



Together we are  
stronger!

**ELPA MEMBERS'  
PROJECTS SUPPORT 2021**



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**Together we are stronger!**

ELPA Members' Projects Support 2021

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# Our mission

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

ELPA aims to promote the interests of people with liver disease and, in particular: to highlight the size of the problem; promote awareness and prevention; address the low profile of liver disease; share the experience of successful initiatives; to work with professional bodies to ensure that treatment and care are harmonised across Europe to the highest standards. ELPA's vision is that all liver patients are diagnosed in time, are treated with respect, and have equal access to the best standard of medical care – regardless of origin, lifestyle, and type of liver disease.

ELPA's efforts are focused on three main pillars.

## **MEMBER EMPOWERMENT**

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

## **POLICY AND ADVOCACY**

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

ELPA is a member of:

- Advisory forum and expert group on HBV and HCV at ECDC.
- Patient and Consumer Working Party at EMA.
- Policy and public health committee at EASL.
- Expert group on HIV, TB, and hepatitis at WHO.
- Expert board at VHPB.

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

## **PARTICIPATION IN MEDICAL RESEARCH PROJECTS**

ELPA is part of 10 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 2021 ELPA collaborated closely with its members on projects developed at the national level. ELPA supported projects in 15 countries: Belgium, Bosnia & Herzegovina, Cyprus, Finland, France, Israel, North Macedonia, Norway, Romania, Serbia, Slovakia, Slovenia, Sweden, Turkey, and United Kingdom.

The results are collected in this booklet, a catalogue of good practices from Sweden to Turkey, from France to North Macedonia,

that testify to how much Europe can be united in diversity. However, this booklet is also proof of resilience. Crises certainly bring about disruptions, confusion, and shocks. Still, they are also the perfect occasion not to give up, be bold, think out of the box, and come up with inventive solutions, especially if the goal is helping people. I could see it in all the activities ELPA members organised during the pandemic.

ELPA Members Project Support was not only a mere exercise of funding but also a real engagement from both parties, and I am very proud of it. On one side, it showed the willingness of ELPA members to support their communities. I cannot avoid stress the effort they put into driving fundamental changes at the local level. On the other side, ELPA had the opportunity to be involved in several patients' activities for the first time.

Together we are stronger!



## The foreword of the ELPA Board of Directors

The idea of supporting members came from several calls ELPA received during the pandemic. They were requests for help: some national associations were on the verge of shutting down, some were struggling financially, and some were facing leadership issues. We had to support them. They are the reason why ELPA exists and its backbone.

Therefore, in 2020 we explore some options coming up with the idea that any help should not have disrupted the connection between local and global, between ELPA and its members. We follow a simple goal: shaping an umbrella association that members are happy to be part of, proposing opportunities to develop their activities further, and an association to refer to in crisis times.

As the Board of Directors of ELPA, we had the pleasure of seeing how all these projects were born and developed, up to the concrete results they have brought within the community of patients with liver disease and throughout the entire society.

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

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

The Bords of Directors also hope that this booklet will be a source of inspiration for other patients' organisations and an opportunity to stimulate new ideas and projects.

We were so proud that we have already decided to repeat this initiative in 2022 and make it a permanent part of the activities ELPA offers its members.

Together we are stronger!

# ELPA Members



## **BELGIUM**

- Vlaams Hepatitis Contactpunt - VHC



## **FRANCE**

- SOS Hépatites Fédération



## **BOSNIA & HERZEGOVINA**

- The Chronic Viral Hepatitis Patients Association, "B18"



## **ISRAEL**

- Israeli Association For The Health Of the Liver, "Hetz"



## **CYPRUS**

- Cyprus Liver Patients Association, "Promitheas"



