. The materials developed will serve as valuable resources for patient education and information dissemination within the healthcare community.

CONTACT

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Association - SLOVENIJA HEP



Awareness rising and free testing

An initiative led by NGOs Slovenija HEP and Blood Brothers aimed to provide free testing services for hepatitis. The support provided included procurement of testing kits, coverage of laboratory expenses, and facilitating communication with major newspapers across Slovenia. For this project, Slovenja HEP collaborated with the Medical University, the Medicine University testing laboratory of Slovenia, the association of medical students, and the Institute for Infectious Diseases in Ljubljana.

The primary goals of the project are to increase awareness about Hepatitis, with a focus on testing and treatment. This will be achieved through traditional media channels such as TV and newspapers, as well as social media platforms. The project aims to encourage the public to undergo free testing by partnering with medical students. Additionally, the association's work will be promoted through social media activities in major Slovenian cities.

The project aimed to provide free testing services for hepatitis to people across Slovenia at a national level. Its objective is to create awareness about the disease and promote early detection and treatment. The project also provides support to families affected by hepatitis. To ensure that the needs of hepatitis patients are addressed, advocates are engaged in the process. Additionally, policymakers are involved in the project to influence healthcare policies related to hepatitis. Support from individuals, organizations, NGOs, and medical institutions amplifies the project's reach. Patients living with hepatitis or at risk can benefit directly from the free testing services offered.

Slovenja HEP reached **160,000 individuals** on social media platforms, spreading knowledge, and promoting engagement. The association also collaborated closely with various media outlets, including newspapers, radio, and TV, which helped us reach even more people. **Over 230 individuals in Ljubljana and Maribor** received anonymous, free, and referral-free testing at the University Medical Centre, which provided them with vital medical services for their well-being.

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Catalan Association of Liver Patients - ASSCAT



24/7 online information line

The ASSCAT project, spanning the entirety of 2023, offers 24/7 online information and support for patients and families dealing with liver diseases. Its main objectives include providing crucial peer-to-peer support, educating individuals and families to enhance health literacy, promoting active patient involvement in healthcare decisions, and offering private consultations on liver health issues.

The project operates virtually through social media channels, enabling individuals to reach out via phone or email at any time. Since its inception in 2000, ASSCAT has steadily grown its online presence, particularly during the COVID-19 pandemic. While initially focused on viral hepatitis, its scope expanded to cover all liver diseases from 2018.

Targeting individuals across Catalonia and Spain, ASSCAT's social network activities have garnered significant user engagement. The project prioritizes transparency, freedom, and confidentiality in its interactions, emphasizing quality over mere quantity in evaluating its impact on the community.

ASSCAT prioritized patient needs and supported Spanish-speaking communities through email, social media, and their website. They provided guidance and assistance to individuals, including financial aid for treatments, while emphasizing the importance of regular liver analysis for early detection. They acknowledged and worked to combat the stigma surrounding hepatitis and liver disease, with committed volunteers possessing scientific knowledge and communication skills, contributing to significant social value.

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National Federation of Liver Patients and Transplanted - FNETH



October Liver Cancer Awareness Month

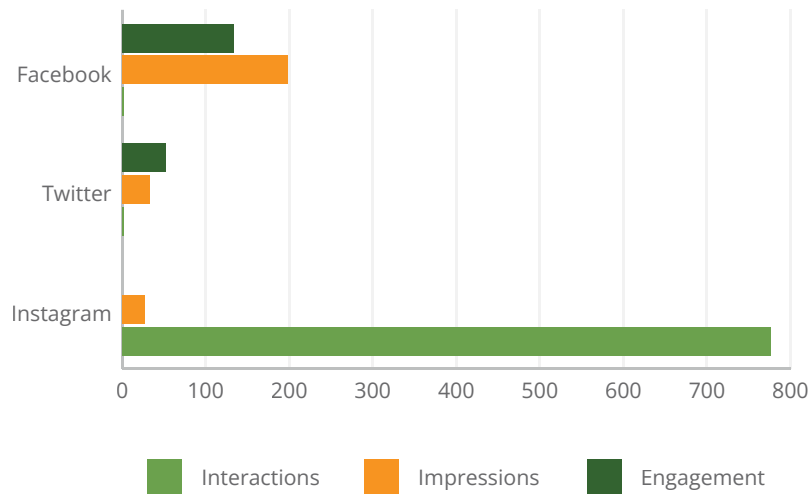
October marks Liver Cancer Awareness Month, a crucial period dedicated to shedding light on the reality and daily struggles faced by liver patients. FNETH primary objectives during this campaign include raising awareness about the importance of prevention and fostering healthy habits within our communities. Additionally, FNETH aims to encourage active participation and engagement from our associations, fostering a sense of involvement and solidarity within our community. Through these efforts, they aspire to bring greater visibility to the challenges faced by liver patients and promote collective action towards improving liver health outcomes.

The campaign was organized into thematic weeks aimed at addressing various aspects of liver health. **Week 1 (October 2-8)** was focused on promoting healthy habits to foster overall liver health and well-being. **Week 2 (October 9-15)** was centered around raising awareness about the impact of alcohol consumption on liver health and advocating for moderation or abstinence. **Week 3 (October 16-22)** emphasis on the importance of sports and exercise in maintaining liver health and overall physical fitness. **Week 4 (October 23-29)** was dedicated to raising awareness specifically about liver cancer, its risk factors, prevention, and available support resources. Finally, the closure of the campaign provided a final opportunity to reinforce key messages and encourage continued engagement in liver health advocacy efforts. On the night of October 30th, which is the International Day of Liver cancer, town halls, hospitals, and other emblematic buildings were lit up to raise awareness about this cancer, serving as a powerful visual symbol of support and solidarity.

The campaign utilized various actions and channels to raise awareness about liver health and liver cancer:

- Informative designs and materials for social media posts, featuring campaign hashtags such as #YoCuidoMiHígado, #CuidaTuHígado, and #MesCáncerDeHígado.
- Articles published on FNETH's blog covering campaign-related topics.
- Distribution of press releases and newsletters to reach a broader audience.
- Two participation activities for associations: a healthy recipes contest and sports activities to encourage engagement.
- Training workshops for associations are scheduled for October 25th and 26th.
- Lighting of town halls, hospitals, and other prominent buildings on October 30th, the International Day of Liver cancer, to raise awareness about the disease.

Some impacts of the campaign



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Spanish Patient Organization Lysosomal Acid Lipase Deficiency - AELALD



Family Congress

On November 10 and 11, 2023, the V Meeting of LAL-D Experts and Families took place in Zaragoza, bringing together a diverse group of attendees including health professionals, researchers, patients, and their families. The primary objective of the meeting was to facilitate the sharing of knowledge, experiences, and the exploration of new horizons in the understanding and treatment of this rare disease.

The event served as a unique platform where clinical expertise, scientific research, and the firsthand perspective of affected families intersected. This year, the congress introduces ELPA (European Liver Patients' Association) to showcase their involvement and support for liver patients.

The target groups include Spanish families affected by LAL-D associated with the association, as well as health professionals such as physicians and researchers listed as part of the LAL-D expert committee. The estimated reach on a national level encompasses Spanish families impacted by LAL-D who relate to the association, as well as healthcare professionals actively involved in LAL-D research and treatment.

Various topics were addressed during the meeting, ranging from recent medical advancements to the everyday challenges encountered by patients and their loved ones. Through collaborative discussions and presentations, participants gained insights into the latest developments in LAL-D research and treatment strategies, while also highlighting the importance of holistic support for patients and their families.

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Riksföreningen Hepatit C – RHC



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

The project titled ‘Organisation, Cooperation, and Research with and Among the Swedish Members of the Multicultural Group’ 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, each bearing its own unique intrigue, the team embarked on the task of selecting the sequence, participants, and priorities for execution. 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. Through this extensive network, the project aspired to generate insights and solutions with far-reaching implications at the national level and beyond.

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Living with Hepatitis Association - HEPYAŞAM



‘Liver and Sport’

The ‘Liver and Sport’ project started **on September 8, 2023**, and concluded **on December 8, 2023**. A sports manager worked at the hospital one day a week for a total of 14 weeks. The main objective of the project was to highlight the importance of appropriate sports in health and to support patients undergoing liver surgery through sports activities to facilitate faster healing. Inspired by positive outcomes from a similar study in Japan, we initiated this project as the first of its kind in Turkey.