## **MACEDONIA**

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



## **FINLAND**

- The Finnish Kidney and Liver Association



## **NORWAY**

- proLAR



### **ROMANIA**

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



### **SWEDEN**

- Riksföreningen Hepatit C – RHC



### **SERBIA**

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



### **TURKEY**

- Living with Hepatitis Association - HEPYAŞAM



### **SLOVAKIA**

- Šanca pre pečeň



### **UNITED KINGDOM**

- Liver4Life



### **SLOVENIA**

- Association - SLOVENIJA HEP



**Hep Yaşam**  
Hepatit Yaşam Hastası ve Hastası Takip eden Toplumun Bilgilendirme, Destekleme ve Yardımlaşma Derneği

**ELPA**  
European Liver Patients' Association  
16 YEARS FOR PATIENTS  
2003 - 2019

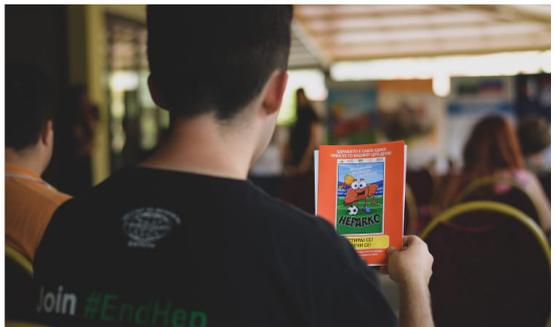
## “KARACİĞERİMİ KORUYORUM”

**Alkole Bağlı Olmayan Yağlı Karaciğer Hastalığına Karşı Alabileceğimiz Önlemler**

**Video 1 Projeyi Tanıyalım**







# Vlaams Hepatitis Contactpunt - VHC



## **New website and updated content**

Online presence is a priority in the hyper-connected contemporary world; this is why VHC decided to give its website a new look.

After an internal brainstorming, the association also realised that the website's emphasis was too much on viral hepatitis. During the last years, the liver diseases environment has changed, and the support to patients as well. This requires an overall approach and focuses on liver cancer, fatty liver, rare liver disease etc.

A new website for the Belgian association represents the gateway to better advocacy activity and increased visibility.

The most important purposes of having a new website for the association:

- Rebrand the association's identity in the online world
- Publish and share information
- Reach out to its audience
- Connect and communicate with its audience
- Build trust among its audience for your business and its products & services
- Promote and boost itself to attract more partners

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## The Chronic Viral Hepatitis Patients Association, "B18"



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

The project run by B18 aimed to promote the elimination of viral hepatitis in the country through raising awareness on social media and using online counselling and a hotline. The support given by the association was crucial during the pandemic lockdown when social distancing measures were in place. The services were run by volunteers who answered by giving peer-to-peer information regarding hepatitis, treatment options, and health care.

In detail, Info Hep Center activities included:

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

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

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### **CONTACT**

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## Cyprus Liver Patients Association, “Promitheas”



### Love your Liver

The COVID-19 pandemic has led to a dramatic loss of human life worldwide and presents an unprecedented challenge to public health. There is no doubt that the COVID-19 pandemic affected most people's lives. Due to COVID-19, most individuals need to change how they live, work, study, and socialise. Combined with the strict isolation measures, these sudden changes influence an individual's emotional and psychosocial well-being.

Another factor to consider is that the dramatic rise in obesity and metabolic syndrome resulted in an increase in fatty liver disease.

The Cyprus Liver Patient Association 'PROMITHEAS', recognising the enormous dimensions and effect of the COVID-19 pandemic on the population, had drawn up a prevention program.

The program, which was called: Love yr Liver, is a guide on maintaining our good health by just taking care of our liver.

The program was based on four pillars:

- Education
- Nutrition / School programs and education
- Physical activities/team building activities
- Identify the problem at an early stage. Prevention from a young age

For this purpose, they organised many events. Some were informative; some were sports activities, some were about nutrition, and others were just team building activities for our good health and prevention against MAFLD/NASH.

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### CONTACT

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# The Finnish Kidney and Liver Association



## **New treatment options available for HCC**

On October 27, 2021, the Finnish Kidney and Liver Association organised a seminar to share information about new medication and criteria for surgery in Hepatocellular Carcinoma diagnosis, as well as share information on patients' unmet needs. This was also a unique opportunity to liaise with the Association of Cancer Patients in Finland to provide more comprehensive patient support for liver cancer patients. Currently, liver cancer patients have been able to join patient groups. Still, sometimes, due to late-stage diagnosis and often rapidly advancing illness, they may have many different needs than regular cancer patient groups. It is also known that stigma in liver illnesses may prohibit patients and their families from seeking the help they need within common groups.

The event provided a platform to discuss these matters nationally and share the latest developments on new medication and treatment options. It was possible to attend for free in-person or virtually.

Active social media marketing started three weeks before the seminar, and a press release was ready to be launched a week before the event. Then the conference has been extensively shared on stakeholders' profiles. Also, a recording was made during the seminar, and it is available on the association's YouTube channel.

Feedback has been positive, and all speakers were happy about the event and followed everyone's presentation. Many people commented that the patient's talk was brave and informative. Also, many patients and pharmaceutical companies contacted the association after they realised that it is dealing with this topic.

The project surpassed the association's expectations, and they realised how much more this topic needs to be kept ongoing.

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## **CONTACT**

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## **Hepatitis B: first information tools for patients and their families following the holding of the First General Survey on Hepatitis B**

On July 28, 2020, World Hepatitis Day, SOS Hépatites and the hepatitis B Collective officially launched the First Estates-General of Hepatitis B to highlight hepatitis B and hepatitis delta (D). The work aimed to highlight better the real difficulties encountered by people living with hepatitis B and the health actors who support them and advocate for effective public policies in terms of prevention and care of hepatitis B. The summary of the work was published in February 2021.

The main objectives of the project could be summarised as follow:

1. Develop information tools on screening and vaccination for "Hépatants B" (persons living with chronic hepatitis B) and their families. How can I protect those around me? How do I carry out my lifelong medical surveillance? How to practice the profession of my choice? How to have children and protect my newborn?
2. Inform to fight against stigma, against the widespread ignorance of hepatitis B, which is complex but very well-treated, must be monitored regularly and against which people at risk must be protected.
3. Fight against healthcare social and territorial inequalities.

The experiences and the related literature were effectively tackled during the work of the First Estates-General of Hepatitis B: the survey "Living With Hepatitis B", more than 200 respondents. Citizen panels in Marseille, Paris and Guadeloupe, 30 participants. 6 regional round tables in Prades, Strasbourg, Bordeaux, Lyon, Rennes and Guadeloupe, more than 200 participants (institutional, health professionals, medico-social actors and others).

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### **CONTACT**

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## Israeli Association For The Health Of the Liver, "Hetz"



### **Webinars on pediatric liver disease and PFIC**

Activities by the Hetz association from Israel focussed on raising awareness of two critical areas of liver disease, younger patients and rare liver disease.

On National Pediatric Liver Disease Day, which took place on May 26, 2021, they organised a webinar with two of Israel's leading experts, Dr Yael Mozer and Prof. Eyal Shtayer. They presented different aspects concerning Liver disease in children. Ms Weinbaum presented the activities of the "Hetz" support groups for parents. They had 240 participants.

Liver disease is increasing in prevalence in children; it is essential to inform the general public about the impact on the young population and not underestimate the role patients' associations can play in supporting patients and families.

On International PFIC Day, which took place on Oct 05, 2021, they hosted a webinar together with the "Shsneder" Hospital and the "Sharey Tzedek" Hospital discussing various aspects of PFIC. Ms Weinbaum presented the activities of the "Hetz" support groups for parents. They had 90 participants.

Too many patients suffering from rare liver diseases fall victim to the unknown. Their causes and effective diagnostics, treatments, and cures remain unclear for many liver diseases. This is why Hetz wanted to put a face on this rare liver disease so that we may work to recognise how to diagnose better, treat, and cure it.

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



### **What to Know About Liver Disease, COVID-19, and vaccination**

The association organised 4 online workshops for students, about liver disease, COVID-19 and vaccination. With the help of evidence-based medical sources, all participants tried to find answers together. Some of the main questions were:

1. Does COVID-19 damage the liver?
2. Are people with liver cancer, hepatitis B or C at increased risk for severe COVID-19?
3. Are people living in areas that experienced an outbreak of hepatitis A still at risk for hepatitis A during the pandemic?
4. What can people with hepatitis B or C do to protect themselves from COVID-19?
5. What can people with substance use disorder and liver disease do to protect themselves from COVID-19?
6. What else can people with chronic liver disease do to protect themselves from COVID-19?
7. Can antivirals used to treat hepatitis B or C be used to treat COVID-19?
8. Are shortages of hepatitis B or C medicine expected?
9. Should people with chronic liver disease travel at this time?
10. Do people living with or at risk of viral hepatitis need to take special precautions to prevent COVID-19?
11. What can everyone do to minimise the stigma about COVID-19?