Collaborating with Istanbul Başakşehir Çam & Sakura Hospital Liver Unit Head, Prof. Dr. İlgin Özden, we decided to implement prehabilitation with sports for patients preparing for liver surgeries. Tailored sports activities, including breathing techniques and exercises to strengthen abdominal muscles, were conducted based on each patient’s age, body structure, and general condition. New sports equipment was procured by HEPYAŞAM, and patients’ relatives were educated on the exercises’ repetition. Each patient had both a sports manager and a doctor present during the sports sessions. The project concluded with an evaluation of the patients’ recovery period by the healthcare team. Although the project was not yet at a national level, we aimed to present the results in a congress and eventually expand the initiative to liver units in major cities nationwide.

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British Liver Trust



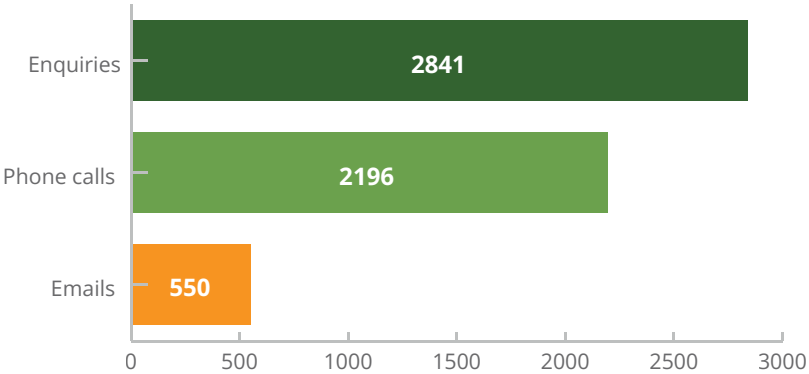
Nurse-led helpline for liver disease and liver cancer patients

The nurse-led helpline for liver disease and liver cancer patients operated from **April 1st, 2023, to December 31st, 2023**, with the main objective of providing support, guidance, and information to patients. Calls and emails were handled by a qualified specialist nurse. Six hepatology nurse specialists, each with different medical experience, were part of the team, all working part-time with a full-time equivalent of 2.3. Last year, the service received 5,000 enquiries. In early 2023, there was a surge in call volume, with an average of 500 calls per month, marking the highest number of calls each month so far. Call durations ranged from 5 minutes to 45 minutes.

The service provided support for palliative care calls and conducted multiple call backs as needed. It aimed to support individuals through their diagnosis and treatment options, particularly those having trouble accessing NHS care and support.

In April to October 2023, there were 2,841 enquiries, comprising 2,196 phone calls, 550 emails, and 95 call backs. In comparison, during the same period in 2022, there were 2,191 enquiries, including 1,609 emails, 521 phone calls, and 61 call backs. This marks a 22% increase in volume over the previous year. The average call duration in 2022 was 16 minutes, whereas in 2023, it decreased slightly to 15 minutes, indicating a similar amount of time spent on calls. Most enquirers learned about the charity from the internet, with only around 2% coming via healthcare professional recommendations.

Results April to October 2023



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Liver4Life



Van Outreach

Liver4Life partnered with local healthcare institutions to identify individuals at risk of liver disease. Through community testing days facilitated by their mobile van equipped with FibroScan and other screening tools, accessible testing and education on liver health were provided.

The Liver4Life testing van was designed to reach out into communities, offering BBV and FibroScan testing locally, eliminating the need for patients to visit their local hospital. Results were provided almost immediately, and we ensured that anyone requiring support was followed up and placed on the correct pathway to care.

The main objective of the event was to utilize a mobile testing van to educate and support individuals with liver conditions. Collaboration with local hospitals and care providers aimed to identify and screen individuals at risk of liver disease.

Throughout March to October 2023, Liver4Life traversed the South Coast of England with their van. Engaging local key workers, we conducted over 150 Blood Borne Virus tests, identifying 14 individuals with Hepatitis C who were promptly offered treatment.

In addition, Liver4Life provided Fibroscan testing using portable 430 device, capable of detecting liver stiffness. A total of 320 individuals underwent testing, with 17 referred for further investigation by local healthcare providers.

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