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#### **CONTACT**

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## Hepar Centar – Bitola



### **The First National Declaration for Liver Cancer**

The project run by Hepar Centar Bitola in 2021 was dedicated to disseminating the First National Declaration for Liver Cancer during the Liver cancer Awareness Month campaign, October 2021. This declaration is the first of its kind in Europe. It has been instituted as part of Europe's Beating Cancer Plan, with particular reference to liver cancer and the need for personalised medicine for prevention, diagnosis and treatment.

This declaration calls on the Government of the Republic of North Macedonia, the Ministry of Health, the Health Insurance Fund and all the parties involved to develop a fully funded national program that will be implemented through partnerships between all relevant entities, both in health and broader social context.

The European Parliament's development legislation and its health program are expected to provide the so-called "wind in the back" in preparation for dealing with serious health threats and improvements in the fast recovery of the health system through:

- Determination in dealing with cross-border health threats;
- Providing access to the necessary medications by making them available to everyone in need;
- Strengthening the national health system.

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#### **CONTACT**

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proLAR

## **Hep C clinic**

The association ProLAR Nett started informing people in their community that they had a new “drop-in” clinic in their office. They also handed out leaflets and sheets about hepatitis C and HIV testing on the streets. Several people got materials and information about hep C and prevention. Due to the pandemic, fewer people were visiting on-site during this period than expected. Still, they had people get tested for free.

One of the main aspects to stress is the fact that this service was peer-to-peer, an important detail considering that it wanted to target mainly people belonging to risk groups such as people injecting drugs.

Because of COVID19, they met some issues regarding “drop-in” face-to-face. They knew that this was a challenging project in this period. However, since they already had the gear and equipment, they wanted to try out a low threshold clinic on-site in the office. The project will be probably repeated in the upcoming future.

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## **CONTACT**

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



## **Patients with hepatitis C can't wait!**

Roapah's initiative wanted to increase awareness of hepatitis C and encourage the health authorities to give access to therapy urgently for patients.

The project started from the necessity to have access to the therapy for hepatitis C in Romania. From the end of June 2021 in Romania, patients with hepatitis C did not have access to the new treatment in hepatitis C because of a lack of negotiations on new contract cost/volume/result between Romanian authorities and pharma companies. Also, from September to the end of November 2021, there was a political and health crisis in Romania because of the pandemic situation that worsened the position of hep C patients.

The association sent many official letters to the national authorities, with the support of the Romanian Society of Gastroenterology and family doctors. They also have discussions with political representatives. In addition, the association also advocated online releasing a press release describing the current situation and working closely with the media.

Finally, the situation was unblocked. From February 1, 2022, patients with hepatitis C will finally have access to the therapy.

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



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

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

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

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

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

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#### **CONTACT**

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# Šanca pre pečeň



## **BE INFORMED AND RELAXED**

The project run by Šanca pre pečeň in 2021 was called 'BE INFORMED AND RELAXED'. The main objectives of the project were to raise awareness in the field of prevention of liver diseases and provide the members with long-expected stay with the aim of education.

The association carried out an educational and relaxing stay in a spa on August 27 - 29, 2021. The training was held in connection with the General Assembly of the organisation.

The General Meeting was held on 28 August 2021 in accordance with the Articles of Association with a standard program, such as the activity report for the years 2020 and 2021, the management report and the draft plan of activities for the next period. Elections for new members of the Administrative and Supervisory Board also took place.

In the afternoon, participants could attend a lecture by Dr Ľubomír Skladaný on the National program of liver diseases and a presentation on autoimmunity in patients with liver diseases by Dr Svetlana Adamcova Selcanova. All the attendees discussed with interest the topics.

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## Association - SLOVENIJA HEP



### **Virtual management of the association SLOVENIA HEP**

SLOVENIA HEP's project was developed on two axes. The first one is the support of the testing services provided by the Medicine Faculty and medical students. The second one is related to the refresh of the association's website.

The project's main objective was to offer free testing services and motivate people to get tested, regardless of the Covid crisis, using the association's communication channels.

Medical students informed people about free anonymous and quick tests for hepatitis C every week, increasing these activities to every day during the period around the World Hepatitis Day on July 28.

Considering the pandemic, in 2021, medical students were also involved in a call centre service where they provided answers to the people calling to have information regarding COVID-19 and health care services.

In addition, pages within social media sites are not the equivalent of an actual website. A social networking presence is a powerful way to engage and connect. Still, they are not a replacement for a digital home base or website where information can be more specific, detailed and verified. This is the reason why the association decided to upgrade its website.

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# Riksföreningen Hepatit C – RHC



## **Gender-based differences in the treatment of patients with hepatitis**

The purpose of RHC was to find out through interviews, questionnaires and discussions involving patients, family members, friends of patients, and health care representatives, whether hepatitis care is similar to other fields of medicine, such as heart attacks, cancer, renal and urinary disorders, mental disorders etc. in treating women with “male symptoms” or failing severe conditions as they look for male symptoms, not present in women. Shortly, to see if “male is the norm-syndrome” is present also in hepatitis care or if hepatology is more advanced and developed in “gender-equal treatment”.

Considering the topic, people are shy or afraid to express themselves wrong. But the huge problem was that the interviewees mixed two different things in answering. They had difficulties separating discrepancies in the treatment based on gender and other things, like class, literacy, etc. The association had to put significant efforts into explaining this topic.

However, I received positive feedback from some people in the group discussion who talked freely about this topic and from the specialists, who were very helpful and cheerful in answering questions.

This activity helped to increase the knowledge of the association. Gender differences are not predominant in hepatitis care. Still, there are things hidden behind the answers, in the shadows of no-reflection, taken for granted, not least from specialists, where females and males answer very differently. That would be interesting to plunge into.

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# Living with Hepatitis Association - HEPYAŞAM



Hepatitisle Yaşam Hastası ve Hastası Yakınları Toplumsal  
Bilgiendirme Dayanışma ve Yardımına Derneği

## I Keep my Liver Healthy

The project run by HEPYAŞAM in 2021 was called 'I Keep my Liver Healthy' (Karaciğeri Korumuyorum). Its main objective was to explain the importance of exercise to prevent and fight NASH, NAFLD, diabetes and obesity. There are patients with obesity, diabetes, and fatty liver disease in almost every home in Turkey. That is why members of the Hepyaşam Association, the sports director and doctors prepared this project together. Also, a unique t-shirt was realised for the campaign. Because of the pandemic, they offered simple exercises that everyone could do at home. Videos were then posted on Hepyaşam social media and website.

**Video 1:** Dr Hilal Ünalmiş Duda speaks about the project.

**Video 2:** Prof Dr Yılmaz Çakaloğlu gives information about NASH disease and nutrition.

**Video 3:** Prof Dr Levent Erdem explains NASH and obesity.

**Video 4:** Prof Dr Kadir Demir gives some suggestions about NASH and cardio.

**Video 5:** Sports at home during the pandemic. With volunteers.

**Video 6:** Sports during the pandemic. With sports adviser Firat Alp.

**Video 7:** Let's protect our muscles during the pandemic. With sports adviser Firat Alp.

**Video 8:** Movement, Movement, Movement. With sports adviser Firat Alp.

**Video 9:** Please repeat these exercises at home. With sports adviser Firat Alp.

**Video 10:** The most basic movement: walking.

## CONTACT

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Liver4Life



## **Reaching Communities**

With this activity, Liver4Life had the main objective of reaching rural communities who engage less with health care providers and provide access to information and education about all liver conditions.

The association partnered with the Royal Bournemouth Hospital. It used its testing van to visit smaller towns and villages around the south coast of England, mainly Dorset, engaging with the local population to provide a hub for information education and awareness about all liver diseases.

They also offered fibroscan tests for people who are at risk. Nurses were present for all testing and to ensure appropriate referrals.

By reaching into more rural communities, they enabled people to access services they would have had to travel for, and many people thanked them for creating this outreach service.

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